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IJPR

Feature Articles

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Twin Reflections: A Consumer-Driven Schizophrenia Workshop for Psychiatry Registrars

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Abstract

This report describes an innovative approach in the education of trainee psychiatrists in Queensland, Australia. Using a multidisciplinary panel with a central role of a consumer, together with an interactive facilitative workshop approach, a training package for schizophrenia was developed and refined, concentrating on the streams of (1) evidence-based treatments (2) modern psychiatry with a consumer centred and recovery oriented approach (3) sensitising trainees to ethical issues. A unique feature of this education approach is the way it brings together 2 paradigms: the dominant professional one with its scientific background, with the less dominant one of the body of knowledge in terms of consumer lived experience. This report describes how the multidisciplinary, multi-perspective group that comprised of this educational panel planned for and managed the inevitable tensions that arise when dominant preconceived beliefs are challenged. This ethical perspective stresses a non-paternalistic approach, informed by psychosocial factors but balanced by important principles regarding professional responsibility. The result has been an involving, richly complex and flexible workshop that has engaged successive cohorts of psychiatrist trainees in reflective discussion that varies according to individual need.

Background:

We are entering an exciting era of paradigm shifts: firstly, in modern public psychiatry where the care of the mentally ill is embracing collaborative and consumer-driven treatment models, with an emphasis on supporting self directed recovery in community settings (Australian Health Ministers, 2003; Onken, Dumont, Ridgeway, Dornon & Ralph, 2002; US Department of Health and Human Services, 1999) and secondly, in educational programs where there has been a distinct shift from didactic models of teaching to interactive learning methods with a facilitative approach (Boud, 1987; Goldberg, 2001). Facilitative approaches to teaching have been found to encourage deeper learning (Kember & Gow, 1994). It is the authors' belief that such facilitative approaches are conducive to seeing and nurturing paradigm shifts, that challenges the dominant models of working with persons experiencing severe mental illness. This report describes the local experience of a multi-disciplinary group comprising of a consumer representative (an expert by experience), an ethicist and psychiatrists in Queensland, Australia who developed a training package for psychiatric trainees which embraced both of these modern approaches.

In Australia, it is now government policy to include consumer participation in all levels of mental health service provision (Commonwealth of Australia, 1996; Connor, 1999). The Australian and New Zealand College of Psychiatrists' curriculum for basic training includes mandatory experiences in consumer and carer-related activity, requiring significant input from those that have experienced mental illness (RANZCP, 2003). While these are important developments, in order for these changes not to be merely "lip-service" and tokenistic embellishments, it is well recognised that a tidal change in terms of attitudes and knowledge of a new generation of psychiatrist leaders will come only from meaningful training experiences, which resonate with real-life clinical activity and that focus on understanding and working with the lived experience of mental distress and self directed recovery.

In 2001, the Academic Subcommittee of the Queensland psychiatric training program decided to move from a traditional student-style lecture program to a series of seminar sessions which stressed adult learning concepts using case studies, interactive discussion and expert facilitation. One of the authors (PP) was given the brief to design and conduct a seminar in the most common chronic conditions encountered by public mental health services, namely schizophrenia. It was felt that the seminar should incorporate 3 streams: (1) Evidence-based treatments (2) Modern psychiatry with a consumer centred and recovery oriented approach (3) Sensitising trainees to ethical issues. To this end, a multidisciplinary "expert panel" was formed by invitation, including a consumer representative (VJ), the psychiatrist facilitator/ moderator (PP), an ethicist (PM) and a psychiatrist with a major interest in the consumer and recovery movement (VK). An important outcome of the initiative was the development of a consumer-focused case study for interactive, reflective educational workshops. The educational session proved to be highly effective in terms of richness of discussion, reflection and student initiated participation. The case study focuses on multiple presentations to a service, across the lifespan (Harvey, 2001) of two adult identical male twins experiencing schizophrenia with varied outcomes. The lifespan perspective being important when discussing the biopsychosocial changes that occurs during illness and recovery. Furthermore, there are ethical challenges posed at each stage of the twins' lifespan and history with the mental health system. For this reason, this article has been written to provide a full description of the content and process of the workshop to assist other educators embracing the philosophy of modern public psychiatry with its focus on consumer advocacy. The focus of this three hour training was to create an opportunity for reflective discussions by the trainees about factors that promoted or hindered recovery from different perspectives. A flexible approach was planned, to allow the discussion to respond to individual needs of different cohorts of trainees. This would also allow the training package to be adaptable to different working environments.

Queensland Rotation Psychiatry Training Program

The Queensland Rotational Psychiatry Training Program is the only pathway by which psychiatric trainees in Queensland, Australia meet their training objectives before sitting examinations which qualify them for advanced training and subsequently, to become specialist psychiatrists. Requirements of training include approved training posts where the trainees garner clinical experience, supervision by specialist psychiatrists, and attendance at an academic program put together by a voluntary body of psychiatrist educators, the Academic Subcommittee of the Queensland Rotational Psychiatric Training Program.

This academic program spans 3 years: the first year dealing with basic assessment and aetiology of mental disorders, the second year dealing with clinical case examples and treatment concepts, and the third year addressing sub-specialty areas of psychiatry. The case study educational session is one of the 3-hour seminars in the second year of the academic program.

Teaching Strategy– An Interactive, Multi-disciplinary Collaborative Approach

Contribution of moderator (Dr Paul Pun):

Recognising that the trainees would have a solid grounding in clinical presentations of mental disorder as well as aetiological concepts, these workshops were designed to capture nuances of management which would be virtually impossible to do in a didactic fashion. There was a deliberate continuity with regard to the vignettes to sensitise the trainees to the subtleties of differences in management depending on the stage of the disorder. The scenarios were based on real clinical scenarios, which most of the trainees would be familiar with, to maximise the opportunities of interactive problem-based learning. The advantage of the case vignettes was the mix of evidence-based treatment, ethical conflicts and attitudinal issues regarding collaborative treatment blending together as in real life, providing a richness and level of complexity to the discussion. Another task of the moderator was to manage the tension that inevitably arises where preconceived beliefs are challenged, and provide balance to debates.

An issue that is perhaps poorly recognised where a consumer is part of a professional panel, is the negative effect of disclosure on interpersonal and academic performance (Farina, Allen, & Saul, 1968; Quinn, Kahng, & Crocker, 2004). This can be managed by:

(i) the facilitator providing adequate time prior to the workshop, so the consumer may read materials and ask questions about the intended teaching plan
(ii) the consumer meeting the facilitator prior to the workshop to discuss how trainees are normally trained and how this is approach will different
(iii) the consumer being given an explanation of medical terms to be used in the workshop
(iv) the facilitator ensuring that the consumer has time to digest complex statements and respond during the workshop, perhaps even rephrasing comments made
(v) making sure that payment has been organised for the consumer

(vi) the consumer being made welcome to bring a "silent observer" if that would help them feel comfortable during the workshop
(vii) ensuring that debriefing is offered to the consumer as part of the plan for the workshop. This should happen immediately afterwards if possible and there should be opportunity to talk at a later stage if required.
(viii) the consumer being given copies of papers (especially this one) and references suggested in this paper. There is also a need to discuss that personal disclosure will most likely result in a temporary drop in ability (interpersonal and academic skills) and this is not due to a psychiatric illness but part of the normal response of fearing stigma by others.

Contribution of consumer perspective (Vivian Jarrett):
Consumers' lived experiences need to play a significant role in education of professionals (Corrigan & Penn, 2004). Negative stereotypes are likely to change when through working together on problem-solving activities during the workshop. The role of the consumer in the educator role is complex, as it attempts to harvest the phenomenological or holistic experience of living with a serious mental illness. The consumer perspective permits reflection on a range of similar personal experiences, which not only enriches the discussion, but promotes critical analysis of current practice and the implications of decisions on the consumer. Consumers bring not only their own experiences of the disorder, but experiences of using systems of care, medications and psychotherapy. More importantly there is opportunity to share experiences which bring out the human side of consumer's experience. Corrigan and Penn (1997) suggest that the disease and discrimination paradigms are conflicting views and interventions not embracing the knowledge of both may cause confusion and tension for consumers in treatment settings. The consumer's participation in this educator role enables discussions around interventions that could be viewed as discriminatory. This may occur when interventions are overly forceful or insensitive to the human suffering that occurs during episodes of severe mental illness (Allen et al., 2003; Carpenter, 2002). The mere presence of the consumer educator also provides a more respectful discussion that prevents over-categorising and inappropriate labelling of experiences that are not part of the disorder (ie. sadness is not always depression). Furthermore there is abundant literature showing that a reduction in negative stereotyping occurs when interpersonal contact is made with a consumer in a respected role (Kolodziej & Johnson, 1996).

In approaching the consumer educator role it is suggested that the consumer is offered adequate educational information (ie. handouts that may be given to trainees), support and adequate reimbursement for participation (NCCF, 2004). Educational support could occur through an opportunity to liaise with the workshop facilitator prior to the workshop and for debriefing after the session. Discussion of the session also contributes to improvements for future sessions, ensuring that the discussion is relevant at the local level. Consumers must also be confident and experienced in the educator role, as it is a daunting task to work freely with personal experiences at such a high academic level. The consumer needs to have an appreciation of environmental or social factors that help or hinder recovery (Onken et al., 2002) and be encouraging to trainees when they have been successful at utilising strategies that they feel would be helpful. This workshop utilises the expertise of the consumer's personal knowledge base as proposed by Trainor, Pomeroy and Pape (2004) and the impact of discrimination knowledge (Corrigan & Penn, 1997). Working in this way creates some amount tension with the medically sourced knowledge base of professionals. One of the desired outcomes of the workshop is a mutual appreciation of both professionals and consumers knowledge, which will work to help bridge the gap in understanding the experience of a mental illness.

Contribution of multi-disciplinary panel:
The interactive, multi-disciplinary collaborative, consumer-friendly approach also informs the ethics teaching strategy for the case-study session. The pedagogical raison d'etre is to 'lead from behind' by building a non-judgemental space where participants are encouraged to articulate and explore their beliefs and assumptions about ethical responses to practice dilemmas that arise from the case material. The approach is Rogerian, rather than didactic, affirming and welcoming all analytic insights. Educational strategies include information

giving, concept introduction, issue clarification and encouragement of ownership by the group of ethical reflective processes.

Putting 'Recovery' on the Agenda

It is only in recent years that the idea of the possibility of 'recovery' from mental illness has been embraced by the mental health literature (Andersen, Oades & Caputi, 2003; Bishop, 2001; Jacobson & Curtis, 2000; McGrath & Jarrett, 2004) even though there are numerous first person accounts of recovery from serious mental disorders dating back over 160 years (Beers, 1935; Percival, 1840). Prior to the collaborative work presented in this article, the trajectory of the case study used in psychiatry training in our department documented a strong bio-medical focus with an escalation of drug therapy and enmeshment of the consumer in the mental health system. One of the significant factors of the present work is that it provides openness to alternative trajectories from the one starting point (that is, identical twins with the same diagnostic condition). The rationale for such change is to affirm and extend the work initiate in recent decades that shifted the mental health paradigm from predictable deteriorative/maintenance course to a therapeutic engagement with the potential for recovery (Drake, Green, Mueser & Goldman, 2003; Harding, Brooks, Ashikaga, Strauss & Breier, 1987a; 1987b). By the very presence of a consumer advocate who is an excellent role model of recovery, the message of the possibility of recovery from serious mental illness is a fact to be observed, not simply abstract theoretical or research evidence (Ahern & Fisher, 2001). The consumer's insights and life story is a powerful medium for embracing the present metaphor of recovery as personal journal, rather than biomedical 'cure' from 'disease' where medication and institutional mental health are the treatments of choice (Deegan, 1997). This educational strategy echoes the present mental health literature that calls for the insights of the lived experience of individuals who have recovered from mental illness to be central to mental health reform (Anthony, 2001; Deegan, 2003; Kirkpatrick et al., 2001; Tooth, Kalyanasundaram, Glover & Momedsadah, 2003). The differential outcomes of the twins gives an opportunity for the educators to facilitate rich discussions about the treatment conditions that impede the recovery process and entrap a person in a life of disability managed entirely with professional dependency. This is in contrast to therapeutic relationships and conditions that recognise and support self directed recovery and promote citizenship through well thought out frameworks of support that are informed by the knowledge of lived experience and traditional knowledge (Trainor, Pomeroy & Pape, 2004).

THE CASE STUDY – Format, context and issues arising.

Figure 1 outlines a verbatim copy of the case study as it is presented to students. As the *modus operandi* for the case study is to suggest rather than prescribe, the following discussion will elaborate on background issues to provide the full context for the detail in the vignette. This discussion will be approached from the perspectives of various members of the panel, namely the psychiatrist, the consumer and the ethicist.

Psychiatrist perspective on slides:

The first scenario (slides 1 and 2) is packed with discussion points. Apart from the obvious clinical issues of confidentiality and the role of the carer, it allows discussion of the current level of evidence of the association between cannabis and schizophrenia, as well as the burgeoning area of early intervention in this chronic disorder.

Slide 3-5 brings about a discussion of alternative models of psychiatric care (mobile teams, assertive outreach, 24-hour community availability, alternatives to hospital admission, psychosocial interventions) and the level of evidence supporting these modern interventions. Slide 4 mentions ARAFMI (2005) which refers to the local support network for carers of those experiencing mental illness.

Slide 6 brings forward the discussion about rational antipsychotic pharmacotherapy in an inpatient unit. Traditional methods of using "as required" antipsychotic medication for sedation are now being replaced by alternative anxiolytics (e.g. benzodiazepines). Intravenous injections of drugs to induce a "sleeping state" level of sedation are also being replaced by other delivery mediums (e.g. wafers, intra-muscular injections) to control agitation without necessarily inducing a non-responsive state in the patient.

Slide 7-8 triggers the clinical management of patients with schizophrenia who are treatment-refractory to conventional antipsychotic agents. The level of evidence for electroconvulsive therapy in treatment-refractory psychosis is explored, as well as the ethical issue of using clozapine, an agent proven in this condition but accompanied by dangerous side-effects.

Slide 9-10 provokes discussion about competency in chronic residual schizophrenia, by putting forward a scenario where the patient receives a substantial inheritance, and is living in sub-optimal conditions. Trainees report that it allows reflection on their "knee-jerk" paternalistic response, rather than respecting the patient's choices and maximising their decision-making ability.

Slide 11-12 deals with the controversial issue of rechallenging patients with clozapine after a previous drop in white blood cell numbers. The balance involves considering the previous positive response to medications as opposed to the problem of subjecting the patient to further harm.

Consumer Perspective on Slides:
The consumer perspective emphasises the need for personal empowerment, choice and ways to manage the effects of fear of discrimination and stigma from others (Brown & Bradley, 2002; Corrigan & Penn, 2004).

Slides 1 and 2 bring forth a discussion on the process of becoming independent in late adolescence. Life goals are hampered by the onset of a mental disorder like schizophrenia. Often families are closely involved with their children in late adolescence, and the impact of the home environment is still very important. A family history of a serious mental illness may infer the family is stigma conscious and sensitive about labelling members in this way, there may also be fear of treatments used in the past.

Slides 3, 4 and 5 discuss the impact of the disorder over time, with the loss of education and work roles. Understanding the difficulty of regaining life roles in the face of stigma from others is valuable. It would also be important to advocate for services that are affordable and accessible in the community. Treatment in the community minimises stigma by focusing on meeting emotional needs, providing self-awareness education and a human face to the assistance. It is important to advocate that medication is only a small part of the multitude of other services that a community can offer an individual in recovery from a mental disorder. The opportunities would be different depending on the local culture.

Slides 6, 7 and 8 give an opportunity to share the personal experience of being medicated and hospitalised. The process of admission can be traumatic (Cohen, 1994) and often the system through which care is accessed, can cause harm to the consumer through excessive administrative processes and assessments. It could be discussed how the consumer is able to maintain choice and empowerment during a hospital admission.

Slides 9 and 10 demonstrate the possibility of positive outcomes when a consumer is given choice and opportunity to recover. It is helpful to discuss how an individual recovers and may take up normal life roles even in the face of some symptoms.

Slides 11 and 12 highlight the differences in possible outcomes for recovery when experiencing schizophrenia. There is a danger in institutional care for consumers to not be permitted negotiate life's natural emotional highs and lows without it being categorised into a disordered state of being. The final summary gives a chance to highlight ideas that were useful to the consumer's experience of recovery during the workshop.

Ethical Reflection:

The conceptual starting point for the discussion is that ethical reasoning is rarely situated in an unqualified 'good' but rather necessitates at its core the tension between conflicting interest of both 'goods' and 'harms'. Engaging openly with the tension within a non-paternalistic framework is posited as one of key factors operating in professional ethics. While using the language of ethical reflection informed by notions of Principlism (for example, Autonomy, Beneficence, Non-maleficence, Justice), the ethicist encourages participants to embrace a sociological perspective. Thus, the framework for discussion is at the cutting edge of ethical theory that in recent years is moving from abstract philosophical reasoning to embrace a sociological understanding of discourse and power (Frank, 2004; McGrath, 1998).

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Figure 1: Schizophrenia Workshop - Case Vignette

1. Case Vignette Mr A and Mr B are identical twins and 17 years old. Both live with their parents and Mr A is unemployed since dropping out of school the previous year. Mr A has been brought to your mental health service by his mother, a general nurse. She is concerned about his mental state, having heard her son describe a device in his head. An uncle and grandparent have also had schizophrenia. Mr A is reluctant to be at the service, stating that his brother says he does not need to see a shrink.	2. Mr A Mr A smokes 4 cones of cannabis per day. The mother has heard from colleagues about "schizophrenia being caused by drugs", "psychosis being toxic to the brain" and the "importance of early intervention". The mother wishes that Mr A could be like Mr B who is doing computer studies at university. She mentioned that Mr A had made friends with a bad group of teenagers, and it was typical of him to do the wrong thing.
3. Several years later Mr A is now 21 and has an established diagnosis of schizophrenia. He has moved out of home and is living with his friends. Mr B also moved into the flat after finding a job in the local area, even though he had dropped out of university several times before finishing. While Mr A has been lost to follow-up for the last year, one day he self-presents to the community health centre describing distressing voices. Mr A does not want to be admitted and asks if he can have intensive counselling rather than medication for his problem, as his brother has suggested this would help. He does not have transport and finds it difficult to get to the centre.	4. In the interim Mr A and Mr B are now 23 years old. Mr B has moved back to his parents' house, and they have bought him a car to get around in. While Mr B has not used illicit drugs, he also starts developing ideas about his workmates planting a bug in his computer, and that they are monitoring him. Mr B does not want to talk to anyone but his parents can't seem to do enough to help him out. Through their membership of ARAFMI, they put Mr B in contact with the local mental health consumer group. They, in turn, suggest he enrol in a brand new young person's program.

5. The “at risk” clinic This turns out to be the early psychosis program, which runs out of a shopfront in the local shopping mall. Mr B makes a good connection with one of the counsellors, who persuades him to try a “Feeling Good” CBT course. Despite initial reservations, Mr B later goes on a low-dose of risperidone. His compliance is encouraged by a good support network including counsellor, parents and members of the consumer group.	6. Mr A’s crisis Mr A is now 24, and one night is admitted to hospital, having been brought in by police who state that he had punched a passer-by in the street. This was reported as a psychotically driven assault. He is put on olanzapine 20mg/day in hospital, but the nursing staff request that they have prn antipsychotics to manage his unpredictable aggression. The charge nurse also raises the query about intravenous neuroleptisation with IV haloperidol and diazepam as there are only female nurses on the night shift.
7. Mr A’s not getting better Mr A’s admission has been prolonged and complicated by the treatment-refractory nature of his illness. He has not responded to adequate trials of olanzapine, risperidone, quetiapine and depot antipsychotic medication. He refuses clozapine because of the blood tests. The nursing staff raise the possibility of ECT, reporting that they have seen other similar patients respond to this treatment. As far as you can see, there isn’t an affective component to his illness, although the uncle that was diagnosed with schizophrenia did suicide.	8. The surprising revelation Mr A does not remember the assault that landed him in hospital. He feels that the medication is poisoning him, but his parents say they’ll never speak to him again if he stops it. Mr B visits Mr A often and seems really worried about him. One day Mr B comes to visit and seems very upset. Mr B says that he feels so guilty because it was him, not Mr A, that hit the guy in the street. He explains that the guy in the street was drunk and confronted both of them. As Mr A had the mental health record and looked more dishevelled, Mr B thinks this is why Mr A was picked out as the one that hit the stranger. He asks you to explain Mr A’s illness and what treatments are available.
9. Six years on After that event at age 24 Mr B chose to not see Mr A again. Mr A is now in his late 30’s and is on clozapine. He lives in a hostel, where his medication is supervised. He has a predominantly deficit state illness, with poverty of thought, amotivation and anergia. He manages his own money, after the hostel deducts his board, which he spends exclusively on cigarettes. Mr A and Mr B receive an inheritance of $500,000 each. Mr A’s psychiatrist thinks it should be spent on his rehabilitation.	10. The other half Mr A talks about Mr B often. Mr B is now married, has 2 children and runs a security business. Mr A complains that Mr B does not contact him any more and seems boring as he is preoccupied with security systems and talking about how to stop others from breaking into your home.
11. ? Rechallenge Mr A develops neutropenia on clozapine, and this drug has to be stopped precipitously. After a long period of stability on clozapine he suffers a severe relapse of psychosis with its withdrawal, which is poorly responsive to all the other antipsychotic agents. His neutrophils are currently in the normal range. He wishes to go back on clozapine, although at the same time he believes that aliens are tracking his movements via a device in his head	12. Grief Mr A seems upset and says he is depressed and asks you to treat it. He says that Mr B recently went overseas on a holiday with his mother. His father passed away last year and he is upset that he wasn’t allowed to visit him before he died. The family said it would be too upsetting for the father to see Mr A, so they told him to stay away and that he should just learn to stay on his medication and stop giving everyone in the family problems. The father had phoned Mr A before he died and said that he did want him to visit.
Summary Overview – Prognostic Factors Affecting Trajectory	

13. ? Prognostic factors	14. ? Prognostic factors
Mr A	Mr B
- Cannabinoids - Critical family - Lack of supportive friends - Stigma (actual and fear of discrimination) - Institutionalisation and poor living conditions - Disconnection from community - Absence of work role, minimal education - Minimal resources - Complications from effects of medication	- Non-exposure to cannabis - Supportive family and friends - Early intervention - Accessible treatment embedded in the community - Retain connections to work, family, peers - Further education - Self-directed use of services - Lifestyle choices

RECOMMENDATIONS

The team's experience of collaboration on the development of the case study, trialling and perfecting the content, and engaging interactively with students, affirmed the value and importance of the multi-disciplinary case study perspective. To complement the content outlined in Figure 1 and the prior discussion on process, the team would re-iterate the following recommendations:

- The case study is not prescriptive; rather it is suggestive of possibilities both in terms of openness to interpreting the consumer experience and the varied therapeutic responses. The case study needs to be used in the spirit of openness as a discussion starter. If used appropriately, educators will find that each session will lead in different directions depending on the interest and experiences of the practitioner study group.
- The case study is designed to be used with Rogerian reflective style of interaction. The modus operandi is to encourage reflexivity in students in a trusting and encouraging environment order where they feel safe to express ideas and attitudes and share exploration of alternate therapeutic possibilities.
- The provision of information is not pedantic or structured. Clinical information and evidence-based directions are introduced in response to issues arising consequentially from the discussion and are open for critique.
- The case study is to be share in small groups (under 15 participants) to allow the time and space for participation from all members of the study group.
- A multi-disciplinary, multi-perspective panel is an essential part of the case study experience. All members of the team are briefed to input into the discussion when issues arise that relate to their particular expertise. The students need to be provided with information on the background and expertise of each presenter along with a message affirming the importance of respecting difference in perspective.
- The consumer perspective is considered to be an essential and perhaps crucial aspect of the case study. Where possible, it is recommended that the team incorporates a consumer advocate with personal experience in the mental health system. The consumer's presence and response to questions conveys an authenticity and experiential learning experience for the study group that would not be captured by just theorising about consumer issues and responses.

LIMITATIONS

To date, the case study has been developed, trialled and perfected for use with psychiatry graduates. The multi-disciplinary perspective suggests it would be an effective educational medium for other groups including mental health nursing, psychology, social work, allied health and consumer groups. However, as yet the case study has not been trialled with this broad range of groups. Furthermore, there are several areas that are not covered in this case study. A further teaching session incorporating bipolar disorder, women's issues, pregnancy and parenting is being developed to complement this first workshop.

CONCLUSION

Engaging in the collaborative process of developing and trialling this educational case study has been an exciting and satisfying experience. It is gratifying to be involved in an educational experience where students engage with trust and humility in a group process and demonstrate their capacity to be reflexive and open to attitude change. It is the experience of our team that this educational instrument goes some way to addressing the enormous challenges of attitudinal change presently required of the mental health system. It is thus our hope and expectation that in sharing our collaborative efforts, others will also find the content and process of the case study a useful medium for responding to the stimulating way forward offered by the philosophy and practice of modern public psychiatry.

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‘In the PinC’
Trialing of a new system of mental health practice (Partnership in Coping (PinC)

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Abstract

This paper describes the trialing of a system of mental health practice (Partnership in Coping). The system was formulated to translate the philosophy of the recovery model into a practical day-to-day approach to be used by mental health workers. The purpose of the research was to refine the operation of the Partnership in Coping (PinC) system using the subjective experiences of clients and mental health nurses participating in the project.Action research was employed. Data collected by individual interviews and Focus Group meetings were analysed using thematic content analysis.The results of the study were that changes were made to the paperwork and four main changes made to the documentation protocol. An indication of the appreciation of the PinC system was that the nurses and clients requested to continue to use the PinC system after the trial was over. This was approved by management within the health service.

Keywords: Partnership in Coping, rehabilitation, mental health workers, mental health nursing, psychiatric nursing, action research.

Introduction

The purpose of this study was to refine the operation of the PinC system using the subjective experiences of clients and mental health nurses employing Action Research. Action Research, using the technical collaborative approach was considered to be the most appropriate method of research for this project because it is grounded in practice, uses real life situations, is collaborative and action orientated and designed to initiate change in clinical practice. The use of Action Research in this study was also seen as an empowering

experience for participants, who played an integral part in the change process.
This method of research is commensurate with the PinC philosophy in that clients take an active part in the refinement of a system that had been tailor-made to address their concerns.

BACKGROUND

Currently mental health services reflect the approach of the traditional medical model in providing a pathological perspective. This view sees people who experience mental illness as being passive with little regard for their views, opinions or wishes. Mental health nursing practice has been criticised as being biometrically orientated to the detriment of the humanistic focus (Barker, 1995; Cole & Shanley, 1998; Cutcliffe, 2000; Dawson, 1997; Horsfall, 1997; Horsfall & Stuhlmiller, 2000). Shepherd et al (1994) pointed out that clinicians emphasise compliance with medication regimes and monitoring of mental state whilst clients focus on social and practical aspects of their lives. The process of nursing diagnosis fails to take into account the client's understanding of his/her own personal situation in a language that is familiar. A consequence is that there is a loss of control of the situation by the client as he/she is forced to accept the expert's redefinition of his/her concern within a medical paradigm using unfamiliar terminology (Williams, 1990).

Whilst some approaches to mental health care contain some elements to commend them no one approach adequately reflects mental health nurses' holistic perspective, the length and nature of their informal contacts, the 'ordinariness' of the nurse's relationship with clients and the nurse's knowledge of the client's social and physical environment (Shanley et al, 2003). Most importantly they fail to provide a framework that sees clients as active participants in the decision making processes relating to their care. PinC was developed as a system of mental health nursing to address these shortcomings.

THEORETICAL FRAMEWORK

Rotter's (1971) Social Learning Theory asserts that a person's behaviour is determined by his/her goals, and that the prediction of a person's behaviour is based on the nature of a given situation in which that person is a part of, as well as his/her past experience (Rotter & Hochreich, 1975). Research that has been carried out in relation to Rotter's theory has indicated that beliefs about personal control can influence behaviour (Lefcourt, 1976). One concept that is central to Rotter's theory is that of locus of control. Locus of control refers to how far individuals see themselves as in control and responsible for the course of both desirable and undesirable occurrences which are experienced (Lefcourt, 1976). Rotter states that there exists both an internal and external locus of control. Internal locus of control refers to the perception of events as being a consequence of one's own actions and thereby potentially under personal control. In contrast, external locus of control is referred to as the perception of events as being unrelated to one's own behaviour and therefore beyond personal control (Lefcourt, 1976). The study gives responsibility for deciding on changes that they may wish to make to the people who are to be most directly involved in the PinC system. According to Stringer (1996, p32), action research 'gives people the sense that they are in control of their own lives and … supports them as they take systematic action to improve their circumstances'. These aspects formed the basis of the theoretical framework for this study. The role of the researcher is to facilitate the provision of feedback from clients and nurses and to arrange for the changes that are recommended by clients and nurses to be implemented.

The approach used in this study is commensurate with the theoretical framework of the PinC system. The PinC system of mental health nursing practice sees mental health clients as the experts in their illness (Shanley et al, 2003). Because this system focuses on maximising the mental health clients' own understanding of their concerns and their strengths in coping with their mental illness they are likely to experience a greater degree of internal control over their lives.

METHODOLOGY

Aim of the study

- The purpose of this study was to refine the PinC paperwork and documentation protocol, through action research, on clients' and nurses' reported experiences and recommendations.

Study Design
The study was conducted in a community mental health clinic that services a rural population. A three day education programme was carried out with nurse participants prior to the commencement of the study to assist them to operate the PinC system.

The Advisory/Steering Group, set up to oversee the project, consisted of the Clinical Coordinator for the nurse participants, the manager and an allied health representative of the service, a nurse participant, two consumer representatives and the developer of the PinC system.

The remit of the Advisory/Steering Group was to:

- Receive feedback from the Focus Group meetings and to consider and act on the changes recommended by the focus groups, and
- Act in an advisory capacity and as a resource in facilitation the progress of the Action research project.

Action Research
The design of the technical collaborative approach of Action Research involved three cycles of planned intervention over the three month period. Each cycle of planned intervention involved the use of four activities, plan, act, observe and reflect. These activities interlink with each other with each activity forming the basis for the next activity (Kemmis & McTaggert, 1992). Reflection for this study involved the use of individual interviews as well as Focus Groups. Changes were made at the end of each cycle in response to feedback from the participants of the study.

Sample
The sampling method used is classified as convenience sampling as it involves the selection of the most conveniently available people for use as participants in a study.

Eight Community Mental Health Nurses (CMHNs), three female and one male, from different geographical locations within the same service were recruited for the study. Two were based in the major town in the area and two from the outlying rural areas. The CMHNs involved in the study were experienced practitioners each of whom had more than 15 years service as mental health nurses.

Only those clients whose health, in the opinion of the treating team, would not be adversely affected were asked to participate. The clients' ages ranged from early twenties to mid fifties. Typical case selection (Le Compte, Preissle & Tesch 1993) was employed in excluding clients with unusual characteristics. Those who participated had diagnoses of the most common forms of mental illness. Clients were approached by the researcher who explained the study details and provided a description of the proposed study in writing. Written consent from each client was obtained From the twelve client participants who initially agreed to participate ten took part, four females and six males.

Interviews
Individual interviews were audio-taped and transcribed then analysed using thematic content analysis. During the study three interview cycles took place approximately one month apart.

Focus Groups
Separate Focus Groups for nurses and clients were held to give participants the opportunity to voice their opinions without feeling inhibited because of the presence of their nurse or client.

Analysis

The analysis of interviews used techniques of thematic content analysis which allows the researcher to categorise and codify interview transcripts.

DATA COLLECTION

Data were collected in the form of individual, semi-structured, taped interviews and also Focus Groups using mostly open ended questions. These methods of data collection were aimed at obtaining knowledge of each participant's own perception of the PinC paperwork and documentation protocol as well as generating ideas for changes that might improve these protocols and documentation.

FINDINGS/DISCUSSION

In keeping with practices of qualitative research the discussion within each of the three cycles of the findings is integrated with their description (Holloway & Wheeler, 1996).

First Cycle

Initial Interview

In the initial interview participants were asked questions centred on possible changes to the PinC paperwork. Seven main categories resulted from these questions. These categories included sequencing of sections, number of concerns, sharing of documents, presentation, involvement of the client, goal setting and coping.

These resulted from the open coding technique (Burnard, 1991) of deconstructing the relevant information and assigning subcategories to this data.

First Focus Group Meetings

Nurses and clients in their respective groups were presented with the seven categories derived from questions asked in the first interviews. The categories were discussed with participants to generate ideas for changes that needed to occur. From their responses several changes to the PinC paperwork and documentation protocol were made.

For example, all the participants felt that there was an expectation that six concerns needed to be documented by the client because the paperwork contained space and numbering for six concerns, despite this not being intended in the design of the documentation. One participant remarked:

> *'I have gone for three concerns because this seems workable. I find it not too time consuming'*

As a result of this discussion it was agreed that clients should not be expected to conform to a minimum or maximum number of concerns with a notation being placed on the paperwork that expressed this. Further changes made during this cycle were that both nurse and client participants agreed that the sharing of documents was desirable. The focus groups decided that the client's sense of ownership could be further enhanced by the provision of copies of the documentation to the client, including a copy of the shortened version of the Practitioner's guide. This view was demonstrated in the following statement:

> *'The Practitioner's Guide (to the PinC system) is helpful, I use it frequently. My clients wanted to look at it I made some copies for them'.*

All participants commended the fact that clients have a major role in the decision making processes in the management of their care. This perception concurs with the PinC philosophy and is reflected in the PinC paperwork and documentation protocol. Clients acknowledged that their nurse used the client's own perspective to guide their practices. This approach is a radical change from both the clients' and nurses' previous experiences in mental health services. Usually the clinician is seen as the expert in mental illness with the client a passive recipient of the treatment (Williams, 1990). Participants stated that the PinC system was a new and exciting alternative to the way the existing system operates. Comments made by both nurses and clients powerfully supported the PinC philosophy:

> '*It reverses the role, when the clinician works with the client to document their concerns, the client is in control not me.'*
>
> *'I typed up the forms for the client and then gave the paperwork to the client to read and they give their approval.'*
>
> *'I liked sitting down with the client and using their own words in the document, their concerns, their goals and strategies.'*

Second Cycle
Initial Interview
New information obtained at the first Focus Group meeting was used as a basis for questions for the second individual interviews.
This information centred on issues related to the level of support a client may require when using the PinC system. Other issues to emerge from the first Focus Group interviews were how the PinC paperwork and documentation protocol assisted clients with problem solving, coping, new concerns and having control and influence over their treatment. Following analysis of the data derived from the second individual interviews four main categories emerged. They included ongoing support, problem solving, coping and client ownership.

Second Focus Group Meetings
Participants were presented with the four categories derived from responses to questions asked in the first Focus Group interviews. The categories were discussed with participants to generate ideas for changes to the paperwork and documentation protocol.
Client participants wanted the option of documenting unhelpful as well as helpful coping strategies because they felt they could learn from these experiences. Several participants also felt that these unhelpful coping strategies could act as a trigger for them to take alternative action themselves.

Another issue to emerge was related to the clients' active involvement in their own treatment – namely the setting up of home file systems. One client participant remarked;

> *''That would be good, I need something as a reminder because sometimes I'm not doing the things I should be doing. At the end of the day I can go back and look at it.'*

There was agreement amongst all participants that a home file system would assist by, reminding the client of their plan, improving continuity of care, reinforcing the clients efforts and increase the clients ownership of their treatment and care. As highlighted by Henderson and Laugharne (2003), home files, where the client holds some records relating to their care and illness are now quite common. Stafford and Hannigan (1997) asserted that client held records can empower mental health clients and also assist clinicians to share information. However, several studies into client held records found that there was no general positive or negative effects associated with the use of client held records (Currell, Wainwright & Urquhart, 2003).
The use of home files was not within the remit of the study namely to refine the PinC paperwork and documentation protocol and therefore this proposal was not acted on, though home files may be adopted in further trialing.

Third Cycle
Initial Interview
Details of new topics raised at the second Focus Group meetings were presented to interviewees and their responses elicited through the use of open ended questions. The new topics related to the PinC evaluation paperwork and the provision of feedback to clients after meeting with their nurse. Clients felt that the

evaluation process worked well. Several clients felt that the second question in the evaluation sheet (If you, nurse or client, were to address this concern again what would you have done differently?) was particularly helpful as it gave ideas for future coping and also encouraged the client to think more deeply about the issue. This was evident in the following quote from a nurse participant;

> *'It does help to talk about what could have been done differently. My client identified that she could do more diary writing. The existing (sic previous) system doesn't have a set review system. It's too loose'*
>
> *'The evaluation was straight forward. We did it together' 'I think it is good. You can separate what's achieved and what's not'*

Following analysis of the data derived from the personal interviews one category emerged, this was, receiving feedback. The issue of 'feedback' was the major topic presented to the third Focus Group Meeting.

Third Focus Group Meetings

The participants expressed satisfaction with what they had been doing with no new comments or concerns about the PinC paperwork and documentation protocol emerging.

The participants were then presented with the category of 'receiving feedback'.

An idea was put forward by one participant that a feedback summary would be helpful each time the nurse and client met However after some discussion the participants did not feel that it was necessary to compile a summary of information or decisions that are made at each nurse – client meeting. Participants believed that the structure of the PinC paperwork, in particular the review process, allowed for decisions to be made together (by both nurse and client) and therefore both parties would be fully conversant with what had been decided at each contact. The response by the focus groups to this issue confirmed the views expressed in the individual interviews.

As no new topics or concerns emanated from the Focus Group meetings, 'saturation' was considered to have been arrived at. Hence no further cycles of Action Research were required.

CONCLUSION

The aim of this study was to refine the PinC paperwork and documentation protocol. The conclusion is that the study achieved its aim. Changes identified earlier were made and participants commented positively on these modifications.

An indication of their positive attitude was their request to the developer of the system and the service managers to continue to use the PinC system with the amended paperwork even though the study had finished. Approval to continue was given.

The use of Action Research as a means of achieving the aim of the study has been shown to be an appropriate method. Its major attraction was that it is context specific, problem focused and participative (Hart, 1996). The use of individual interviews and focus groups in a cyclical process ensured that no major issues or concerns were missed. The capturing of major concerns about the paperwork and the documentation protocol was evidenced by the 'drying up' of new data, particularly recommendations for change, as the process of data collection in each cycle continued.

Within each cycle the use of Burnard (1991) thematic content analysis provided a useful structure in which to analyse the data and facilitated a stepwise method of organising participants in exploring, discussing and recommending changes to the PinC paperwork and documentation protocol.

As well as changes to the paperwork there were four main changes made to the documentation protocol. These changes included:

- Provision of a shortened version of the Practitioners Guide to PinC to clients.
- A copy of the completed paperwork is given to clients using this system.
- Any number of concerns may be prioritised by the client.
- Unhelpful coping strategies may be included in the plan of care unless the client does not wish to include them.

Each of these changes was intended to ensure, in varying ways, that clients were to take responsibility for their plan of care. The nurse's role was to assist them. It is evident that these documentation protocol changes related to the issue of sense of control, with clients clearly wanting to have more influence over what happens with their treatment.

Apart from the success in refining the paperwork and documentation protocol other interesting issues emerged. For example although the majority of the findings from both clients and nurses related to changes in presentation and format there were some differences in emphasis between them. Nurses focused, in the main, on improving documentation clarity whilst clients focused on content, for example, the opportunity to include unhelpful as well as helpful strategies in the PinC paperwork. These proposals from clients allowed changes to be made that resulted in a greater sense of control over their treatment situation. The implications for mental health nursing practice of this study, in which clients, nurses and managers had played a crucial role in producing changes, means that it is likely that the modified PinC system would also be accepted by other major stakeholders as applicable and appropriate for their needs.

Theoretical Framework in light of Findings

The Action Research approach used in this study has been shown to be commensurate with Rotter's (1971) locus of control concept which formed the theoretical framework for the study. Giving participants the responsibility to make changes in the documentation conveys a sense of control (internal locus of control) that has immediate and direct relevance to them. An example of internal locus of control can be seen in cycle one of the Action Research where participants recommended that a client should not be forced into identifying a limited number of concerns. As a result of this a notation was placed on the first sheet of the paperwork that reads 'Any number of concerns may be prioritised'.

Future Research

Several issues emerged from the study that may warrant further investigation; firstly investigation into the perception that having a shared plan gives the clients a sense of feeling empowered and secondly research into the advantages and disadvantages of using home files when working with mental health clients.

Because this study was carried out in a community setting no conclusions can be drawn about its applicability to inpatient settings. Replication of the study within an inpatient setting would therefore be required to ensure the paperwork and documentation protocol is adapted to suit the needs of this setting.

As indicated earlier in the project report the next step in the development of the PinC system is to carry out a full trial across a mental health area.

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Family Caregiving Of Clients With Mental Illness In The People's Republic of China

(PART I: HISTORICAL BACKGROUND)

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Abstract

In this paper, the writer attempts to describe a brief historical review of family caregiving of clients with mental illness in the People's Republic of China. Family responsibility in taking care of persons with mental illness was encouraged by traditional Chinese culture. However, political movement and ideologies in Marxism and Communism tended to replace family caregiving by political education and class brother concern. Later, the decline of the Cultural Revolution and modernization of economy brought back the importance of family caregiving in treatment and rehabilitation of persons with mental illness.

INTRODUCTION

Mental illness has long been a great problem in our society. The treatment and rehabilitation of clients with mental illness are regarded as a heavy burden for every government. In the People Republic ofsd China, it is estimated that there are 16 millions of adults with mental illness; 30 millions of adolescents and children with emotional and behavioral problems and numerous old people with dementia and mental problems (Ministry of Public Health, Ministry of Civil Affairs, Ministry of Public Security and Disabled Persons Federation, 2002). Apart from psychiatric treatment and rehabilitation services, the effort of the family caregivers can never be undermined. In the U.S.A, about 65% clients with mental illness who are discharged from mental hospitals returned to their own families (Goldman, 1982; Lefley, 1987). In Canada, around one to two thirds of persons with schizophrenia live with their family members (Seeman, 1988). However, in the People's Republic of China, over 90% of persons with schizophrenia live with and are taken cared by their family members (Phillips, 1993; Pearson & Phillips, 1994). The burden of family caregiving in the People's Republic of China is further intensified by its unique social, cultural and legal contexts. In this paper, the writer discusses the plight of family caregivers of clients with mental illness in the People's Republic of China.

FAMILY CARE : THE ENDLESS BURDEN

Family care of clients with mental illness is an endless burden to family caregivers. Lefley (1996) identified three types of burdens faced by family caregivers. These burdens are also echoed by related studies.

1. Objective burdens in coping with the mental illness (financial burden, time and effort in caregiving, disruption of daily routine and social life) . (Lefley, 1996; Lefley, 1992; Estroff, et.al. 1994; Saylor, 1994; Hatfield & Lefley, 1999).

2. Subjective burdens in facing the mental illness (feelings of loss, shame, worry, anger and hopeless towards the client with mental illness) (Lefley, 2000 & 2001).

3. Burdens in management of problem behavior of clients with mental illness (assault, mood swing, unpredictability, negative symptoms) (Lee, et.al. 2000; Bayer, 1996).

Regarding various types of family caregivers, parental caregivers seem to be most responsible ones. But they are also highly stressful, frustrated in taking care of their children with mental illness (Lefley, 1996; Lefley, 2000; Lee, et.al.,; Hatfield & Lefley, 1987 & 2000). For spouse as caregivers, they suffer the transformation of their beloved ones with strong feelings of loss and grievance (Judge, 1994). Also, behavioral problems and functional difficulties of their spouses with mental illness are difficult to handle and explain to their children (Noh & Avison, 1988). Facing all these burdens, family members possess various types of coping strategies. There are various factors influencing the coping of family caregivers. These factors are availability of social support and network, opportunities and their willingness to join various types of family support services and programs (Solomon & Draine 1994 & Johnson, 1994). In fact, stress and coping of family caregivers are also influenced by mental health services and policy, as well as social and cultural contexts (Lefley, 2001; Lefley, 1998; Milstein, et.al., 1994; Manderscheid & Barrett, 1987; Manderscheid & Sonnenschein, 1992). In this paper, the writer tries to discuss various factors that influence the family caregiving of clients with mental illness in the People Republic of China. As related issues can be covered within the length of an article, this paper is divided into two parts, Part I and Part II. In Part I, the writer will give a historical overview of mental health services and family caregiving in China. In Part II, the writer will discuss the current situation of family caregiving in China.

A BRIEF OVERVIEW OF MENTAL HEALTH SERVICE AND FAMILY CAREGIVING IN THE PEOPLE'S REPUBLIC OF CHINA

Before the Establishment of the People's Republic of China

Before the establishment of the People's Republic of China, mental asylums were built by western missionary. The first one was built by an American missionary, John Kerr (Tucker, 1983; Spencer, 1981; Pearson, 1991). Gradually, small size asylums were found in Beijin,. Shenyang, and Suzhou. Only a few people with mental illness could be treated in these asylums, including five major hospitals and psychiatric wards (Bowman, 1948; Kao, 1979; Pearson, 1995; McCartney, 1926). Most clients with mental illness were in fact, either not being recognized or taken care by their own families. Within traditional Chinese medical perspective, mental illnesses were perceived as `insufficient spirit and air' (weakening of mind due to poor condition of body) or `saliva blocks one's mind' (failure of one's immune system confusing one's mind and mentality). In terms of Buddhism, mental illnesses were consequences of one's previous bad deeds done by oneself and his or her family members. Under such condition, persons with mental illness were only treated by Chinese herbalist doctors. Most Chinese may seek the blessings from gods in local temples in curing the mental problems of their family members.

Initial Political Care from 1949 to 1963

After the establishment of the People's Republic of China, the Communist Party embraced a political orientation in delivering related social and welfare services. Political ideologies such as Maoism and Socialism and political bureaucracy played a vital role in shaping mental health services. In 1958, the First National Conference of psychiatrists at Nanjing determined to abandon westernized individualistic treatment and replaced by collective political education (Lin, 1985); open door policy (Shen, 1985); rural home based treatment and indigenized Chinese treatment (Ho, 1974; Chin & Tuan, 1969; Pearson, 1995). Within this period, communist oriented `class brothers and sisters' as well as `class enemies' challenged the traditional Chinese family structures. Chinese people were taught to criticize their family members' Capitalistic evil thinking so as to defeat class enemies. Under this circumstance, family care for clients with mental illness though still practiced by Chinese people, but was suppressed by related policy makers and professionals. Instead, medical professionals identified clients with mental illness as `class brother' to fight against `mental illness' which originated from `evil Capitalistic thinking'. In fact, class brother and bourgeois within Communism, was a challenge to traditional Chinese family orientation. In traditional Chinese culture, the family is so important to the Chinese that a special kind of strong familism has been formed, stressing the undeniable predominance of the family over its members in almost all domains of life (Yang, 1995:22). Under the influence of traditional familism, individual Chinese have to subordinate their personal goals, interests, and welfare for the sake of their families (Yang, 1995) or sacrifice himself or herself for the sake of family honor, harmony, prolongation, and family reputation and wealth. However, under the influence of Communism, class brothers and the benefit to Community Party tended to challenge or even diminish the importance of familism. Family caregiving for persons with mental illness seemed to be replaced by caregiving rendered by political brothers and sisters.

Full Political Care During Cultural Revolution (1964- 1976)

During the Cultural Revolution (1964- 1976), the whole China was fully occupied by a zealous worship of political leader, Mao Zedong. His idea and ideologies were regarded as most responsible way to build up the `New Communist China'. Perception, treatment and rehabilitation of clients with mental illness were interpreted by Mao's thinking and ideas. Revolutionary Committees in mental hospitals, neighborhood and in working places monopolized diagnosis, admission, discharge of clients with mental illness in mental hospitals as well as their integration within own communities. Political education of Mao's ideas was regarded as the most effective way to cure mental illness (Yip, 1989; Kao, 1974; Kao, 1979; Leung, Miller and Leung, 1987; Pearson, 1995). Under this circumstance, family was no long regarded as the cohesive social unit for everybody in the society. Instead zealous political worship encouraged mutual criticism and battle among family members with different political orientations. Family care of clients with mental illness was totally ignored by related parties. In some cases, those family members with close connection with Capitalistic linkage might bring extreme mental stress or political torture to other family members. There were considered as the sources of `Capitalistic Evil'. A mechanism of `self criticism' and `mutual criticism were used in political education group for persons with mental illness. In this group, members would critically debate, argue and criticize every one's Capitalistic thinking so to eliminate `class evil' in one's mind and one's family. Very often, one had to be highly critical about his or her Capitalistic family members. Such family members were labeled as `class enemies' and Capitalistic thinking is regarded as the sources of mental illness. Some `Red Guards' in those days even tortured their family members to death so to demonstrate their faithfulness to Maoism, Marxisim and Communism (Yip, 1989; Yip, 2004). Within this period, family caregiving, was in fact, totally replaced by `political caregiving' for persons with mental illness.

Mental Health Services Reform (1976- 1987)

After Mao's death and the fall of the Gang of Four, under the strong, leadership of Deng Xio Ping, China was gradually regained its momentum on economic development and modernization. Related welfare and social services examined their deficits and weaknesses. In 1987, the Council approved a formal document. `Opinions about Strengthening Mental Health Work' (Pearson, 1995). In this document, the Chinese government admitted that measures had to be done to face the drastic increase in the prevalence of mental illness from 0.7% in 1970s to 1.54% in 1980s. Furthermore, because of serious inadequacy in related services, only 10% clients with schizophrenia could be treated in mental health services. Most of clients with schizophrenia could thus be cared by their own family members (The Second National Meeting on Mental Health Service: 1987) Within this orientation, the role of family care and family responsibility in taking care of clients with mental illness were resumed. However, because of the prolonged closed door policy in isolating influence of western countries, related professionals and policy makers did not propose any services or intervention to support family caregivers of clients with mental illness. Also, there

Commericalization of Mental Health Services (1988 to Present)

Drastic economic development in the People's Republic of China brought along not only change in industrial production and urban life but also commercialization of welfare and medical services. China government began to withdraw funding from mental hospitals. In 1990s, staff in hospitals run by the Ministry of Public Health had to find 30% to 50% for their take home pay from the charging of admitted patients (Phillips, 1993; Pearson, 1995). In 2000, many hospitals have to run on a self- sufficient basis. For those deprived and poor clients with mental illness, they had to be admitted by mental hospitals run by the Ministry of Civil Affairs. On the one hand, under the influence of western scholars, professionals in China began to implement various types of family interventions including family counseling, home based care and family support group, (Zhang, Yan & Phillips, 1994; Zhang, Wang, Li & Phillips, 1994; Wang, Gong and Niu, 1994; Wang, 1998). On the other hand, all these new developed services only support these clients' families who were enough to pay for their services.

SUMMARY

As a summary, this paper is a brief description about the historical development of mental health service and family caregiving for persons with mental illness in the People's Republic of China. It seems that family caregiving in China was influenced by two forces. One was the political control and sanctioning on mental health services that reached its peak in times of Cultural Revolution. Another force was the traditional Chinese cultural perception of mental illness and family caregiving. Facing the drastic economic development and commercialization of social and medical service, there evolve another forces of scarcity of resources of in providing adequate mental health services and related support to both persons with mental illness and their family members. In the next article (Part II: Current Situation), the writer will discuss how these three forces shaped the challenges and opportunities of family caregivng for persons with mental illness in China.

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Family Caregiving Of Clients With Mental Illness In The People's Republic of China

(PART 2: CURRENT SITUATION)

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Abstract

Family caregiving for clients with mental illness is crucial in psychiatric treatment and rehabilitation. It is particular important in the People's Republic of China where over 90% of clients with schizophrenia are taken care by their family members. In this paper, the writer attempts to describe current situation of family caregiving of clients with mental illness in the People's Republic of China. Within social and cultural conditions in the People's Republic of China, family is regarded as the most important caregiving for clients with mental illness. However, family caregivers in the People's Republic of China are not properly supported by related professionals, interventions and services.

FAMILY CAREGIVING FOR CLIENTS WITH MENTAL ILLNESS: OPPORTUNITIES AND CHALLENGES

Family caregiving for clients with mental illness are influenced by various factors such as political, social, cultural contexts and related policies and services (Lefley, 1998; Lefley, 2001; Solomon & Draine, 1994; Johnson, 1994; Milstein, et.al. 1994). In the People's Republic of China, all these factors played a crucial role in shaping the family caregiving of clients with mental illness. There are both challenges and opportunities in facing the current and future development of mental health services in the People's Republic of China.

Social and Cultural Context of Family Caregiving

Under the influence of the traditional Chinese culture, family is regarded as the most important cohesive unit in the society. Based on related research findings in Taiwan, Hong Kong and the People's Republic of China, Yang (1995) asserted that Chinese people are deeply influenced by `familism' which means individual Chinese are accustomed to place family honor, family continuation, family prosperity and stability more than individual interests. On the one hand, individual family member should sacrifice themselves to preserve, maintain and enhance family honor, stability and prosperity. On the other hand, members of family can be or should be protected continuously by their families. Lau's (1993) studies showed that Chinese families were unwilling to seek outside help in caring family members with disabilities as it may imply shameful disgrace to the whole family. Under that sort of Chinese social orientation, it is understandable that families in the People's Republic of China are inclined to assume the responsibility in caring their family members with mental illness. They feel shameful to disclose family members' mental illness to others. They may feel inadequate in asking external help including professional intervention.

Traditional and Superstitious Perception of Mental Illness

Within traditional Chinese superstition, mental illness is perceived as something mythical like demon possession or by some evil spirit. In Buddhist thinking, one's suffering is the consequence of previous misdeeds. Thus, mental illness may be perceived as punishment of misdeeds done by clients themselves or their family members. Within this orientation, mental illness is shameful label for Chinese persons with mental illness and their family members. It implies that related family member may have done something immoral or mischievous in this life or the previous life (in Buddhism, one has three lives, the previous, the present and future. One is a man in this life but may become an animal in the next life because of his misdeeds) Being influenced by such superstitions, family members of clients with mental illness, especially those in rural areas where traditional superstition still prevails, family members may feel reluctant to disclose or even admit their relatives' mental illness. Sometimes, even though the family members have good knowledge about mental illness, still their neighbors or friends may gossip around suspecting or believing that the occurrence of mental illness is a kind of punishment of misdeeds and immorality done by family members. Perhaps, the following self narration told by a Chinese farmer can briefly describe the influence of traditional superstition on family members of clients with mental illness:

> *`Oh heaven, what misdeeds I have done in my previous life that deserve that kind of punishment. I cast all my hope on my son. I spent all my money for his schooling but he was crazy just because the leaving of girl friend. He talked to himself frequently saying that he was the God of heaven that attracted beautiful girls. Everybody in the village knew that he was crazy. It was a terrible shame to our whole family. My neighbors gossiped around me thinking that my son's madness was a consequence of my misdeeds done in my present and previous life. In fact, I have done nothing immoral in my life. I tried to be kind hearted to everybody. The only misdeed I had done so far was killing of my cow that had worked for me for fifteen years, but it was so sick and painful. My wife blamed me that my son's craziness was due to my misbehaviors toward our god in our village temple. Last year I refused to go the temple and attended the annual ceremony for our god's birthday. '*

Shifting of Caring Responsibility from Government to Family

The central government of the People's Republic of China presumes that family members should shoulder the caring responsibility of clients with mental illness. In the Marriage Law enacted 1980, Article 14, Article 15 ensured the obligation of a spouse to take care one another as well as their children in times of incapacity including mental illness (Pearson & Phillips, 1994). The obligation to care is further complicated by the withdrawal of the government in providing free care for clients with mental illness. Family members, especially parents and spouse are obliged to provide food, accommodation, and other facilities to support living of clients with mental illness. Furthermore, related legislation sanctions family members in making health care decision such as admission by mental hospital, accompanying clients in psychiatric outpatient clinics. In many cases, doctors can refuse to treat a client that is not accompanied by his or her family member (Phillips, 1993; Pearson & Phillips, 1994). The following story told by a Chinese psychiatrist can briefly show these situations.

`Very often, we can do nothing. It all depends on whether or not related parents and spouses are willing to take their children and spouses for treatment. Our legislation authorizes immediate family members including parents, spouses and children to make health care decisions rather than medical professionals. Once there was a client with mental illness with disposition of violence. He hurt his sister at home by a knife and was taken to our hospital by his neighbors. However, as his father refused the admission. They went home. We could do nothing, except waiting for next time the re-occurrence of another violent incident.'

Legally speaking, only those mental hospitals run by the Ministry of Public Security (forensic hospitals) can make involuntary admission and compulsory detention of clients with mental illness, disposition of violence and criminal records. For those mental hospitals that are run by the Ministry of Civil Affairs and Ministry of Public Health, family members are the final decision makers in determination of admission and discharge of clients with mental illness in mental hospitals. For those areas where forensic mental hospitals are absent, admission of clients with mental illness and disposition of violence is still determined by their family members.

Family Coping with Mental Illness

Facing the endless burden in taking care of the clients with mental illness, family caregivers in the People's Republic of China have to cope by using their own resources and connection. In taking care of their children with mental illness, Chinese parents tried to ensure continuous care by having a marriage, finding suitable jobs and having grandchildren (Pearson, 1995; Phillips, 1993; Pearson & Phillips, 1994). Under the influence of traditional Chinese culture, an normal adult should be married, having a decent job and having one child (under the family planning law of the People's Republic of China, every couple is only allowed to have one child). In fact parents with adult children with mental illness are kept between a dilemma. On the one hand, they feel shameful about their children's mental illness. On the other hand, they may try to prove that their children are in fact as normal as other persons. The pursuit of arrangement of marriage, job and having grandchildren are highly symbolic in meaning in their coping of their children's mental illness. First, it symbolically means that their children are normal adults as others. Secondly, it implies that their only child, especially the son can still succeed the family line in the next generation. Thirdly, it means that their children with mental illness can be taken care by their spouses.

Coping by Marriage Arrangement

Despite the disapproval of the Marriage Law which prohibited marriage with a person with schizophrenia and bipolar disorder, many parents still try their every mean to arrange marriage for their children with mental illness, in particular their sons. There are trade offs within these arrangements (Phillips, 1993; Pearson & Phillips, 1994). For example, a country girl living in highly deprived rural area may be willing to marry a rich man in a developed city so that her unit of residency can be transferred from deprived area into highly developed cities. In some cases, the parents concerned may disguise the mental illness of their sons or daughters in marriage. However, in real situation many of these marriages may end up with divorce or legal accusation. Related document and records show marriage of persons with schizophrenia bears ten times divorce rate in comparing with those average couples in the People's Republic of China (Pearson, 1995).

Coping with an Arrangement of Job

Parents of clients with mental illness in the People Republic of China may try the very best to arrange a job for their children. As vocational rehabilitation in China is not well developed with only a few work station therapy units in well developed cities (Luo & Yu, 1994), clients with mental illness and their parents have to find their own resources. In rural areas, where labor intensive farming is needed, farmers like to keep their sons with mental illness as a manual labor to help in farming work (Qiu and Lu, 1994). In urban areas, family members have to utilize their own social connection to secure a job for clients with mental illness. They may try to bring their children to the same factory they are working as simple manual labor. For those parents with authority and social status such as government official, heads of factories or managers in companies, they can easily make job arrangements for their children with disability including mental illness. For those parents who are poor, powerless and deprived, they have to keep their children with mental illness at home.

Pseudo-Coping with Avoidance, Denial and Tolerance

Drastic economy development in the People's Republic of China does not bring along equality in wealth distribution. Instead it intensifies the difference between the poor and the rich. Within the 1.3 billion population, only a few are much more richer than before, most population still have to live a hand to mouth life, especially those in deprived rural areas. In family caregiving of clients with mental illness, only a few family caregivers can afford to pay charges for related medical treatment and rehabilitation for their family members with mental illness. Only few of them are able to use their own connection and resources to secure a job, and arrange a marriage for their children with mental illness. For most family caregivers in the People's Republic of China, the coping mechanism they can use is avoidance, denial and tolerance. Avoidance implies the following:

1. avoidance of admitting the mental illness of their family members;
2. avoidance of contacting others, including neighbors, friends and relatives.
3. avoidance of seeking for help from related professionals.

Denial implies denying that their family members having mental illness. Within the influence of traditional Chinese culture, denial may appear by attribution the cause of mental illness to superstitious and mythical demon possession and follow by seeking the help from gods in local temples. Tolerance means endless tolerance of clients' bizarre behaviors, fluctuation of emotions, withdrawal, inert and passivity. In some cases, parents in well developed cities may send their children with mental illness back to their mother village in rural areas and look after by close relatives there. In some families, one of the parent may bring the child to other city so to avoid the labeling effect on both the family and the client (Pearson, 1995). Perhaps, the following narration told by a family member in People Republic of China can briefly describe the plight of the family member in caring clients with mental illness.

> *`My son has suffered from schizophrenia for ten years. Within these ten years, life is a total torture. At first, we sent him to hospital for one month by borrowing a huge sum of money from my friend. When he was discharged from hospital, he looked better. But no sooner, he relapsed again, indeed, we could not afford for further treatment. He simply turned worse by locking himself at home and refused to go outside. We could do nothing. You know, my wife and me have to work very hard to earn a hand to mouth in this highly competitive city. We could not look after him. Later, his grandfather brought him to my mother village and he was then looked after by his grandparents. Unfortunately, his grandfather died of heart attack one year later. My mother was sick and was too weak to after him. I brought him back home. His schizophrenic symptoms prevailed. I had tried every mean including praying to my God in local temple, seeking help from Chinese traditional medicine and tried to encourage him to work as manual labor in my factory. The manager in my factory was my classmate in high school. He was kind enough to care about my son. However, months later, he refused to work. He continuously isolated himself from the reality, absorbing in his delusion that he was a talented scientist that one day he could make a lot of money by new invention. Frankly speaking, apart from keeping him at home, I can do nothing. He is a shame to my family. I and my wife suffered a lot in taking care of him. To avoid being labeled by others, we avoid meeting with our friends, our relatives and our neighbors. My son is hopeless and my life is helpless. We have to endure the burden endlessly. Our worry is that when we die no one can take care of my son.*

INADEQUATE FAMILY INTERVENTION AND SERVICES

Facing the insurmountable demand and burdens of family caregivers in the People's Republic of China, there are only a few services and interventions provided by related parties. These services and interventions are: home based care, family counseling, guardianship network, psychoeducational programs and family support group.

Home Based Care

For those highly deprived rural areas where services accessibility is definitely a problem, home based care was tried out in some areas in the People Republic of China. Wang (et.al, 1994) described this in the following details:

> `The home care treatment program is provided to patients with acute symptoms if their families are willing to manage them in the home and if their behavior does not pose a threat to self and others….The program which is primarily provided by the township level non-psychiatric physician, combines pharmacological treatment, counseling, family education, supervision and rehabilitation.

> Acute symptoms are managed with does of neuroleptic medication, but if the illness is too severe to manage in the home, the patient is sent to the country psychiatric hospital for treatment and then returns to the community after the symptoms have improved….The township-level physician and the village doctor instruct family members in the basic principles of rehabilitation and assess the patient's functioning regularly.' (Wang, Gong & Niu, 1994: 109)

In other words, basic outreaching services are provided by physicians with the help of a local village health worker which may be par-trained with experience in working with clients with mental illness. This sort of program is good in covering a wide range of rural areas. The one implemented by Wang, Gong and Niu (1994) in Yantai, Shandong was provided free of charge to clients with mental illness (Phillips & Pearson, 1994). However, in other places in the People's Republic of China, outreaching services provided by physicians to rural areas are charged similarly as medical consultation provided by outpatient clinic which are unaffordable to those clients in deprived rural areas.

Guardianship Networks
Guardianship network was proposed by The Eight Five Year Plan for Disabled People, as indigenized service model for community integration of people with disability including clients with mental illness. However, only a few areas such as Shanghai, Guangzhou, Nanjing and Suzhou implement this type of services in psychiatric treatment and rehabilitation (Zhang, Yan and Philips, 1994). Each client with mental illness was cared by a group of three individuals, a family member, a local health worker, and a local community worker. This network was closely linked up with professionals in mental hospitals and psychiatric outpatient clinics. In Shanghai, these networks had already been established in 3630 of the lane committees (grass root political committees) throughout the city. In most cases, officials from lane committees appointed volunteers, usually retired teachers, professionals or workers to take care of the family and clients with mental illness. In 1989, there were in total of 52, 487 community members participating in these networks, supervising 51,232 clients. They played a total of 234,698 home visits. In fact, this service model is similar to case management and social support network in western countries. It can provide a comprehensive local network in community integration of clients with mental illness. However, it also implies a strong local control that governing the behaviors of both clients and family members in every day life. Within the political control of the Communist Party, it easily becomes a kind of political manipulation on political dissidents. Also, the organization of this local network requires a high input of para-medical staff or well educated volunteers with good mental health literacy. All that can hardly find in other less developed areas, especially in rural areas.

Psychoeducational Programs
Despite the influence of superstition and traditional perception of mental illness, family caregivers in the People Republic of China are, in fact, seeking for explanation of mental illness, especially those well educated ones. In a study conducted in mental hospitals in Hubei Province, the causes of mental illness regarded by family caregivers were personality problems (78.3%), social causes (75.6%), supernatural causes (40.5%) and somatic causes (18.9%) (Pearson, 1993). Thus, psychoeducational groups and programs in providing information such causes, treatment and rehabilitation of mental illness as well as daily care and management of clients with mental illness are important to family caregivers in the People's of Republic of China (Phillips & Pearson, 1994). Preliminary psychoeducational programs had been tried out in some mental hospitals in developed cities like Shanghai, Guangzhou, Nanjing and Suzhou. These programs were proved to be effective by related studies (Zhang, et.al, 1994; Zhang, Yan & Phillips, 1994; Phillips & Pearson, 1994; Xiong, et.al, 1994; Wang, 1998; Zhang & Yang, 1993). However, all these programs are only implemented in a few mental hospitals in a few well developed cities. They have not been widely accepted by mental health practitioners in the People's Republic of China.

Family Counseling and Therapy
Under the influence of western oriented family therapy and family counseling, some mental health practitioners in the People's Republic of China are keen on conducting family counseling and therapy. Zang (et.al 1994) had conducted family counseling in Suzhou, Jiangsu. The content of family counseling is:

`Typical discussion topics at family counseling sessions were as follows: life events that occurred before and after the patient fell ill and methods for avoiding or resolving these stressful circumstances; family members' attitudes about the patient's illness; the importance of thinking of the patient's symptoms as manifestation of illness, not the result of a `bad personality' or `fate'; the necessity of not reprimanding the patient in a hostile manner; and value of not being over concerned that one excessively restricts the patient's contact with the outside world' (Zhang, et.al., 1994: 97)

From Zhang's description, it seems that what they did was giving advice or conducting psychoeducation to individual family caregivers rather than doing family counseling or family therapy. They might not have sufficient training in family counseling and family therapy. Nevertheless, mental health practitioners in mental hospitals might still be fond of conducting family therapy and counseling. The reasons behind may be that family therapy and counseling are regarded as the basic requirement to upgrade the status of the mental hospitals. Also, among different types of services, family therapy and counseling can charge expensive consultation fees. In a less developed city in China, the average charge for clients in receiving family counseling is about 2 US dollar per hours and 4 US dollars per hour for family therapy (it more or less equal to the average daily salary of a factory worker). Many of these counselors and therapists are not properly trained. That means, though family therapy and counseling seems to be favorite of some mental health practitioners in the People's Republic of China, its standard of professional practice is still questionable and its affordability to the general public is also highly doubtful.

Serving the Rich but Neglecting the Poor

The central government of the People's Republic of China tends to withdraw funding in mental health services, related treatment and rehabilitation services, like hospitalization, outpatient medical consultation. Because of that, family counseling, family support group and family therapy have to run on a self sufficiency basis. Clients with mental illness and their family members have to pay for their own treatment and services. As a consequence, these services may only be accessible and available to those rich enough to pay for their charges but not for those poor and deprived. For instance, the monthly fee for hospitalization is about 250 U.S. dollars in some less developed cities in China. It is more than five times of monthly take home of a factory worker. Similarly, for each consultation in an outpatient clinic, the client has to pay about 20 U.S dollars. Thus, instead of taking a client with mental illness for proper treatment, related family members may ignore treatment and rehabilitation as they can not afford to pay related fees.

RECOMMENDATION: FACING THE OPPORTUNITIES AND CHALLENGES

Facing all these challenges, the following suggestions may create opportunities to improve family caregiving of clients of mental illness.

1. Supporting Family to Support Clients with Mental Illness

It is important that the government can shoulder responsibility in supporting family caregivers in caring clients with mental illness. Instead of regarding all related services should be self sufficient by imposing fee charging on clients, government should finance related services so that family caregivers, especially those poor and deprived can receive proper support in caring clients with mental illness.

2. Relative Mutual Support Group and Locality Support Network

Instead of developing and rendering clinical services that are highly resource consuming and are unaffordable to most family caregivers in China, it is important that professionals can assist family caregivers to develop relative mutual help groups and locality family support network. Mutual help groups for family members encouraged family caregivers support each others in family caregiving of clients with mental illness. They can share feelings and experiences with one another. They can help one another in daily family caregiving such as reminding clients to take medication, dealing with client's symptoms, facing public stigmatization and facing clients' negative symptoms. Locality family support network ensures that clients can seek help from other relatives, neighbors and friends. All these natural informal support system are crucial in facing the scarcity of resources. All these social support and networks can also help clients with mental illness to integrated back to the community naturally.

3. Professional Training and Commitment

Many medical professionals in the People of Republic of China are still biochemical oriented. They tend to neglect the psychosocial aspects, in particular family influences. It is important that sufficient professional training can be given to related professionals so that they can appreciated the importance of family caregiving in the process of treatment, rehabilitation and community integration of clients with mental illness. Related workshops and courses on family caregiving should be jointly organized by schools of medicine, Ministry of Public Health and Ministry of Civil Affairs and departments of social work in universities. These courses can run in a self- sufficient basis and taught by related experts from western countries as well as Chinese scholars from Hong Kong and Taiwan.

4. Culturally Sensitive Family Counseling

It is crucial that professionals in the People's Republic of China can develop their own culturally sensitive family counseling and therapies rather than straightly borrow from those in the western countries. Family counseling and therapies done to clients with mental illness and their relatives should be modified, indigenized and shaped according to the unique political, cultural and social contexts in China.

CONCLUSION

As a conclusion, this paper is an attempt to describe the family caregiving for persons with mental illness in the People Republic of China. It seems that under the influence of traditional Chinese culture, family is regarded as the most important structure in caring vulnerable family members including those with mental illness. The shifting of the caring responsibility from the China government to the family further intensifies the endless burden of family caregivers of persons with mental illness. Furthermore, recently developed intervention and services for family caregivers seem to benefit only those rich ones but not the poor those as they can not pay the expansive charges on these services. As a result, many family caregivers are left unattended in an endless struggle with family members with mental illness. Facing all these challenges, recommendations are made in this paper to may create opportunities to improve family caregiving of clients of mental illness. All these suggestions should be further explored and supported by continuous research, pioneering projects and support form central government of China to make theme workable and applicable within, cultural, social and political contexts in China.

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Drug –Specific Responsiveness of Negative Symptoms

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Abstract

Introduction: negative symptoms in schizophrenia are among the important barriers against psychosocial rehabilitation of such patients. Adjunctive drugs can be used for reducing the severity of these symptoms. In this research we studied the specific efficacy of different cluster of drugs on negative symptoms to see that whether there is any relationship between symptom's responsiveness and drug's variety.

Materials and method: after a primary prevalence survey regarding Negative symptoms, 170 schizophrenic patients were divided into three different groups, and then the aforesaid adjuvant drugs were examined in three double-blind clinical controlled trials. Estimation of negative symptoms by "SANS" were done at the beginning of each trial for the first time and then three weeks later, after prescription of drugs in lower dosage and finally at the end of sixth week, means three weeks after doubling the dosages. The data were analyzed by z and chi-square (X2-test) formula.

Results: Attention Deficit was the most responsive symptom in comparing with other negative ones. Nortriptyline, Fluexetine and Bromocriptine had ameliorated it in 40%, 41.6% and 24% of the patients in their own groups, respectively. The best effect of Clomipramine, Fluvoxamine,and Citalopram was on Affective Blunting ,which showed amelioration in 40%,50% and 50% of the patients, treated by the aforesaid drugs ,respectively. All of them are grouped as Serotonoin Reuptake Inhibitors .Maprotiline (a noradrenergic tetracyclic) had reduced the severity of Alogia and Anhedonia-asociality in 50% of cases in its group, which was remarkably more than other negative symptoms in the same group. The best effect of Alprazolam (as a benzodiazepine) was on Avolition-Apathy (40%).

Conclusion: Different adjunctive drugs had different profile of benefit on negative symptoms in schizophrenia. This phenomenon can guide the therapist towards a better and more effective amelioration of such symptoms, which need to be overcome in a rehabilitation goal setting process.

Introduction

Negative symptoms in schizophrenia as one of the major criteria in addition to other ones in DSM TV-TR, include presentations as follows: 1)Restricted up to flat affect 2)Apathy 3)Alogia 4)Anhedonia 5)Avolition 6)Asociality 7)Attention Deficit (1,2). According to Carpenter existence of at least two of these symptoms or more for duration not less than twelve month is enough for diagnosis of deficit syndrome, as a subtype of schizophrenia (3). In DSM IV-IR, too, negative symptoms in addition to one of the positive symptoms (delusion, hallucination, disorganized speech, and disorganized behavior) for duration of at least one month is enough for diagnosis of acute phase. Anxiety, suspiciousness, mental retardation, depression, Parkinsonism and lack of environmental stimulants can result in secondary negative symptoms or reinforcement of primary ones. The importance of negative symptoms can be deduced also from the hidden firm barrier which is constructed by them between patients and others around them. Inaccessibility to patients which is resulted from such cluster of symptoms, after suppression of positive symptoms, can make different psychosocial interventions, which are employed in the framework of community psychiatry, futile. Adjunctive pharmacotherapy can reduce the severity of such symptoms in a variety of ways. Different drugs like Heterocyclics , Serotonin-Reuptake Inhibitors and Dopaminergic ones, have different profile of benefit on these symptoms .This variety of profit deserves an appropriate amount of attention because it can prevent unnecessary pharmacokinetic interactions or side effects due to application of more beneficial ones. Although the existing data are not enough yet to guide us towards a comprehensive formulation of these relationship but nevertheless it remains its clinical importance and looking for further findings in the future. As a preliminary investigation for portraying the problem of negative symptoms among our schizophrenic patients and its amplitude we did a prevalence survey on a sample of our patients and then applied the different cluster of adjunctive drugs on some of them.

Methods and Materials

70 patients with diagnosis of schizophrenia (according to the DSM IV-TR criteria) had been chosen randomly in Razi Psychiatric Hospital in summer of 2003, for a survey regarding to the prevalence of negative symptoms and their severity. In this regard some of the patients had been excluded due to some intervening factors (table 1). This cluster of symptoms had been estimated and scored by Scale for Assessment of Negative Symptoms (SANS) (4). After determining this prevalence, they had been divided to three different groups. Group A (n=40) for a Clinical Controlled Trial (CCT) regarding the effectiveness of Clomipramine, Alprazolam, and Citalopram on reducing the severity of negative symptoms

Table 1- Inclusion and Exclusion criteria

Inclusion criteria	Exclusion criteria
Schizophrenia	1-Depression 2-Schizoaffective 3-Mental retardation 4-Bipolar disorders 5-Neurological disorders 6-Using atypical antipsychotic 7-Using antidepressants or lithium 8-Medical complications 9-Unstable, irritable, aggressive patients 10-Duration less than one year 11-Parkinsonism 12-Medical deafness or muteness

Groups B (n=100) with a similar approach with respect to the moderating effect of Bromocriptine, Fluoxetine and Nortriptyline, and finally group C (n=30) regarding similar effects of Fluvoxamine and Maprotiline. In every group and at the beginning of the related trials, before addition any adjunctive drug, a new estimation of the negative symptoms by SANS had been performed as the baseline and then the adjunctive drugs had been added to the patient's current treatments, including typical antipsychotics (one of the Chlorpromazine, haloperidol, Perphenazine, Trifluperazine or Fluphenazine decanoate). Each drug in each group was started with its lower dose and then at the end of the third week after beginning adjunctive treatments, again another estimating of negative symptoms by SANS had been performed. Then the dosage of the aforesaid drugs had been doubled and after another three weeks the final severity of negative symptoms and their changing had been registered. Generally grade 1, 2 and 3 were regarded as non-severe (mild) symptoms and grade 4 and 5 as severe. At the end, data had been analyzed by Z and chi-square (X2-test) formula. All of the controlled trials had been done in a double-blind fashion and by the same team.
Interview with the patients and their relatives, and also observations and remarks put forwarded by their nurses, social workers, psychologists and occupational therapists had provided the necessary resources for this research.

Results: the prevalence of negative symptoms among schizophrenic patients was remarkable. Almost no patient was free from negative symptom, and no specific or similar pattern could be found among them. Although some of the patients had similar severity in all of their negative symptoms, but many of them had discrete symptoms with different severity. The prevalence of Affecting Blunting, Alogia, Avolition-Apathy, Anhedonia-Asociality and finally Attention Deficit among this sample (n=270) were: %96/28 (n=260), %94/80 (n=156), %99.62 (n=269), %98.88 (n=267) and %99.25 (n=268) respectively

Table 2 – Prevalence of Negative symptoms among 270 schizophrenic patients in RAZI Psychiatric Hospital

Severity Negative Symptoms	Normal		Mild Grade 1,2,3 SANS		Severe Grade 4 , 5 SANS	
Affective Blunting	10	%3.72	160	%59.25	100	%37.03
Alogia	14	%5.20	155	%57.40	101	%37.40
Avolition-Apathy	1	%0.38	171	%63.33	98	%36.29
Anhedonia-Isolation	3	%1.12	144	%53.33	123	%45.55
Attention Deficit	2	%0.75	115	%42.59	153	%56.66

(Table 2). The age of these patients were between 24-68 years (mean=43.6) and the duration of their residency in hospital was between 2.5-28 years (mean=17.83) and all of them were male. Then we selected forty (40) patients among them, as group A, for performing the first trial with Citalopram, Alpazolam Clomipramine and placebo, after dividing them into four subgroup, with every subgroup containing ten (10) patients. The starting dose was 20mg, 0/75 mg, and 25 my respectively for Citalopram, Alprazolam and Clomipramine which were doubled after three weeks. The whole of trial had been done according to the aforesaid processes in method and material's section. According to the resulted data, Citalopram ($p<0/001$), Alprazolam ($p<0/01$) and Clomipramine ($p<0/01$) were more effective than placebo in reducing the severity of negative symptoms. This different was not large between them themselves ($p<0.25$). Generally this reduction in severity was restricted to 20% from baseline, and only in Clomipramine group 40% reduction was seen in Alogia and Attention Deficit in two separate patients respectively. There was not any relation between response to adjunctive drugs and the severity.

Table 3- Improvement of Negative symptoms by adjunctive drugs in schizophrenic patients.

Negative Symptoms	Affecting Blunting		Alogia		Avolition Apathy		Anhedonia Asociality		Attention Deficit		Total	
Drugs	No of patient	Percent	No of patient	Percent	No of patient	Percent	No of patient	Percent	No of patient	Percent	No of patient	Percent
Citalopram 20-40 mg	5	50%	4	40%	4	40%	3	30%	4	40%	20	80%
Alprazolam 0.75-1.5 mg	3	30%	3	30%	4	4%	2	20%	2	20%	14	50%
Clomipramine 25-50 mg	4	40%	2	20%	1	10%	3	30%	3	30%	13	50%
Placebo	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%

of symptoms. These reductions were discrete and there was not uniform decreasing in all of such symptoms in every patient. Patients who had received placebo did not show any benefit. Only one patient in every subgroup except placebo, showed 20% reduction in severity of all of their negative symptoms. Affective Blunting showed the most and Anhedonia-Asociality the least response in this group. (Table 3)

In second trial we selected another one hundred (100) patients and divided them into four subgroups (25 cases in each subgroup). Here we started Bromocripme, Fluoxetine, and Nortiptyline with dosage, of 2.5 mg, 20 mg and 25 mg respectively for the first three subgroups and placebo for the last subgroup. One patient in the Fluoxetine subgroup, due to his inclination and one in the placebo subgroup due to cardiac infarction were omitted from this trial. After three weeks the aforesaid dosages doubled and the adjuvants prescribed for another three weeks before trial's termination. 37.5% (n-9), 44% (n=11), 62.5% (n=15), and 8% (n=20) of patients in subgroups showed 20% reduction in the severity of some of their negative symptoms under the influence of placebo, Bromocriptine, Fluoxetine and Nortriptyline respectively. Only in three patients in the Nortiptyline subgroup and one patient in the Bromocriptine subgroup there was shown 40% improvement of their negative symptoms. Generally these reductions were taken place discretely among five clusters of such symptoms. There was no difference between mild or severe symptoms regarding their response to the adjunctive drugs.

Table 4 - Improvement of Negative symptoms by adjunctive drugs in schizophrenia patients.

Negative Symptoms Drugs	Affecting Blunting		Alogia		Avolition Apathy		Anhedonia Asociality		Attention Deficit		Total	
	No of patient	Percent	No of patient	Percent	No of patient	Percent	No of patient	Percent	No of patient	Percent	No of patient	Percent
Bromocriptine 2.5-5 mg	3	12%	5	20%	3	12%	3	12%	6	24%	20	44%
Fluoxetine 20-40 mg	4	16.6 %	4	16.6%	7	29.1%	2	8.3%	10	41.6%	27	62.5%
Nortriptyline 25-50 mg	6	24%	9	36%	8	32%	9	36%	10	40%	42	80%
Placebo	2	8.3%	6	25%	1	4.1%	4	16.6%	6	25%	19	37.5%

In comparing with placebo, Nortriptyline was the most effective ($P<0.005$) and then Fluoxetine ($p<0.1$) and the last one was Bromocriptine ($p<0.75$). Attention Deficit in comparing with other negative symptoms responded more frequently to the adjunctive drugs and Affecting Blunting less than others. Only in one patient in the Nortriptyline subgroup all of the negative symptoms showed improvement. (Table 4).

In the third trial, another thirty (30) patients were divided into three subgroups (included 10 cases in each subgroup) and 25 mg Maprotiline, 50 mg Fluvoxamine, and placebo were added as adjunctive drugs to their current antipsychotic drugs respectively. After three weeks these dosages doubled and maintained for another three weeks, before ending the trial. %80 (n=8) 60% (n=6), and 20% (n=2) of patients showed 20% improvement in some of their negative symptoms under the influence of Maprotiline, Fluvoxamine and placebo respectively. (Table 5). This effect was remarkable for Maprotiline in comparing with placebo ($p<0/01$), and it was greater for Fluvoxamine too ($p<0/1$).

Table 5 - Improvement of Negative Symptoms by Adjunctive Drugs in Schizophrenia Patients.

Improved Negative Symptoms Drugs	Affective Blunting		Alogia		Avolition Apathy		Anhedonia Asociality		Attention Deficit		Total	
	No of patients	Present %	No of patients	Percent %	No of patients	Percent %	No of patients	Percent %	No of patients	Percent	No of patients	Percent %
Maprotiline 25-50 mg	3	30%	5	50%	0	0%	5	50%	3	30%		80%
Fluvoxamine 50-100 mg	5	50%	3	30%	1	10%	3	30%	1	10%		60%
Placebo	0	0%	2	20%	0	0%	1	10%	0	0%		20%

In this sample severe symptoms responded more than mild ones to adjunctive drugs and in %79.41 of cases this improvement was started with higher dosages. There was not any patient with improvement in all of his Negative symptoms, and generally these reductions had been taken place discretely, like the previous trials (Table 5).

Generally in these trials, Attention Deficit was the most responsive symptom (31.2%, n=39:125) and Avolition-Apathy the least responsive one (22.4%, n=28:125) (Table 6).Also Maprotiline was remarkably more effective than Bromocriptine ($P< 0.05$) and Fluoxetine ($P<0.01$) in amelioration of Anhedonia-Asociality and Alprazolam and Citalopram were distinctively more beneficial than Maprotiline in reducing the severity of Avolition-Apathy ($P<0.025$) .On the other side ,Affective Blunting was more responsive to Fluvoxamine and Citalopram in comparison with Bromocriptine ($P<0.025$) or Fluoxetine($P<0.05$).In addition , Maprotiline was more effective on Alogia and Anhedonia in its subgroup than Avolition-Apathy($P<0.025$).

Table 6. Individual and General Response of Negative Sumptoms to Adjunctive Drugs.

Drug Symptom	Bromocriptine	Alprazolam	Clomipramine	Maprotiline	Nortriptyline	Fluoxetine	Fluvoxamine	Citalopram
Affective Blunting	12%	30%	40%	30%	24%	16.6%	50%	50%
Alogia	20%	30%	20%	50%	36%	16.6%	30%	40%
Avolition Apathy	12%	40%	10%	0%	32%	29.1%	10%	40%
Anhedonia Asociality	12%	20%	30%	50%	36%	8.3%	30%	30%
Attention Deficit	24%	20%	30%	30%	40%	41.6%	10%	40%

Discussion

Effectiveness of adjunctive drugs in reducing the severity of Negative symptoms is interesting. Although the positive effects of Clomipramine had been reported by LindenMayer (1990-1993), but there was not any description regarding its specificity or else on each negative symptom individually, except than general increase in function and also reduction of obsessive symptoms in treated patients. Regarding Bromocriptine, too, there was some positive amelioration in anergia, accoding to Brief Psychiatric Rating Scale (BPRS), reported by Wolf (1992) and Leviminzi (1991) (5). Also there is some evidence that Amisulpride (a standard antipsychotic) can ameliorate to some degree Apathy, lack of spontaneity and Affective Blunting in some patients (5).Clozapine and Olanzapine too, as atypical antipsychotics, have been reported to have positive effects on Negative symptoms in schizophrenic patients. But their profit, too, is not unlimited. The major benefit of Clozapine had been on Anergia (Kane, 1988) and also on Alogia and Anhedonia (Picker, 1992) (6).The first trial had been scored by BPRS and the second one by SANS. But regarding Olanzapine, according to an important controlled study on 325 schizophrenic patients, which was comparing its effect with Haloperidol and placebo, there was positive effect peculiarly on Affective Blunting and Avolition-Apathy. But its effect on Anhedonia-Asociality was not remarkable in this regard. The mean dosage of Olanzapine in the aforesaid study was 15mg daily (Tollefson, 1997) (7).

In our trials there was some relationship between some kind of negative symptoms and their better reponse to different adjunmctive drugs. For example Affective Blunting had been ameliorated mainly by Serotonin Reuptake Inhibitors, like Clomipramine, Fluvoxamine and Citalopram in 40%, 50% and 50% of their samples respectively. Or as another example, Attention Deficit had been influenced mainly by Nortriptyline, Fluoxetine and Bromocriptine in 40%, 41.6% and 24% of the patients respectively. As is known these drugs belong to different classes with different pharmacodynamic properties.But such a response were weakest for Fluvoxamine. Meanwhile in this regard the most benefit of Maprotiline, a tetracyclic with mainly noradrenergic characteristics, was on Alogia and Anhedonia –Asociality, which was evident in 50% of the patients in the related subgroup. The most profit of Alprazolam (as a Benzodiazepine), too, was on Avolition-Apathy, which had not responded at all to Maprotiline and also had showed a weak response to Bromocriptine, Clomipramine and Fluvoxamine. Therefore in addition to the current standpoint that says that schizophrenia is not a single illness but rather a heterogenic entity with different physiopathologic causes and morbid expressions, it seems that this point of view may pertain to its symptoms too, and especially with regard to negative symptoms ,their variety of response may result from different involvement of neuronal pathways and dependent neurotransmissions , which leads to a variety of interpersonal disturbances according to the impaired function and resulted disability. Compensatory adjunctive pharmacotherapy or psychosocial interventions for overcoming this kind of communicative disturbances in the framework of modern integrated rehabilitation paradigm can be accounted as a triumph in this field. But this rehabilitative process needs to be reinforced by more meticulous investigations in the future which can specify the interplay between basic pathology and resulted symptoms, whether deficit(negative) or excessive(positive) ones.

Conclusion

Conservative prescription of adjunctive drugs can be a useful strategy for making schizophrenic patients more prone to psychosocial interventions and in consequence increasing the effectiveness of rehabilitative programs. In this regard it seems that: 1) some of the Negative symptoms (like Affective Blunting and Anhedonia-Asociality) are more prone to be influenced by some specific adjunctive drugs (like SRIs and Maprotiline, respectively) and 2) some of the drugs (like, Maprotiline) are specifically more effective on some of the negative symptoms (like, Alogia and Anhedonia-Asociality) in comparison with the other ones (like, Avolition-Apathy).

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Common Problems in Psychosocial Rehabilitation

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Abstract

Many of the problems in rehabilitation in the third world countries arise due to the lack of financial resources. The lack of financial resources causes difficulty in regular continuation of medication and subsequent relapse of the illness. The lack of job opportunities also interferes with the rehabilitation. Sometimes societal insensitivity and expressed emotions in a family are responsible for the reemergence of the psychiatric symptoms. While in some cases long term stay in hospital also interferes in rehabilitation, because long-term hospital stay may produce the secondary negative symptoms in a patient. The difficulties also arise due to the lack of trained staff and psychiatrists. The burn out problem cause rapid turn over of the staff and the staff have to be train again. The bureaucratic hurdles also slow down the processes of the rehabilitation. The field of rehabilitation is also preferred less by the Psychiatrists.

Key Words: Rehabilitation, Financial Problems, Burn Out.

Introduction:

Psychosocial rehabilitation is a term used to describe services that aim to restore the patient's ability to function in the community. It not only includes the medical and psychosocial treatment but also include ways to foster social interaction, to promote independent living, and to encourage vocational performance (Cook et al.1996). Unlike past now psychosocial rehabilitation aims to integrate patients back into the community rather than segregating them in separate facilities. The goal of psychiatric rehabilitation is to teach skills and provide community supports so that the individuals with mental disabilities can function in social, vocational, educational and familial roles with the least amount of supervision from the helping professionals. The professionals must involve families in treatment planning and implementation. So rehabilitation is labor intensive and person-to-person venture. The developing countries are having dearth of financial resources, which causes the tremendous difficulties in rehabilitation of the patients. A study of the status of the mental hospitals commissioned by the National Human Rights Commission revealed gross inadequacies in all aspects of care, clinical services and rehabilitation (National Human Right Commission, 1999). I would like to discuss common problems, which one face while rehabilitation of patients in the developing countries, which are having scare financial resources. The developed countries may have the different set of problems. But some of the problems like bureaucratic hurdles, uncooperative attitudes of relatives and societal insensitivity may be seen in both, developing as well as the developed countries.

Irregular Follow Up due to financial problems:

Most of the patients coming into government institute in the developing countries are from lower socio-economic strata and most of them are daily wage earners. They are living hand to mouth existence. Even the patient from “well to do families” faces financial problems when some member in families develops mental illness. And when earning member of family develops illness, the problem becomes more acute. A survey of an urban community in southern India, served by four state-run general hospitals with psychiatric services and a large psychiatric institution, found that a third of people with schizophrenia had never accessed any treatment (Padmavati et al, 1998). Even after these individuals and their families were offered treatment, a third of them continued in their untreated state (Srinivasan et al, 2001).

The processes of rehabilitation start with medication. But due to lack of money they cannot come for regular follow-up. They cannot afford bus-fare or train-fare. Sometimes illness of earning member of families ensures that they don’t even have money to eat, let alone for bus-fare or train-fare. Sometimes hospital has to arrange for bus fare or train fare from the poor patient’s fund. So patients cannot come to take medication regularly. They cannot take medicine form outside because cost of medicine is high. And medicines have to continue for long time or in some cases for the lifetime. This leads to frequent relapses of illness.

The other major reason for discontinuation of the medicines is necessity of taking medicine for long time and in some case for a lifetime. And some times side effects of medication are responsible for the discontinuation of medicines.

Lack of medicines in governmental Institute:

Sometimes government institutes in developing countries lacks even the basic medicines. Patient’s condition may be stable on long-term depot preparation (e.g. Fluphenazine Deconate) and suddenly the stock of injection is finished. They cannot purchase the medicine form outside because cost of medicine is high. And medicines have to continue for a long time or in some cases for the lifetime. They are reluctant to purchase medicines from the outside because they believe that despite taking the medicines patients are not going to improve completely. They believe that schizophrenia like diabetes and hypertension is controllable but not curable. But in the case of hypertension and diabetes the patients are mostly productive. They know that in the most of cases the patients are not going to earn money in the future, so they are reluctant to purchase the medicine from outside the hospital.

Difficulties in a Vocational Rehabilitation:

Sometimes the patients want to come to day care center for vocational training. But due to lack of money, he is unable to do so. Even the governments in the developing countries cannot arrange for the transport because of the lack of the fund, so the patients cannot come regularly.

Sometimes patient may manage to have bus fare for attending daycare activities. But sometimes the hospitals don’t have the materials for the daycare activities; e.g. patients may be doing tailoring work but sometimes there is no stock of the clothes. Even number of the vocational training centers is inadequate. Some private day care centers are there but cost is prohibitive. There are no buyers for the materials produced in rehabilitation center, because most of the time the materials produced by the patients are not as good as the material produced by the professionals. The only buyer is the government, but the governments in the developing countries have limited requirements and limited purchasing capacity.

Lack of Job Opportunities:

In developing countries with a limited job opportunities and burgeoning population (e.g. population of India is more than one billion), even educated people don’t get job, so it is very difficult for the mentally ill patients to get job. Irony is some person develops the mental illness because they are not having job. The occupational functioning of men is still crucial in the Indian setting, where the man is largely the main breadwinner. Unemployment and underachievement act as threats to his social status. Compounding this situation, the social security system in India does not consider patients with schizophrenia as its beneficiaries. In India mental illness are not yet eligible for any welfare measures (Thara et al, 2004). Employment provides not only a monetary recompense but also 'latent' benefits — non-financial gains to the worker which include social identity and status; social contacts and support; a means of structuring and occupying time; activity and involvement; and a sense of personal achievement (Shepherd, 1989). People with mental illness are sensitive to the negative effects of unemployment and the loss of structure, purpose and identity, which it brings (Rowland & Perkins, 1988). Studies show a clear interest in work and employment activities among users of psychiatric services, with up to 90% of users wishing to go into (or back to) work (Grove, 1999). There is a tendency for mental health professionals and others to underestimate the capacities and skills of their clients and to over-estimate the risk to employers (Boardman J, et al.2003). Satisfactory working life may reduce the need for clinical support, but such support should remain available and be tailored where possible to the constraints of the individual's working life (Secker et al, 2002). Unemployment is associated with physical ill health, including premature death (Wilson & Walker, 1993; Bartley, 1994). Social isolation is often particularly problematic for people who experience mental health problems, and work is effective in increasing social networks (Boardman J, 2003). Lack of job and ensuing financial crisis causes tremendous stress which cause relapse of symptoms, which in turn lead to difficulty in psychosocial rehabilitation.

Hospital as a Shelter:

In developing countries, where poverty is widespread, many relatives of the patient don't want to take discharge, even when patients have improved completely. This happens in case in which patient is admitted in open ward along with his relative. Sometimes when doctor asked them to take discharge, then relatives and patients describe fake symptoms. And when one cross check with the attendants and nursing staffs the said symptoms are absent. The reason for not taking discharge is they may not be having food, shelter or job. Sometimes patient with substance addiction may develop with friendship with other patient having addiction. They may exchange address of secret places where drug is freely available. Some relatives are reluctant to take discharge because they feared that patient may relapsed at home and they again have to borrow the money to bring patient to the institute. All these things may interfere with rehabilitation, treatment and improvement of patients.

Hospital as a dumping site:

Many relatives of the patients are not interested in the treatment or rehabilitation of the patients. There main aim is to get patient admitted in institute and get rid of him. Although they are not at all at fault because treatment and rehabilitation of psychiatric patients is always difficult due to frequent exacerbations and relapses of the illness. So to get rid of a patient they may give wrong address of home or change the home after patient is admitted in the institute. Some times they give the wrong history and the wrong symptoms, which are not observed when patient is subsequently admitted in the institute.

The reasons why they want to dump patients are many. First, some families' economic conditions are poor. So they cannot feed the patient. Second many families' lives in small house, which has no room for the patient. Third, many patients though improve up to quite an extent are still unable to find a job. So they stay at the home throughout the day. The male members, when they go out for a work in daytime, don't want to keep patient near female members. They fear that the patient might not be manageable by the females if he becomes aggressive or the patient may do sexual assault on the female members of the family. Fourth reason is social stigma attached to the mental illness. Family member fear that their sons, daughters, sisters and brothers may not be able to get good spouse because almost all knows the fact that mental illness is inheritable and no one wants see illness in their off springs. Besides this newly wed spouse may be unwilling to stay with mentally ill patient in the same house. Fifth reason is, in today world with breaking social support systems; many people want to live in a nuclear family. So even a patient who has completely improved and doing a job and earning, still many families are not willing to keep them in their house. Sixth reason is patient's parents may be getting old so they are unable to take care of patients. Sometimes condition is so worse that when patient' s parents wants to keep patient at home, then his other relatives (e.g. son) may threaten that he will expelled the parents along with the patient. Seventh, reason is, in some case husband and wife both are working, so there is no one to look after the patient at home and no one to give him timely dose of medication. Sometimes, even after patient is improved completely, he cannot be sent to his home because his parents might have passed away and no one is left behind to look after him.

So for all this reasons patient's relative don't come to take patients at home even after the patient has improved completely. So when despite of repeated reminders when patients' relatives don't come to take patient home, then hospital has to arrange for police escort and send patient to home via court order. Sometimes they refuse to obey court order saying that they are ready to undergo punishment but they will not take patient home at any cost. The amount of punishment according to 'Indian Mental Health Act ' is two thousand rupees (40 dollars), which is ridiculously low. So they don't obey court order.
So it causes difficulty in rehabilitation of patient in the society.

Expressed emotions and relapse:

Brown described five components of expressed emotion (Brown, 1985): emotional over involvement, critical comments, hostility, positive remarks and warmth. Sometimes over involvement, hostility and criticism within family may worsen patients. Sometimes parents are extremely close to the patient and they fulfill his each and every whims and his unreasonable demands. They may not restrain his undesirable behavior so patient illness may relapse. The Patients in high expressed emotion settings were more likely to relapse (56% compared with 17% for low expressed emotion). Also, there was a high relapse rate (68%) among those in the non-medicated high expressed emotion group, whereas there were no relapses at all in the medicated low expressed emotion group (Leff & Vaughn, 1985).

Sometimes after long hospitalization, when a patient returns home, his relatives treat him as an outsider. They may have established a family equilibrium without patient so when the patient returns this equilibrium is disturbed. They unconsciously treat the patient as alien. The patients continuously feel that he is unwanted. Subtle hostilities and criticism of patients, who although improved but having fragile defense mechanism may worsens patient illness. In some patients with schizophrenia who were living as part of an extended family accessed treatment less often, even when it was considered essential to do so. The families, when interviewed on the issue, replied that they were used to their relative's illness and that other family members compensated for the person's non-productivity. Once they had reached this equilibrium they did not want to disturb it by seeking treatment. (R thara et al, 2004.)

Problems of Hospitalization:

We know how damaging many of the traditional practices of the asylum were, even when they had been adopted for the best of motives. The official practices (such as the locking of doors, constant oppressive security, continual counting of people, cutlery, bed linen and so on) were bad enough, but far worse were the unofficial happenings – the beating up, the garroting, the use of padded cells and ECT as punishments, and the occasional killing (David.H, 1998). But there are problems from patient's side also due to their inability to adjust in outside world.

There is one popular folk story according to which, there was a fisherwoman, who daily used to sleep amidst smell of fishes. One day while returning to her home, she lost the way. So she had to sleep in house of flower vendor. But she was sleepless through out the night. She found smell of flowerers irritating because she used to sleep in room with a fishy smell. However during next night she was able to have sound sleep in her familiar surroundings. Same thing happens to some mentally ill patients. When they are discharged in society they feel awkward, because they are used to the hospital routine environment. They feel at home in mental hospital. Many have developed friendship with the other patients. When they go outside, many of their friends are married and well settled doing job or business. The patients are unable to establish relationships and friendships again with them. They feel like the fish outside water. The feeling of emptiness and worthlessness, get exaggerated, when they see that their friends relatives and colleagues are well established in society. This act as a stressor and patient illness may relapse again. However this happens in only small numbers of patients, otherwise most of the patients don't like the hospital stay and they are always eager to go back in a society.

Societal Insensitivity:

Many patients when returned to the society, face insults. The society keeps overt as well as covert discrimination with them. They don't admit them in their friendship circle and other activities. So the patient becomes lonely and isolated. A recent report, based on responses from 556 UK users, shows that 70% have experienced discrimination in some form: 47% in the workplace, 44% from general practitioners and 32% from other health professionals (Mental Health Foundation, 2000). Manning & White (1995) reported that 90% of mental health professionals who had a family member with mental illness, frequently heard colleagues make "negative or disparaging remarks" about patients: the majority of these professionals stayed silent and did not disclose their relative's illness. Lefley (1987) reported UK employers' reluctance to hire someone with mental illness. Mansouri & Dowell (1989) report that stigma is a significant source of distress in, for example, people with severe enduring mental illness in a community-support programme, where it correlates with self-esteem. In cinema and television, mental illness is the substrate for comedy, more usually laughing at than laughing with the characters (Byrne, 1997). Negative attitudes to people with mental illness start at playschool and endure into early adulthood: one cohort confirmed the same prejudices on re-examination eight years later (Weiss, 1994). These add tremendous strain to already poorly compensated defense mechanisms of the patient and patient may worsen again.

Problems while rehabilitating patient with substance addiction:

Sometimes patient with substance addiction has to return in the same environment, because of lack of job opportunities (e.g. Rickshaw driver or taxi driver may have to stand on the same site with his same group of friends having addiction). When he returns to friend circle having addiction, he again relapses. Sometimes patient develops addiction because he doesn't have job. The patient faces same problem, when he is discharge from the hospital, so he again develops addiction. So this may also interferes with rehabilitation of patients.

Burn out of hospital staff:

As stated earlier, rehabilitation is labor-intensive processes. The results are slow to come and relapses are frequent. The term burn-out has been used to conceptualize the long-term negative effect of such stress and includes emotional exhaustion, tendency to develop cynical and negative attitudes towards others and negative self-evaluation, especially regarding personal accomplishment at work (Maslach & Jackson, 1986). The daily work of continual confrontation of illness, sadness, suffering, fear and pain makes staff insensitive towards patients. Power relationships between patients living together in intimate and anxiety-provoking circumstances have the potential to become sexualized and to affect staff. Staff finds it particularly challenging to handle these difficulties with sensitivity; they can contribute to poor outcome, characterized by treatment dropouts, lack of meaningful therapeutic relationships and acting-out behaviour (Sarah Davenport, 2002). Sometimes staff is unable to balance compassionate concern with dispassionate objectivity. A sense of futility and failure can begin to permeate their attitude and can set the stage for anger and frustration about their profession, their patients and themselves. Sometimes staff stops correcting the unacceptable behavior of patient as slowly insensitivity creeps in their behavior, without their own knowledge. This leads to rapid turn over of staff engaged in the rehabilitation. New staffs have to be trained again. The field of rehabilitation is preferred less by the psychiatrists.

Lack of staff and over burdened Staff:

The staffs of the hospitals are woefully overburdened in the developing countries. The ratio of staff to patients is rarely in accordance with law and requirement. There are now 37 mental hospitals in the country with a total bed strength of 18 024 (National Human Rights Commission, 1999). The beds are grossly inadequate in comparison to number of patients and population. In the developing country like India the psychiatrists have to manage the average OPD of 70 to 80 patients. Along with managing OPD they also have to do the administration work and management of staff. Along with this work sometimes there is deputation of psychiatrist at the remote places. So sometimes there is no psychiatrist to run the OPD, let alone to do the rehabilitation work. So the very little time is left for rehabilitation work and its supervision. The low salary in comparison to private practice make government job unattractive, so many posts of psychiatrist in the government hospitals are vacant. So the work of rehabilitation remains in a sorry state. Another major problem is brain drain of psychiatrists and nursing staff to developed countries, which provides better working conditions and higher salaries.

The bureaucratic hurdles:

The delay due to bureaucratic hurdles may slow the processes of rehabilitation; example is sometimes demand of seeds for plantation work is put before the monsoon but sometimes seeds arrived after the completion of monsoon. Sometimes due to procedural delay there is delay in procurement of medicines. And patients have to put on a medicine other than he was taking for many years. The patient may worsen on another molecule of medicine due to psychological so physiological reasons.

Sometimes the task is so frustrating that one feels that the processes of rehabilitation, rehabilitates no one except those involved in the work of rehabilitation.

Conclusion:

To sum up the matter, mental illnesses would assume gigantic proportion in coming years. And governments must deployed more resources to tackle the illnesses and rehabilitate the patients. The mental illnesses not only affect patients but also his kith and kin in financial and social ways. We must rehabilitate the patients and thus save them, because as one wise sage wrote, “ No one will be saved till all are saved.”

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The Experience Of Bipolar Disorder At Work

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Abstract

People experiencing bipolar disorder have a strong desire to maintain employment, and display high academic achievement compared with people with other forms of affective difficulties. AIMS: To explore the views of people with bipolar disorder (BD) about how their experiences of BD influences their employment, and how being in work can change their experience of BD.

METHOD
Eleven semi-structured interviews were conducted with people with BD who had been in employment. Grounded Theory was used as the framework for analysing the data.

RESULTS
A complex interaction between BD and work functioning emerged. These included phases of mutually disruptive and mutually beneficial influences between people's health and work. Transition from one phase to another occurred over time.

CONCLUSION
The experience of being a worker can be greatly enhanced as well as compromised by bipolar disorder.

KEY WORDS: Bipolar, employment, rehabilitation, recovery

Introduction

Paid employment is a high priority for users of mental health services (Pozner & Jones, 1994). Among users of these services, people with bipolar disorder (BD) are associated with some of the highest rates of open employment. They do not, however, have higher rates of employment than people with other forms of affective disorders, despite their relatively greater academic achievement. Following diagnosis of BD, people achieve greater educational success than matched people with unipolar depression, but with no evidence of better occupational status or higher likelihood of being in employment (McGlashan, 1984).

BD is a form of affective disorder that results in severe, enduring and pervasive consequences on people's lives (Coryell, Scheftner, Keller, Endicott, Maser & Klerman, 1993). Moreover, high relapse rates are associated with BD (Keller, Lavary, Kane, Gelenberg, Rosenbaum, Walzer & Baker, 1992). For both professionals within the mental health services and potential employers, attitudes towards the employment of such individuals are associated with fear and uncertainty (e.g. Black, 1992; Scheid & Anderson, 1995). Mental health professionals often discourage patients from seeking employment (Crowther & Marshall, 2002), and in the workplace any person who is known or is thought to have a mental illness may be subject to severe stigmatisation (Harding, Strauss, Hafez & Lieberman, 1987).

The impetus to extend knowledge of the experience of individuals with mental health problems in the workplace is currently being provided by an increasing focus on supporting such individuals within governmental legislation, both in the health and the employment domains. The necessity for incorporating employment support into community mental health service provision was crystalised within the National Service Frameworks (NSFs) for adult mental health services in England (Department of Health, 1999) and subsequently in Wales (Welsh Assembly Government, 2002). Similarly, employers' responsibilities towards employees with mental health problems were enshrined in the publication of the Disability Discrimination Act in 1995.

A model for understanding the interaction between the experience of BD and the experience of being at work is provided by the Interactive Developmental Model (IDM: Strauss & Carpenter, 1981). It provides a structure that aims to define the interaction of an individual's vulnerability from experiencing BD with the stress arising from environmental events or factors. In contrast with the diathesis-stress model, it proposes that the course of disorder is strongly affected by interactions between the individual and the environment. Within these interactions, either the individual or the environment can act as the initiator of change. Secondly, the individual develops over time, in that the person's strengths and vulnerabilities change over time.

There are relatively sparse data on work functioning for people with BD. The information that does exist indicates that job functioning and status may be independent of the person's recovery from symptoms (e.g. Dion, Tohen, Anthony, & Waternaux, 1988). For instance, Anthony and Jensen (1984) concluded that there seemed to be no symptoms or symptom patterns that were consistently related to individual work performance. More recently, it has been proposed that it is the long-term nature of such chronic conditions as BD, rather than the specific symptoms, that impact detrimentally upon work outcome (Anthony, Cohen, & Farkas, 1990).

With no substantive direct impact of BD symptoms upon work functioning, a number of indirect routes to work impairment have been evidenced empirically. Work productivity has, for instance, been found to be negatively correlated with the psychopathology of conceptual disorganisation for workers of BD (Massel, Liberman, Mintz, Jacobs, Rush, Giannini, & Zarate, 1990). Secondly, such mental health problems have been reported to form a barrier to effective coping with stress which is compounded by the impact of side-effects from medication (Secker, Grove, & Seebohm, 2001). Thirdly, the disabled status of people with mental health problems has itself been referred to as an impediment to work functioning (Massel et al., 1990). Finally, poor occupational functioning by people with BD (but not other forms of mental health problems) has been associated with negative labelling by friends and relatives (Beiser, Bean, Erickson, Zhang, Iacano, & Rector, 1994). Empirical exploration of the positive impact of experiencing BD on work functioning has largely been limited to the proposed association between the illness and heightened creativity (Andreasen, 1987). Some evidence is also available supporting an indirect link between bipolarity and high occupational achievement, mediated by the effect of socioeconomic advantage (Coryell, Endicott, Keller, Andreasen, Grove, Hirschlield, & Scheftner, 1989).

The impact of work on the experience of BD is thought to be both negative and positive. To address the negative forms of impact firstly, entering work entails an increase in psychological distress and loss of function (Anthony & Jensen, 1984). Entering work likewise entails removal of the potential for continued access to social and therapeutic support networks. Relapse of symptoms of BD have moreover been associated with work-related critical events, and events involving some aspect of goal-attainment more broadly (Johnson, Sandrow, Meyer, Winters, Miller, Solomon, & Keitner, 2000). Work activity was once regarded as a central component of comprehensive psychiatric treatment due to the emphasis placed on its therapeutic effects. It provides social identity and status, social contacts and support. It structures and occupies a person's time in addition to providing a valuable alternative to the 'patient' role, and assists in decreasing symptomology and dependence on services (Bennett, 1978; Rowland & Perkins, 1988; Shepherd, 1984;).

It is apparent that the interactions between experiencing BD and workplace functioning involve a complex array of positive and negative influences. These are likely to be different for different people, as well as varying considerably over time. The extent and type of support will therefore also vary according to these interactions at any given time. It was therefore the aim of this study to survey the perspectives of people with BD on how their employment had impacted upon their experience of BD, and vice versa. In achieving this aim, knowledge would be gained of how to support workers with BD effectively, and inform the decisions they make regarding employment.

Method

Design

Data collection and analysis were led by the principles of Grounded Theory (Glaser & Strauss, 1967), in line with the study's exploratory nature. This involved a multiple case study approach, during which people with BD were engaged in semi-structured interviews.

Participants

The participants were 11 adults (8 men and 3 women) who had received a formal diagnosis of BD (or manic depression), and who had been in employment at some time since their initial experiences of BD symptoms. Establishing whether or not potential participants had received such a formal medical diagnosis was based on their verbal report only. For the purposes of this study, employment was defined as any part-time of full-time work activity for which there had been a formal arrangement to receive a salary from an employer. By this definition, employment did not include periods of self-employment, voluntary work, education of vocational training.

Participants were recruited via non-statutory independent organisations throughout South Wales that provided information and support services for individuals experiencing mental health problems (e.g. Mind; the Manic Depression Fellowship; non-affiliated community services). People who wished to participate in the study contacted the researcher directly after being fully informed about the nature of the study and its purpose. They did this by posting signed participant consent forms to the researcher. The participants' ages ranges from 37 to 68 years (with a mean age of 47.5 years and a standard deviation of 10.1 years), and all were first-language English speakers. 4 of the 11 participants were in paid employment, 2 of whom were employed on a full-time basis and 2 part-time. Both of the full-time workers and one of the part-time workers were in employment with a non-statutory mental health organisation.

Data Collection

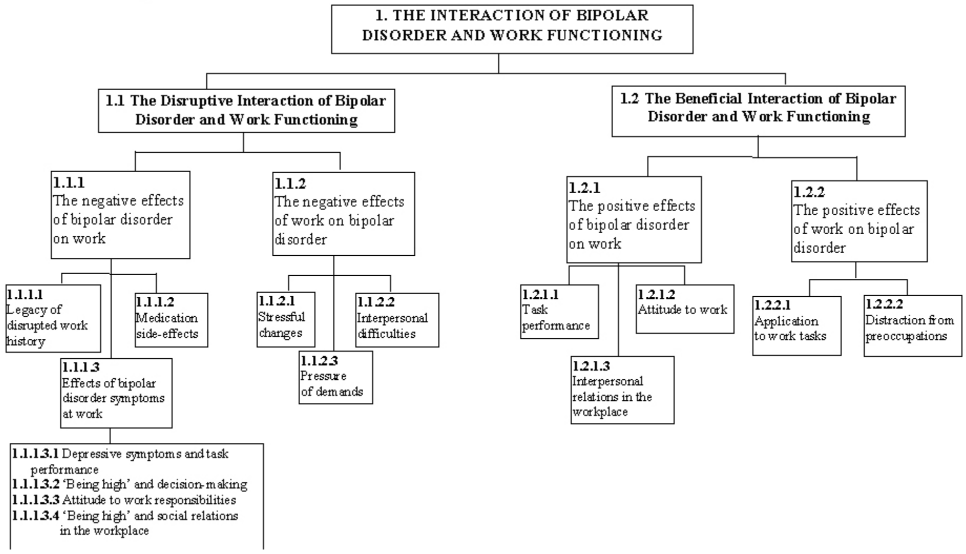
Each participant met individually with the researcher on only one occasion, when a semi-structured interview was held. These interviews took place either at the participants' places of employment, at the bases of the organisations where they were undertaking voluntary work, or at their homes. The duration of the interviews varied between 50 minutes and 1½ hours, mostly lasting between 1 hour and 1 hour 10 minutes. The schedule for the semi-structured interviews comprised of a series of key areas to discuss with each participant. These included their views of the perceived positive and negative effects of experiencing BD on their employment, and vice versa. Each interview was tape recorded and subsequently transferred to a typed transcript, when all identifying information were removed from the data.

Data Analysis

In line with the principles of Grounded Theory, the process of data analysis adhered to the guidelines outlined by Miles and Huberman (1984), and Strauss and Corbin (1998). Three phases of analysis were undertaken (Henwood & Pidgeon, 1995): During the first phase, open coding facilitated 'data reduction', where transcripts were read and reviewed repeatedly to identify and catalogue apparent themes and categories. During the second phase of data analysis, the data was organised in such a way as to facilitate interpretation, through axial coding. For each preliminary concept, all the corresponding data were identified and compared in order to consolidate categories of concepts. The third and final phase of data analysis saw the categories and their dimensions being integrated to construct an explanatory scheme.

Results

Fig. 1: A diagrammatic illustration of the categories, sub-categories and concepts within the Core Concept 'The interaction of bipolar disorder and work functioning'



The following section provides an overview of the dominant themes to emerge from the data. In order to facilitate the account of the findings, categories and their subcategories are printed in **bold** type, and concepts are given in <u>underlined</u> type. Within the text, numbers given within parentheses indicate the number of participants to have contributed to the relevant category or concept. A diagrammatic representation of the links connecting the categories and concepts is given in figure 1.

Participants reflected extensively on the dilemmas encountered as people with BD who were either in employment or wished to be in work. A key issue involved attempting to maintain good health (in this respect entailing minimising the severity of BD-related symptoms) while also maximising work involvement. The interaction of BD and work appeared to fluctuate between a phase of mutually disruptive effects and a phase of mutually beneficial effects in line with such variations. In this sense, a disruptive interaction would involve predominantly detrimental effects of working on the experience of BD at the time. By contrast, a beneficial interaction would involve predominantly beneficial effects of working on the experience of BD at that time.

BD was described as influencing people's experiences at work in a detrimental way in two ways: The **negative effects of BD on work** included both immediate situational effects, and also an indirect impact of having a history of episodes of BD on a general experience of being in employment. An example of such an indirect effects was the legacy of a disrupted work history (n=2) frustrating attempts to gain secure employment. This also entailed being unable to provide a good reference for future employment and a sense of being stigmatised as a potential employee:

Ian:
"Things aren't going well. I'm in a bit of a catch-22 situation. Part of me wants to get another job, which hopefully would be better. But I can't really, because I just can't get a reference from my manager. And I've got a sick record, a bad sick record. So I'm stuck there."

A second form of indirect impact of BD upon working life was in terms of the side-effects of medication (n=2). This included tiredness from taking tranquilliser medication, and sleepiness as a result of a regimen of depot injections, as illustrated by Dawn:

Dawn:
"I'm not blaming the doctors, the doctors have been quite good. But I was left on heavy medication for a lot of years, which affected the way I could work, actually, because even though I was working, I was very very tired. So obviously when you're on sort of twenty tablets for a long time, you know, it's quite difficult, and they were heavy tranquillisers."

The direct and immediate effects of **experiencing BD symptoms** on work were expressed in several ways. Effects of depressive symptoms on work task performance (n=4) included compromising ability to make decisions, social withdrawal within the workplace, and a sense of being detached from one's surroundings. For instance, Albert described an array of difficulties that appear to be regularly associated with depressive symptoms and which impacted detrimentally on his working life:

Albert:
"Oh, I was crying, not concentrating, I couldn't do anything, I couldn't take any decisions, I saw everything in terms of worries, rather than problems that come up in the course of things. And although I'd been quite successful in the six months, I was, well, in a bad way."

Limitations of decision-making were not only attributed to depressive symptoms, however, as the effect of 'being high' on decision-making (n=2) was also noted:

Dawn:
"You go so high that you can't think straight at all and you are absolutely talking rubbish. And it's not the fact you're talking rubbish, but it's distressing, all those thoughts. Thoughts that are not coherent or anything. It's a horrible time."

Changes in attitude to work responsibilities (n=4) varied both across the participants who commented on this area, and also individual participants described different experiences at different phases of their illness. The depressive phase of BD was perceived as causing both a strengthening and weakening of the sense of responsibility at work for different participants, and a manic phase of the illness was described as bringing an unrealistic tendency to assume responsibility for resolving colleagues' work -related difficulties. Moreover, manic symptoms were implicated in the disruption of social relations in the workplace (n=3).

Barbara:

"When I'm ill I don't think about responsibilities, or they don't seem as important as what I want to do."

Keith:
"And the worst time for me was on the down side, because I wasn't doing what I should have been doing, and that's consequently followed by guilt."

Harry:
"When it went too far I started thinking that I could kind of help people at work who were kind of having problems, and I could change the course of events."

Fred:
"I talked to people I worked with ever since, and what they're always coming up with was they never knew what mood I was going to be in from day to day. . . They just couldn't cope."

The **negative effects of being in employment on the experience of BD** as identified by the participants were threefold. In all three examples, BD was affected in a detrimental way by work, where participants spoke of the precipitation of BD-related symptoms by events in the workplace. These events encompassed work scenarios involving stressful changes, interpersonal difficulties, and excessive pressure of demands. As examples of stressful changes (n=3) at work, participants referred to events over which they felt they had little control, such as needing to adapt to organisational changes in the workplace or changes in personal roles and responsibilities:

Craig:
"I was their manager, and I was being told that the department was going to remain in force, but by September of that year I was told that the department and all its activities was closing down. At the same time as all that happened, the managing director of that company and my immediate line manager also moved away."

Interpersonal difficulties (n=4) in the workplace were also implicated in the onset of manic symptoms. These included conflict with superiors, working to support clients who were in distress (as in Gail's experience included below), and frustrations related to an unreciprocated attraction towards a colleague:

Gail:
"Just the pressure from the every-day problems when we're working with that kind of group of people where there's a lot of stress as well. Dealing with a lot of unhappy people."

The pressure of demands (n=3) at work emerged as a perceived precipitant of manic symptoms, with these people attributing the onset of such symptoms to over-work, and pressure of performing work duties, with also a possible role of performing undemanding work.

Harry:
"The main thing I can remember is that I was in charge of the commissioning team, and that became too much for me. . . We ran into problems, and I needed a bit of guidance, but my boss at the time was a different boss, and I didn't know who to turn to."

The **positive effects of BD on work** life were identified by participants in three areas. These included an effect of experiencing manic symptoms of enhancing task performance (n=5) in undertaking work duties, in improving participants' general attitude to the work (n=3) that they engaged in, and finally in improving interpersonal relations in the workplace (n=4). In all three of these areas, work functioning was thought to be facilitated by the immediate and direct effects of experiencing the manic symptoms that are associated with episodes of BD, and also by the cumulative effects of having a history of BD episodes. By contrast, the experience of depressive symptoms were not identified as facilitators of work functioning in any particular way.

The effects of manic symptoms in improving task performance was portrayed mainly in terms of enhancing productivity and creativity, as described by Keith:

Keith:
"Somebody said once that I had a kangaroo mind, because I could think about four or five different problems at the same time. And I could handle them. So in that respect, being high helped."

The experience of such symptoms was thought to enhance attitude to work in that people with BD were portrayed as good workers. This was described in terms of loyalty to the employing organisation, punctuality, responsibility of attitude, energy and enthusiasm:

Ian:
"I guess that people who are slightly mad, they've got more energy, and they've got more joie de vivre, you know, got more enthusiasm. And I have heard of some people who try to adjust their medication so that they're always sort of slightly a little bit manic."

The impact of experiencing BD on interpersonal relations in the workplace was highlighted by participants in two ways: Firstly, the experience of manic symptoms appeared to facilitate social interaction with others. Additionally, a history of BD episodes enhanced the workers' empathy with they colleagues and clients, as in Craig's case:

Craig:"I think that my illness had made me a stronger manager because of that. I could see people getting stressed-out, visibly, within their working environment."

2 of the 11 participants identified **positive effects of being in employment on BD**. One of these (Dawn) highlighted the effects of employment in providing application to work tasks (n=1) and also in serving as a distraction from preoccupation (n=2) related to mental health problems, which was echoed by a second participant:

Dawn:
"I think the work has helped me to have structure and motivation and all sorts of thing, really. . . It's quite important to work as far as possible, and keep a routine, I found, that's really helped with my highs. Recently I've had a few low moods with the change in the anti-depressants, but it hasn't lasted that long. It's something that comes over me. But the work would actually take my mind off it actually. And being sort of focused."

The profile that was gained of such interactions provides an indication of where participants' focus lies in thinking about being a person with BD at work. Participants' contributions varied widely, and the breadth of their individual and collective accounts can provide an insight into the issues that they prioritise within this discussion. For instance, the impact of BD on work was commented upon more widely by participants than the impact of working on BD. These findings may suggest that the issue of being a worker with BD was dominated by thoughts of how BD impacts on work, more than how work affects BD. The positive and negative effects of BD on work were reflected upon equally by participants.

Discussion

There appeared to be common themes within the changing interaction of BD and work over time. These indicated phases of disruptive and beneficial influences between the domains of health and work in participants' lives. Transition from one phase to another occurred over time, with the main determining factor being the presence of BD-related symptoms. Specifically, in the absence of BD symptoms, participants reported being able to maintain good work functioning, while the negative influences of a history of BD (e.g. a legacy of disrupted work history and medication side-effects) were out-weighed by such positive effects of

BD as facilitating interpersonal relations in the workplace and attitude to work. This beneficial interaction of work and health was enhanced by engaging in work activities that reduced the likelihood of BD symptoms emerging, such as providing application to work tasks, and distraction from preoccupation.

Episodes of BD-related symptoms occurred with varying frequency within the participant group, with each participant reporting at least one occasion when they endured such symptoms whilst at work. The onset of BD episodes was attributed by the participants to a range of causes, amongst which were work-related events such as stressful changes in the workplace or their own work duties, feeling the pressure of work demands in the absence of adequate support, or interpersonal difficulties at work. Regardless of the cause, onset of BD symptoms typically catalysed the transition of participants from experiencing a beneficial interaction of health and work to a more disruptive interaction of influences. Many of the factors that were operating in the beneficial interaction phase remained present at all times. However, with the onset of symptoms these were commonly accompanied by symptom-dependent negative influences between work and health. This was particularly clear from accounts of times when depressive symptoms were ongoing, which disrupted participants' performance of work-related tasks and their attitudes to work responsibilities. These work-related consequences of depressive symptoms in turn increased the pressure of demands they endured from their responsibilities, thus establishing a cyclical pattern of deteriorating health and work functioning.

In the case of onset of manic symptoms, there appeared to be a period of time early in the episode when symptoms enhanced work performance and attitude towards some participants' duties, while also disrupting ability to make decisions and maintain appropriate social relations in the workplace. Such positive effects of manic symptoms appeared, however, to be relatively short-lived, or over-shadowed as further increases in the severity of symptoms led to continued deterioration in the ability to perform tasks and function in the workplace. A number of identifiable phases in the course of a disorder are laid out by the IDM, and there was considerable evidence of such phases in the accounts in the present study. For instance, during a moratorium phase, individuals are thought to experience stability in symptoms and functioning, when little measurable change in symptoms is occurring. This notion of a moratorium phase may apply to the periods when participants reported being in work in between episodes of BD. At these times, symptoms were minimal, and participants were able to benefit from their BD histories in the workplace in a sustainable way. For instance, a history of BD enhanced participants' interpersonal skills and sense of empathy with their colleagues and employees. Change points in the course of disorder focused on participants' accounts on the onset of BD-related symptoms. These were perceived as being caused by stresses in the working environment and the accumulation of work pressure in the absence of adequate support. The research findings were intended to inform the integration of employment issues within the remit of both generic community mental health services and the development of more specialist employment services for people with mental health problems. For instance, within a generic service, the process of assessing clients' difficulties and clinical needs might be enhanced by considering the impact of their employment on their experience of BD symptoms. With a knowledge of how stressful changes and processes in the workplace can precipitate the onset of symptoms, episodes of illness can be predicted beforehand and avoided. Secondly, the possible ways in which BD can affect experiences at work (both positively and negatively) and vice versa could be summarised for clients at the point of diagnosis. Clients would then be able to make informed decisions about whether or not to seek employment can be prepared for the challenge and opportunities that arise. Relevant to the context of specialised employment services, it was clear that people's experiences of the interaction between an illness and the working environment change over time. An employment service would therefore need to be flexible enough to be sensitive to those changing needs and provide different levels of support at different times.

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The Social Construction of Mental Illness and its Implications for the Recovery Model

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Abstract

The mental health profession has somehow missed out on the evolution of the postmodern perspective and linguistic paradigm prevalent now in philosophy, history, the social sciences, literature, and art – the exception to this being postmodern consultation (formerly known as postmodern psychotherapies). From the linguistic paradigm and postmodern perspective we see how language *creates* realities as opposed to “discovering” them. What this means for the mental health profession is that “mental illness”, diagnoses, and associated concepts are social constructions. This paper will illustrate how this is so and will also explore the consequences of not recognizing this fact. Additionally, the implications of this knowledge for the recovery model will be explored. Recently in California with the passage of the Mental Health Services Act (Nov, 2004) implementation of the recovery model has become a priority for most community mental health agencies. The recovery model is a great advance in the movement towards client self-determination, empowerment, and independence. Another purpose of this paper is to bring to light how the medical and psychological models are alive and well in recovery programs in the way in which they are still thought of and spoken as essential truths - despite programs and relationships that are structured around client self-determination.

Introduction

> *Words, like the chisel of the carver, can create what never existed before rather than simply describe what already exists. As a man speaks, not only is the thing which he is declaring coming into existence, but also the man himself.* **- Martin Heidegger**

The metal restraining chains are gone – now it is time for those "invisible chains" to go: WORDS. The vocabularies of the medical and psychological models with their disease terminology and deficit-focus have got to go. It is about time that the mental health profession enters into the light of the broader historical and philosophical revolution of postmodernism and its consequent linguistic paradigm. In this light we will finally recognize that words are much more powerful when used as "tools" to facilitate change and connection as opposed to when used to try to describe some "objective reality" (such as a psychiatric diagnosis). The purpose of this paper is to help free participants on both sides of the helping relationship from the socially constructed and socially destructive illusions created by the current medical-psychological-pathologizing and deficit-based languaging.

This goal will be accomplished from several different points of view: the history of philosophy, linguistics, power, cognitive science, and an examination of consequences. We will conclude with the implications this knowledge will have for the recovery model.

History of Philosophy

Philosophy since Plato has been about the search for absolute Truth through the use of reason. Science and the scientific method were a natural extension of this. Since the Enlightenment, science had been trying to "discover" a "reality" that our senses and scientific instruments only detect shadows of. Comte's philosophy of Positivism (about 1853) held that everything could be understood in terms of science – in opposition to a historical reliance on metaphysical, and theological explanations. The scientific method sought to explain phenomena by analysis, i.e. by reducing them to constituent interacting parts. Science soon found application in medicine and psychiatry, which continue this tradition of "discovering" and labeling parts of the whole. This reductionism taken together with the medical-disease focus has produced the familiar clinical terms of diagnosis and treatment in the mental health profession.

Another product of the Enlightenment that has been foundational in the mental health profession is Newton's laws of motion and mechanistic view of the universe. The universe was seen as operating like a giant clock set into motion by God. Soon everything was seen as a machine, including human beings. From this perspective human beings can be diagnosed and treated just like computers and automobiles can be fixed. This mechanistic view of human beings is foundational in mental health despite all the contradictory evidence.

Along came Ludwig Wittgenstein (1889-1951). Prior to Wittgenstein philosophy involved the use of reason to arrive at absolute truth – a search similar to that of science. Having taken philosophy to its limit, Wittgenstein decided to inquire into the nature of language, that taken for granted substrate of philosophy and science. Wittgenstein concluded that the typical problems of philosophy (the nature of reality, mind, etc.) were unsolvable and he focused instead on the role of language in everyday social activities. Furthermore, he asserted that communication was better seen as "language games" that influenced human action as opposed to exchanges of representations of "reality." Wittgenstein later became one of the founding fathers of postmodernism.

Postmodernism asserts that there are no absolute truths, and, instead, there are only different interpretations formed in language. Pragmatism later adds the requirement of utility to the mix. Postmodernism acknowledges how human relationships and communication create vocabularies that interpret our experience – that is, our "realities" are socially constructed. This is also referred to as the linguistic paradigm.

To illustrate how realities are socially constructed let's look at a thought experiment from Berger & Luckmann's (1966) *The Social Construction of Reality* (from *Narrative Therapy*, Jill Freedman and Gene Combs, 1996):

> "Imagine two survivors of some ecological disaster coming together to start a new society. Imagine that they are a man and a woman who come from very different cultures. Even if they share no language, no religion, and no presuppositions about how labor is to be divided, or what place work, play, communal ritual, and private contemplation have in a good society, if culture of any sort is to continue, they must begin to coordinate their activities. As they do this, some agreed-upon habits and distinctions will emerge: certain substances will be treated as food, certain places found or erected to serve as shelter, each will begin to assume certain routine daily tasks, and they will almost certainly develop a shared language.
>
> Between the two founding members of the emerging society, the habits and distinctions that arise will remain 'tenuous, easily changeable, almost playful, even while they attain a measure of objectivity by the mere fact of their formation' (Berger & Luckmann, 1966, p. 58). They will always be able to remember, 'This is how we decided to do this,' or 'It works better if I assume this role.' They will carry some awareness that other possibilities exist. However, even in their generation, institutions such as "childcare," "farming," and "building" will have begun to emerge.
>
> For the children of the founding generation, 'This is how we decided …' will be more like 'This is how it's done.' Mothers and farmers and builders will be treated as always-having-existing types of people. The rough-and-ready procedures for building houses or planting crops that our original two survivors pieced together will be more-or-less codified as the rules for how to build a house or plant corn. In all likelihood laws will have been written about where, when, and how buildings may be built or crops may be planted. It is hard not to imagine that customs governing the proper rites for starting a family or harvesting a crop will have come to be, and that certain individuals will be identified as the proper people to perform those rites. Institutions like women's societies and masons' guilds will have begun to emerge.
>
> By the fourth generation of our imaginary society, 'This is how it is done' will have become 'This is the way the world is; this is reality.' As Berger and Luckmann (1966, p. 60) put it, 'An institutional world… is experienced as an objective reality.'"

This is true not only from the perspective of the evolution of civilization and culture – it is also true in terms of the development and institutionalization of professions. If we replace the original two survivors with the original thinkers and arbiters of psychology and psychiatry we have development of the mental health profession together with its vocabulary (meaning words, concepts, and practices). Like the children in the thought experiment, everyone receiving a formal education in mental health receive the words and concepts as "reality." This process is called reification. Reification, according to Berger and Luckmann (1966, p. 89), is

> "… the apprehension of the products of human activity as if they were something else than human products – such as facts of nature, results of cosmic laws, or manifestations of divine will. Reification implies that man [sic] is capable of forgetting his own authorship of the human world. (emphasis in original)"

So what does this all mean in terms of the mental health profession? The vocabularies of the medical and psychological models, indeed the idea of "mental illness" itself, are social constructions – THEY'RE MADE UP. Furthermore, they are vocabularies that describe disease and deficit. They view a human being as something that can be "assessed", "diagnosed", and "treated" much like a machine – hence comes the obsession with "compliance." These models make distinctions between "normal" and "pathological." They position practitioner as expert and client as more or less passive recipient of "treatment." The focus of "treatment" is on the elimination of "symptoms." As will be discussed later, the recovery model is a state of partial transformation: it is truly client-centered; however, it is contextually "weighed down" by the vestigial and anachronistic use of the medical and psychological vocabularies. These vocabularies invisibly and insidiously support the old paternalistic roles.

From a postmodern perspective these medical and psychological vocabularies are not representing reality, but, in fact, creating a "reality" or perspective. The fact is that words simply "carve up" our undifferentiated sensory experience leading to many possible interpretations of the human condition. The question then becomes "What is the best 'reality' or perspective with which to help people reach their goals?" John Walter and Jane Peller (2000), both prominent leaders in postmodern consultation, describe this shift from *belief* to *utility*:

> "From our reading of postmodern philosophy and pragmatism, we decided to abandon the debates over epistemology and the debates over the foundation of knowledge. Taking his cue from Nietzsche and William James, the contemporary author of the new pragmatism, Richard Rorty, suggested: 'Instead of saying that the discovery of vocabularies could bring hidden secrets to light, [the pragmatists] said that new ways of speaking could help us get what we want' (1982, p.150). So, instead of asking, 'How do we know what is real about the client?' we have decided the more relevant question is 'What do our clients want and what new ways of speaking or conversing might help?'" (p. 32)

Yet the power and importance of language goes beyond even this. Like "water is to the fish," language and its implications are very difficult for human beings to discern. When we create words and concepts describing aspects of ourselves or of our environment (also know as *making distinctions*) they appear as "truths" and, consequently, they dictate our actions. Martin Heidegger (1971), widely regarded as one of the most original and important philosophers of the 20th-century, put it this way: "we do not use language"; rather, "language uses us".

Linguistics

From the perspective of linguistics we see that the reified categories (e.g. mental illness, schizophrenia, bipolar disorder) are abstractions defined by clusters of what we call "symptoms." Schizophrenia is defined as the presence of audio hallucinations (or other "thought disorders") in the absence of a "mood disorder." You can even throw in other correlates like "negative symptoms", PET scans, response to medications, etc. The issue of the DSM's poor reliability and validity aside (Caplan, 1995; Sparks, Duncan, & Miller, 2005), the term "schizophrenia" is a word used to communicate the presence of these "symptoms." The various human manifestations of thought, feeling, and behavior (aka "symptoms") exist like the chair you are sitting on as you read this exists. But the next level of abstraction, the word "schizophrenia", and the next, "mental illness", only exist through consensus and only persist by convention. Even if the correlations of defining symptoms was perfect (which it is far from), in light of the linguistic paradigm we have to ask ourselves whether using a pathologizing, deficit-based vocabulary is useful in helping people improve the quality of their lives.

One of the traditional rationales for diagnosing is to have a shorthand way of communicating with other professionals, presumably for the purposes of "treatment." One thing that gets communicated is a cluster of "symptoms" under the heading of the "diagnosis." Unfortunately, what also gets communicated is the hierarchical role relationship as well as the pathologizing and deficit-focused context.

Often so called "mental illness" is described as similar to physical illnesses, such as diabetes, where the patient needs to manage it the rest of his or her life with medications. This comparison is used to explain how medications work as well as to make the diagnosis and treatment more palatable to the client – as if to imply that their "mental illness" is something they "have." This analogy completely breaks down for the following reason. When we are talking about a person's thoughts and feelings we are essentially talking about their identity (which includes values, beliefs, memories, fears, and desires). This is not like something physically wrong with part of their body. A "disorder" of thought or feeling is a labeling of a person's identity. The labeling of subjective experience feeds on itself and perpetuates itself. Paula Caplan (1995), former consultant to the creators of the DSM, writes:

> "The professionals most concerned with labeling claim that they assign people to categories of mental illness so that they will know how to help them. If such assignments to categories really did help very much, that would indeed be encouraging, but treatment of emotional problems and conflicts is very different from medical or surgical treatment. If I broke a limb, I would want to be properly diagnosed as having a broken arm so that the surgeon

> would not mistakenly set and put a cast on my leg. But diagnosing individuals as mentally ill has not been shown to do much to alleviate their anguish and indeed often makes it worse." (p. 12).

Remember that the rest of the postmodern-enlightened world understands that words associated together comprise PERSPECTIVES and not descriptors of some discovered "objective reality." Another way to look at this is that symptom clusters are like stars comprising a constellation. The constellation (say the "big dipper") only "exists" from our point of view on earth. From another point of view far from our solar system the abstraction "big dipper" no longer exists. We have to get beyond our entrenched perspective.

Psychology, like psychiatry, has found ways of linguistically contorting, convoluting, and confusing lived experience with essential "truths" of its own. Bill O'Hanlon, a preeminent postmodern consultant and author, uses his holiday cookie making experience to communicate what happens in the therapy room (O'Hanlon and Wiener-Davis, 1989). A client's problem that s/he brings to therapy is like cookie dough. The experience of it is vague and malleable. Once the "blob" of cookie dough is forced through the cookie press (a tube, funnel, and mold pressed against a baking pan) it becomes a Christmas tree, star, or Santa Claus. Similarly, when a client exposes his or her problem to a therapist it gets "molded" or interpreted in the language of the therapist. So a client attending a psychodynamic therapy session would leave having unresolved childhood conflicts. The same client leaving a behaviorist's office would walk away with problem behavior shaped by reward and punishment. An interaction with a Jungian therapist would result in the need to deal with the various archetypes that apply to him or her. Talking with a diagnostically (and thereby pathologically) minded clinician will leave one with the idea that they "have" "bipolar disorder", "depression", "obsessive compulsive disorder", a "mental illness" – along with all the stories that go with them ("chemical imbalances", life-long duration, the need to "comply" with a treatment regimen, etc.). Like cookies, continued exposure to the "heat" of the theoretical lens causes these interpretations to "harden" or "reify" (to make real). O'Hanlon concludes that if our languaging creates "the problem" then why not leverage the use of language and create a problem that is easiest to solve. Harlene Anderson (1997), author of *Conversation, Language, and Possibilities*, adds:

> "What seems to be an identifiable objective reality – a problem – is only a product of descriptions, the product of social construction. (p. 73)"

From a linguistic point of view, the recovery model is still saddled with the baggage of pathological and deficit-based vocabularies. Let's take a look at the recovery model concept of hope. Hope, an integral component of recovery, is constantly being weighed down by the languaging of diagnoses, "treatment", neurochemical correlation to "disease", psychiatric history taking, predictions of life long "illness", and on and on. In contrast, postmodern consultation (therapies) use language to maximize strengths and optimism. For example, presuppositional questions such as "What will you be doing differently when the current difficulties are resolved?" have a built-in supposition that the client *will* resolve the current difficulties. Simply by answering the question the client affirms the presupposition that they *will* resolve their current difficulty. Is there any proof that a client will resolve a current difficulty? Of course not. But if you speak as if they will, they become empowered – and, empowerment is the point.

This is one of the many ways in which language is used to empower people as opposed to coming from the scientific paradigm where reason and rationality are mistakenly applied to human beings in order to reductively nail down "objective" truths about them. Such misapplication of reason is an example of what is referred to as *scientism*: the attempt to use scientific method in domains where it does not belong (Barzun, 2000).

The power of language and positive expectations has long been observed in the forms of placebo effects and self-fulfilling prophecies (Miller, et. al, 1997). Common sense has had an insurmountable problem penetrating the theoretical lenses of mental health professionals. And, as if common sense wasn't enough, cognitive scientists have discovered that the human brain operates according to complexity theory (as opposed to mechanistic theory described above) and, as such, it conforms to role expectations and resists overt or covert means of control or manipulation (McCrone, 1999).

Power

The mental health profession's isolation from other disciplines such as history and philosophy, as a whole, has left it with only a superficial understanding of the power of language. In the best cases, experienced practitioners view diagnosing as a "necessary evil" and do it with caution or, in the case of the recovery model, clients are seen as "having" a diagnosis rather than *being* a diagnosis. In addition to the understanding of language above, language is involved in setting and maintaining power relations in society. In postmodern circles this is referred to as the *political* aspect of language.

The mental health consumer movement has long recognized its struggle as similar to that of other marginalized (to use another postmodern term) groups such as women, gay men and lesbians, African Americans, and other minority groups. How this relates to language is as follows.

The vocabulary of the medical and psychological models inherently positions the clinician as expert interpreter of the client's experience. Seemingly benign words like "clinical", "treatment plan", "case", etc. also bring with them a context in which the client is seen as "abnormal" or having a "pathology" while the clinician has the role of performing "interventions" or other activities (such as wellness centers) to help the client overcome their "pathology." The power of definition is in the hands of the clinician. Once labeled "abnormal" (aka "mentally ill") you've been pushed to the edges of society – where your views and concerns are considered not important.

Humanitarian, political, and financial pressures have given birth to the recovery model. Being outcome-driven, recovery programs have had to bend to the truth of what works. This includes being client-centered, being passionate about helping clients get what they want and find meaningful roles in life, having a vocational and community integration focus, and really meeting clients where they're at. However, the discourse of the medical and psychological models still lives in the language spoken in recovery programs.

So you can have the best recovery program in the world and still be linguistically casting clients in roles in which they are in fundamental ways different from the rest of humanity. The discourse, the spoken language, creates the distinction "mentally ill" versus "not mentally ill."

Let's switch gears and take another look at the where the rest of the world has been heading. Michael Foucault, the very influential French philosopher and social critic, around the mid 20th century began to inquire into the relations between language and power. In short, he revealed that part of the way the powerful stay in power is through a monopoly on "truth" or "knowledge." With the emergence of democracy, politicians understood the need to manipulate public opinion. In developed countries corporations, through marketing, *create* need. The mental health profession says what's "normal" and what's "pathological." Furthermore, the vocabularies of the medical and psychological models together with the professional titles become something that seemingly elevates the professional from the persons subject to the labels (and, in many instances, from all non-professionals).

The designation "being insane" or "having a mental illness" originally implied the need for incarceration in mental hospitals. Through political and humanitarian pressure "treatment" became the alternative. The distinction "mental illness" became differentiated into all the diagnoses we have today. The point being that, though we have more humane treatment and more sophisticated designations, our languaging is still defining people as "abnormal" and subject to "treatment" where, despite more empowering structuring of roles (as in current recovery models), the center of power and definition lies in the clinician. Then it follows that these power relations, maintained in the vocabulary, powerfully undermine efforts at community integration and self-determination.

Though recovery-oriented programs are more client-centered, the double-bind communications of days of old are still alive and well. The content of our conversations with clients can be about their goals, their quality of life, accountability, community integration, high expectations, self-determination, independence, self reliance, etc.; but the context of our communication is "you have a pathology that makes you different from the rest of society" and "we have the expertise to help you overcome this pathology in order to live meaningfully like normal people do." Don Jackson (1965) drawing on Gregory Bateson's work on systems theory, asserted:

> "Every message (communication bit) has both a content (report) and a relationship (command) aspect; the former conveys information about facts, feelings, experiences, etc., and the latter defines the nature of the relationship between the communicants." (p.8)

The "command" or role relationship aspect of the communication, brought forth in the vocabulary, creates and privileges clinician knowledge and marginalizes the client's knowledge and skills. This will be the case no matter how much the client accomplishes. This is true no matter how many wonderful recovery-based systems you have in place as long the medical and psychological vocabularies are still being used. The result: many so-called "mentally ill" people have skills and resourcefulness that go unnoticed and therefore uncapitalized on. The skills of negotiating the public transit system, living off welfare (in California about $250 dollars plus food stamps per month), adapting to often dangerous and unhealthful living conditions, negotiating the bewildering and often unfair social service and child protective agencies, coping with the "mental illness" stigma and ostracization, dealing with being "infantilized" (treated as a child or infant) by others, struggling with being pathologized by helping professionals, coping with being manipulated and taken advantage of by family members, and developing a whole array of "street smarts" – are all barely noticed behind the "mountain" of pathology "heaped" upon them from the medical and psychological perspectives.[1] Often their quite understandable reactions to so many of these challenges get thrown into the "symptom list" which adds support to "the diagnosis," which implies an inherent and internal "pathology" – all of which contributes to feelings of shame, humiliation, and self-blame. The "iron-grip" of these pathologizing discourses causes us to rarely sufficiently consider a client's life circumstances when the pathologizing labels are applied.

This brings to mind the fact that the Euro-centric version of "intelligence" and skill is but of one kind. Anthropologists were among the first to discover how the human brain does amazing feats regardless of the environment in which it finds itself – that is, regardless of such conditions as time period, geography, or degree of technological or economic development (Pinker, 2002). Individuals in primitive societies used to be viewed as having undeveloped brains (e.g. lacking intelligence). Their lack of technology (among other factors) prejudiced researchers (who are predominantly immersed in the dominant western Anglo culture) from seeing the amazing ways in which their genius and creativity manifested themselves. The most obvious example of this is the ancient Egyptians. The contributions of non-dominant cultures and those of other marginalized groups such as the so-called "mentally ill" are often devalued in a similar way. Real acknowledgement of these knowledges and skills in some fundamental way puts all of us humans on an equal footing: it's not about being better or worse, just different.

Our clients often are talented poets, artists, and musicians – traditionally vocations for those on the fringe of society. The long list of accomplished people with so-called "bipolar disorder" includes: Ted Turner, Jimmy Hendrix, Sting, Francis Ford Coppolla, and Jane Pauley. The link between "mental disorders" and creativity has been well established (Rothenberg, 1990). How many potential future Van Gogh's, Schumann's, Tolstoy's, Beethoven's, Hemmingway's, etc. have been prevented from enriching our society because their talent has been disabled and hidden by these vocabularies. The wealth of creativity and genius lost is incalculable.

Non-dominant cultures have had to liberate themselves from the pathologizing "lens" of mental health professionals as well. The "gays" in the 70's got themselves out of the DSM. Since the 80's cultural pluralism and cultural competency have been emphasized to keep the arbiters of what's "normal" and "healthy" away. Now it's time for the rest of us!

The point being that the powerful in society promote a dominant discourse (ideas and practices) that often pathologizes and devalues practices of non-dominant cultures and marginalized groups. The mental health profession acts as an agent of society in this way. Harlene Anderson (1997) asserts:

> "The dominant voice, the culturally designated professional voice, usually speaks and decides for marginal populations – gender, economic, ethnic, religious, political, and racial minorities – whether therapy is indicated and, if so, which therapy and toward what purpose. Sometimes unwittingly, sometimes knowingly, therapists subjugate or sacrifice a client to the influences of this broader context, which is primarily patriarchal, authoritarian, and hierarchical." (p. 71).

The very words and concepts used create a perspective in which clients and their talents are subjugated to the professional knowledges. To review, because of the way language works this happens despite all the rhetoric and programs promoting client self-determination, client strengths, client empowerment, etc.

The movement to put an end to the use of the medical and psychological models and vocabularies has every element of a social-political movement – with something like emancipation, liberation, or inclusion being the objective.

Cognitive Science

What about the old favorite "chemical imbalance" – the often called-upon "proof" of the "disease model" or the "reality" of "mental illness?" Once again we look outside of the profession of mental health in order to get perspective. During the last half of the 20th century there has been a strange and wonderful confluence of scientific disciplines – including evolutionary psychology, sociobiology, genetics, cognitive science, and anthropology – that have dramatically changed our view of the human condition. Steven Pinker, Richard Dawkins, Robert Wright, Daniel Dennett, E.O. Wilson, and Noam Chomsky are among the contributors. While keeping in mind this inter-disciplinarity, for the purposes of this article we will focus on cognitive science.

Perhaps due to the hegemony of psychiatry and perhaps due to power of the pharmaceutical industry (another powerful interest group that promotes the medical vocabulary) the mental health profession has been shamefully unaware of what's been happening in non-disease-model-presupposed brain research: cognitive science. What does cognitive science or its cousin, neurobiology, have to say about the notion of "chemical imbalance" and its relation to people's various mental conditions?

The distinction "chemical imbalance" is employed among other reasons to give credence to the "illness" interpretation and to justify the use of medications. The argument is made that a biological basis means it is a disease like other physical diseases.[2] The causality is assumed in the direction from biology to mind and behavior. Much current research, however, is revealing that mind and behavior (e.g. that which happens with psychotherapy) equally influence brain chemistry. Harrop, et. al. (1996) states:

> "[It] is possible for physiological differences associated with the condition [schizophrenia] to be the result of the condition and not the cause. . . . [The] relationship between the psychological problems and the physiology should be viewed not as a simple cause-and effect relationship, but more as a reciprocal and iterative relationship where psychological effects can affect the physiology that can in turn affect the psychology." (p. 641)

Since Harrop's research in 1996, the effect of psychotherapy on brain chemistry has been well documented (Teasdale, J., et. al., 2000; Shapiro, F., 2000; Schwartz, J., 2002; Goldapple, et. al, 2004; Etkin, et. al., 2005; Otto, et. al., 2005). Researchers now use the terms and "bottom-up" and "top-down" to characterize the effects of psychotropic medications and psychotherapy respectively. Medications are thought to change brain chemistry in "lower" or emotional regions of the brain (i.e. limbic system) which, in turn, effects the "higher" or thinking regions (i.e. the cortex). Psychotherapy (most researchers used cognitive-behavioral or mindfulness approaches), on the other hand, works from the "top-down." Better thinking results in changed brain chemistry. The term "biological basis" needs to be replaced with "biological correlate" where there is correlation and bi-directional causation.

Like diagnoses, the concept of "chemical imbalance" is an abstraction used mistakenly with universal application – despite similar validity and reliability problems (Sparks, Duncan, & Miller, 2005). Both the concepts of "mental illness" and "chemical imbalance" comprise some of the arsenal used to try to break down the "denial" and persuade (or coerce) clients into treatment. The question of "chemical imbalances" becomes moot when we look at all the negative consequences.

An equally important finding of cognitive science to the mental health profession is that of *neuroplasticity*. The old functional mapping of the brain has been discarded in favor of neuroplasticity. In his groundbreaking book *The Mind and The Brain: Neuroplasticity and the Power of Mental Force* (2002), Jeffrey Schwartz chronicles the discovery of neuroplasticity by Edward Taub during the famous Silver Springs Monkeys experiments. In short, monkeys were used to show that in response to environmental demand and repetitive effort the brain will recruit healthy neuronal networks to perform the function of damaged ones. These findings have subsequently formed the basis for treatment of stroke victims and people with dyslexia.

Similar to the situation in California, where the Mental Health Services Act has provided the financial incentive to removing other entrenched-paradigms in favor of the recovery model, Schwartz points out how it was the potential for profit in the treatment of dyslexia that finally broke the grip of the old brain paradigm. Schwartz:

> "When Ed Taub once expressed frustration about how slow the rehabilitation community was to embrace constraint-induced movement therapy for stroke, Merzenich responded that only the profit motive was strong enough to overcome entrenched professional interests and the prejudice that the brain has lost plasticity after infancy." (p.234).

Merzenich's company, Scientific Learning, was so successful in treating dyslexia – having a 90% success rate – that in July 1999 it announced its initial public offering.

Schwartz took it a step further. In trying to help people diagnosed with "obsessive-compulsive disorder (OCD)" he recognized that traditional cognitive behavior therapy didn't work because knowledge of the irrationality of their cognitions made little difference to "OCD" clients. Instead, he *redescribed* the obsessive thoughts as products of "brain lock" (using PET scans showing lockstep functioning of the orbital frontal cortex, anterior cingulated gyrus, caudate, and thalamus), impressed upon them the idea that "thoughts were not facts" and that "they were not their thoughts", and devised alternative behaviors to replace the compulsive ones. He essentially divested the thoughts of their reality status thus making mindful awareness possible.

The results were astounding. The mindfulness training proved better than all other psychotherapies used with "OCD" and, more importantly, they produced the same neuronal changes seen on PET images after treatment with powerful psychotropic medications (Schwartz, 2002). Similar mindfulness-neuroplasticity mediated changes have been reported in the process of EMDR (Shapiro, 2001) and in the "treatment of depression" (Teasdale, et. al., 2000). Mindfulness continues to be a pioneering modality among many that live and thrive outside of the confines of the medical and psychological models (Bennett-Goleman, 2001; Shapiro, 2001, Hayes, 1999).

I am not trying to disqualify the use of chemicals (aka medications) to help people improve the quality of their lives. I am saying that psychiatry will have to recognize that it is an art to be applied in a highly individualistic, non-pathologizing, collaborative way – perhaps something akin to how the East practices herbal medicine. [The book to read is A Road to Recovery by Mark Ragins, MD]. We have to view chemicals as "crutches" in order to reduce the all-to-prevalent dependency and to position clients as responsible for taking many other actions that support their personal and spiritual growth. The chemicals sometimes are a helpful and temporary "tool" – it is the "story" that goes along with them that carries with it the iatrogenic problems (problems caused by the attempted solution).

These findings all point to the need to replace the paradigm of "chemical imbalance" with that of "neuroplasticity" – replacing determinism with possibility, medication dependence with better linguistic tools. So much industry attention on "bottom-up" change using pharmaceuticals has made clinicians "dependent on medications" in the sense that clinicians have not paid enough serious attention to developing their empowerment skills – making "biochemical determinism" a self-fulfilling prophesy. No doubt the neuroplasticity paradigm will result in practitioners with much greater empowerment skills; hence, greatly reducing the need for medications. Mindfulness is one of the perspectives and practices that will eventually replace the old medicalization of experience (see Implications for the Recovery Model section).

In light of neuroplasticity, rigid abstractions such as "chemical imbalance", "mental illness" and psychiatric diagnoses, such as "borderline personality disorder", are linguistic "balls and chains" when it comes to helping people become self-determining.

Examination of Consequences

Ignorance of the linguistic paradigm has resulted in profound iatrogenic problems (commonly referred to as iatrogenic illness): problems caused by the attempt at helping. Mental health professionals may be *creating* much (being conservative) of that which they are trying to cure.

When we speak as if someone has a diagnosis or has a "mental illness" we are unwittingly *creating* a reality – a reality in which human beings are transformed into the "mentally ill". When we use words such as "mental illness", "schizophrenia", "symptoms", "tangential speech", "clinical this or that", "treatment plan", "assessment" – we are unwittingly bringing forth the entire context, the hierarchical and paternalistic role relationship together with the sticky morass of pathological and deficit-based perspectives. Jill Freedman and Gene Combs (1996) write:

> "Speaking isn't neutral or passive. Every time we speak, we bring forth a reality. Each time we share words we give legitimacy to the distinctions that those words bring forth." (p. 29)

Words, abstractions, theories, and beliefs focus our attention. Heinz von Foerster (1984), the famous cybernetician and constructivist, concluded: "Believing is seeing." We "see" those behaviors that confirm the diagnosis and hardly notice those behaviors that don't. Because those are the behaviors noticed and responded to, the client experiences herself defined as such, and, by way of self-fulfilling prophecy, feels a strong "relational pull" to behave accordingly. It doesn't take an advanced knowledge of systems theory or cybernetics to see how we amplify the "symptoms" and reify (make real) the "labels" by the use of the pathologizing language. The irony and tragedy is profound.

We know not what we do. By seeing the medical and psychological vocabularies as truths (as opposed to perspectives) we cannot see the profoundly destructive consequences of them. These vocabularies comprise closed conceptual systems in which everything can be explained within them (not unlike a so-called "delusional" system). Martin Heidegger called these often impenetrable, closed interpretive systems *hermeneutic circles*. For example, a client who doesn't fit into the Procrustean bed [3] of "treatment" is seen as resistant, not ready to change, irresponsible, employing "defensive mechanisms", at the effect of "transference", manipulative, etc. The therapist's actions (frustration, resignation, avoidance, etc.) are in perfect accord with this cadre of pessimistic terms and, of course, have their complementary responses in the client (further lack of desire to participate with the therapist, increased pessimism about their own prospects, more inaction) – thus confirming the initial interpretation. Ironically, such "client blaming" keeps the professional from taking responsibility for doing something different that might produce a better outcome. Equally disturbing is the fact that this "hermeneutically sealed" conceptual system keeps us from hearing and taking seriously the emerging "voice" of the people we are trying to help (e.g. the Mental Health Consumer Movement).

The emerging client-centered recovery model acts as a counterbalance to this. Recovery programs look to make client goals (as well as removing barriers to these goals) and strengths the focus. In this way recovery programs go a long way towards ameliorating much of the negative effects of the medical and psychological vocabularies in which they are immersed.

Without a recovery focus pathologizing runs rampant: A client can't be angry without being accused of "not taking their medications". A client can't be persistent in getting his needs met without being written off as being "manipulative." A productive day becomes hypomania. A tired day means signs of depression. A client asserting themselves with their clinician is defensive or resistant. And, of course, the "spin" put on client's behavior confirms the clinician's expectations. Despite the gains of the recovery focus the disabling conceptual reality continues to "live" in the minds and "breath" in the speaking of these recovery programs. Paula Caplan (1995) writes on some of these effects:

> "When terms like abnormal or mentally ill are spoken, what kinds of images come to mind? Usually, images of difference and alienation, suggesting that 'they' are not as competent, human, or safe to be around as the rest of 'us.' And often, 'abnormal' and 'mentally ill' are equated with 'crazy,' a label that calls forth images of someone who is out of control, out of touch with 'reality,' incapable of forming a good relationship, untrustworthy, quite possibly dangerous, and probably not worth one's attention, time, or energy. If such labeling had some positive effects, it might be worth risking the negative consequences for those who are labeled abnormal."

Furthermore, recovery's focus on community integration is continually sabotaged by the medical and psychological vocabularies. The normal ups and downs of working or being in relationship quickly get pathologized. Remember, it's about focus and language; recovery programs are currently only addressing focus. A problem with managing work tasks or a pang of jealousy in a relationship is quickly referenced back to a "mental illness." Shery Mead and Cheryl MacNeil (2004) in their paper titled Peer Support: What Makes it Unique? poignantly illustrate this problem:

> "Recovery in mental health has most often been defined as a process by which people labeled with mental illness regain a sense of hope and move towards a life of their own choosing (President's Freedom Commission Report, 2003). While this definition on the surface seems obvious, what remains hidden is the extent to which people have gotten stuck in a medical interpretation of their experiences. With this stuckness comes a worldview in which one is constantly trying to deal with their perception of what's wrong with them instead of what's wrong with the situation. In other words, even if I have hope of moving into a better life, I have been taught to pay a lot of attention to my 'symptoms.' This interpretation of my experiences leaves me constantly on guard for what might happen to me should I start to get 'sick.' Even with recovery skills (learning to monitor my own symptoms), I find myself creating a life that is ultimately guided by something inherently wrong with me. With this understanding, I may continue to see myself as more fragile than most, and different than 'normal' people. I then continue to live in a community as an outsider, no matter what goals I achieve." (p. 7).

Mead and MacNeil advocate client peer support that is free from the vocabulary of the medical model – I am advocating this for the profession as a whole.

Another devastating consequence of the medical and psychological vocabularies is their effect on our ability to recognize and capitalize on client's strengths. There are several ways in which client strengths are wasted. First, the hierarchical role relationship wherein the clinician is the expert and the client is the passive recipient of "treatment" puts the focus on the clinician and her expert knowledge. Secondly, the expert knowledge that both clinician and client are relying on focuses on current deficits (e.g. symptoms) and historical failure & tragedy (aka psychiatric history). Thirdly, the vocabulary hides, minimizes, and explains away strengths as "flights into health", superficial in comparison with "the illness", or even manifestations of "the illness" (e.g. hypomania, manipulation). Fourthly, the medical and psychological vocabularies comprise "normative perspectives" where clients are implicitly compared to what is "normal" in society; hence, making their strengths, accomplishments, and incremental change seem insignificant (or not given nearly enough attention, admiration, wonder, and analysis). Finally, even if the professional wants to build on client strengths, there is no vocabulary and associated practices in these models with which to do it. Let's get a taste of such empowering perspectives and practices by taking a look at an example from postmodern consultation.

Postmodern consultation leverages the power of language and focus. For example, in solution-focused therapy (a postmodern modality) we start by building on “exceptions”: times when the problem is less intense or less frequent. For example, with a client whose goal is social skill, we might ask, “What is different about those times when you’re a little more socially skilled?.” Often clients say that they are more socially skilled in one-on-one situations where they are talking about common interests. Exceptions are always occurring, even BEFORE any contact with the helping person. After engaging in them in a collaborative inquiry into the *interpretive structure* that made this exception possible, I ask them to do more of this and keep track of what else they do that works. Therapy quickly becomes about reporting all the new distinctions (ways of viewing situations) and strategies that are working. This process immediately makes client’s feel more confident. Moreover, all the life-enhancing strategies, derived from exceptions, are tailor-made to the client’s temperament and circumstances. By focusing on pathological constructs exceptions are hardly noticed, ignored, minimized, or explained away. The very building blocks of change are ignored! Instead, “symptom management” and skill building programs start from scratch, assuming everything must be taught to the client – which also communicates to the client that what they already know is of little or no use.

The roles taken and words used by mental health professionals prevent an existential “I-Thou” (Buber, 1958) connection with clients. There is a maddening kind of inauthenticity and duplicity that comes with interactions with today’s mental health professionals – not unlike the patronizing experienced by many minority groups. A kind of gulf between their personhood and professional role makes real human connection impossible. This disconnect manifests in barriers to effectively listening, accurate empathy, limit setting, etc. For example, labeling people as having “borderline personality disorders” has historically retarded clinician’s interpersonal skill development (such as being able to compassionately set limits). The label creates the problem in the client as opposed to between two people – effectively relieving the professional from the responsibility for maintaining a warm, nurturing, and respectful relationship.

Only someone hypnotized by the current medical and psychological dogma – hence blind to their effects – could not see the isolating and otherwise debilitating consequences of being inauthentic in a helping relationship (assuming they can recognize their own inauthenticity) and of designating someone as having a “mentally illness.” These relational and definitional acts isolate the person from the rest of society, from the so-called “normal people.” Being contextualized by the medical and psychological vocabularies, it would be a miracle for so-called “community integration” to be truly successful. You’d be better off having a case of amnesia and being kidnapped to a developing country where, by the way, the outcomes are much better (Jablensky & Shapiro, 1977).

Implications for the Recovery Model

The recovery movement reflects a humanitarian impulse prevailing despite the power of medical and psychological dogma; however, most recovery model practitioners still use the vocabulary of the medical and psychological models. I hope that this paper has made clear the double-bind communication with all its consequences. The content says go after what you want in life, find meaningful roles, and integrate with the rest of society. The context says you are different from “normal” people, you are classified as “mentally ill” (with all those connotations), and you have “pathologies” or “symptoms” to overcome; which is why you need mental health professionals who are themselves “normal” to “explain” your “condition” and to provide expert advice (i.e. knowledge and perspective you can never possess) designed to help you reach your goals which are modest compared to “normal” people because you are by nature of your classification “weaker” and more “fragile” than “normal people.” You will have to be on the alert for your “symptoms” as you try to work and maintain relationships – for you must manage your “illness” for the rest of your life. The content says “go” while the context says “no”.

There are many effective tools currently employed by recovery programs, such as wellness centers, peer advocacy, community integration, and employment programs. The culture of recovery programs is undeniably client-centered. Collaborative (and, in many cases, collegial) relationships replace the old paternalism. So why keep the invisible chains of the most powerful factor of all – language?

The belief that the medical and psychological vocabularies represent scientifically "discovered truths" is the biggest obstacle for traditional community mental health programs transitioning to recovery-based services. If "mental illness" and psychiatric diagnoses are seen as being essential "realities" then so are the associated constructs that are part of the same closed-conceptual framework: pathological interpretations, the focus on deficits, the hierarchical-paternalistic role relationship, practitioner-as-expert role, and client-as-fragile role. Recovery leaders are asking their staff to overlook these "realities" and instead focus on things they can hardly "see" or take seriously (i.e. client strengths, client self-determination, client goals, independence, etc.) given the context they're embedded in. The initial weak, vague, and superficial understandings of the recovery process will be layered over the "realities" of medical and psychological dogma. The transition from the medical/psychological paradigm to the linguistic paradigm is essential.

A similar revolution is occurring in the substance abuse field. Like current mental health recovery models emphasize finding meaningful roles outside that of being a mental health client, substance abuse recovery is increasingly emphasizing the importance of a non-addict identity (McIntosh & McKeganey, 2000). The "disease" model of substance abuse is being challenged as well. Arthur Horvath (2001), president of SMART Recovery Inc., illustrates three other important parallels: 1.) the disease model is based on dogma versus fact and does more harm than good; 2.) forcing acceptance of having a disease/illness actually delays or prevents people from dealing with their problem; 3.) the biggest leverage a person has in changing is to focus on what's most important to her or him:

> "The disease model does more harm than good. If someone has a firm belief in it, and finds it helpful, I make no effort to persuade otherwise. However, public policy is better based on facts than dogma. Almost our entire US treatment system is based on treating this 'disease.' Individuals with addictive behavior are led to think that the most important question is, am I an alcoholic/addict? Of course, rather than admit this, many just ignore problems until they get worse. A more rational system would encourage earlier problem identification, and present a range of options for responding to problems. When you have a receptive audience, I suggest you present our message of hope: You don't have a disease, you are not powerless. By staying focused on what is most important to you (which might be a higher power, but could be all sorts of things), you can gain full control of your behavior, and learn to lead a wonderful life!" (p.3)

This paper is calling for nothing less than a total transformation in education in the mental health profession. The labeling has disconnected both professional and client from humanity. The elaborate psychological theories have led to what Bill O'Hanlon calls "analysis paralysis." Emphasis on categorizing and analyzing has severely hampered the development of professionals' empathetic, empowerment, and coaching skills. Paula Caplan (1995), asserts:

> "…Furthermore, much of the time and energy that professionals who use the DSM invest in learning about and trying to apply its contents could be more usefully invested in such endeavors as paying careful, caring attention to what one's patients say and working, free from dogma, to understand and help them." (p. xviii)

Despite the scientization and medicalization of the mental health profession, practitioners have all acquired certain common sense skills that work and that, by themselves, don't have all the disabling "side effects" of the medical and psychological vocabularies. These include skills such as rapport building, empathy, Socratic inquiry, persuasiveness, etc. No longer embedded in their pathologizing context, these skills will serve as our foundation in a post-medical-psychological-model world.

Postmodern (including solution-focused, narrative, and collaborative perspectives) consultation and coaching will build on this foundation and carry us into the 21st Century. Motivational Interviewing, life coaching skills, EMDR, Acceptance and Commitment Therapy, mindfulness-based therapies, and others not mentioned in this paper – and still others not yet invented – will also forward this movement.

Many dialogic skills are necessary for an authentic and collaborative relationship. The medical and psychological ways of relating have left most mental health professionals in the habit of somewhat mechanically reflecting back, nodding their heads, or saying "uh ha" while their minds are preoccupied with interpreting the client and his experience through the lenses of all the medical and psychological constructs. Remember: believing is seeing. Authentic and collaborative dialogue is an exhilarating experience and is the means to connect and stay connected with the people we consult with. It is a learned skill and requires a significant amount of training.

We all could use consultation or coaching in order to more efficiently reach our goals. Without all the negative connotations and stigma it is likely that the market for mental health services will expand.

Another common reason for labeling people as "mentally ill" and having such and such "diagnosis" is for insurance reimbursement and disability benefits evaluation. The need for services needs to be established. Currently this is done by some combination of description of "functional impairment" combined with psychiatric diagnoses.

This is where it is necessary to have a true understanding of the postmodern perspective. From a postmodern point of view there are no absolute or essential truths; instead all we have is interpretation. Furthermore, there can exist multiple valid interpretations – multiple descriptions. We can use different interpretations for different purposes. When it comes to third-party reimbursement, we simply have to change our point of view from that of empowerment of the individual to that of the institutions of our society – we take a "normative perspective" (i.e. comparing to that which is considered "normal" from the perspective of society as a whole). Using descriptions of behavior we illustrate what our clients can't do.

If insurance reimbursement requires psychiatric diagnoses we simply remember that we're changing focus (i.e. to that of "symptoms") and using different abstractions (i.e. those of diagnoses) to make summary statements. Insurance companies "believe in" (i.e. see them as essential "truths" or "entities") these reified linguistic constructs only as a result of their having been sanctioned by the medical profession. The profession can certainly establish the need for services or benefits based on behaviors, without resorting to making up "fictive diseases."

Remember from the old scientific-reductionist rigidly held perspective holding two contradictory points of view is impossible – because, as you will recall, the point is to reduce things to some unique essence. From the linguistic paradigm we're looking for words and perspectives that will help us solve a problem. To receive insurance reimbursement and to establish disability benefits simply requires an occasional translation from one language to another. Words are tools, not truths.

The recovery model as it currently exists is an incomplete transformation of the mental health profession. We are finally helping clients get what they want, taking them seriously, having high expectations of them, and eliminating barriers to employment, housing, financial stability, and relationship. The basis of our helping interactions has to be freed from the vocabularies of medicine and psychology.

We human beings are all struggling with our feelings, thoughts, impulses, and habits. The illusory difference between "clinician" and "client" evaporates, like a bad dream – leaving us with one "condition": the human condition. It was Shakespeare that understood how our human roles are mere fabrications, where power and authority are based on image and ceremony.

The cultural pluralism in our country has led to an emphasis on "cultural competency" in the profession. Gays won their freedom from the DSM in the 80's; various non-dominant-culture-specific practices did so in the 90's. There doesn't seem to be any pride in membership in the DSM. I'm advocating freedom for all.

Finally free from the chains of the medical and psychological vocabularies, many people would immediately fit into society with a little extra help. Others would blend in immediately into artist studios, universities, and musician & literary communities. 19th century Paris was the mecca for such creative people. Bohemian was the term for the artists and intellectuals that didn't "fit in." Avant-garde referred to those who didn't "fit in" and led the rest of us. Something to think about.

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Endnotes

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[1] This list doesn't include all the "smaller" accomplishments that are the building blocks of a client's preferred lifestyle such as: reading, dressing tastefully, having various hobbies, raising children, and maintaining various aspects of a household (e.g. being clean and organized).

[2] This conveniently counters Thomas Szasz's (1961) assertion that "mental illness" is only a metaphor for "bad" or "idiosyncratic" behaviors – like societies with bad fiscal policies are only metaphorically

“sick”. The argument is made that if there is a “biological basis” for a dysfunction then it falls under the definition of illness (even as Szasz defines “illness").

[3] According to the Encyclopedia Britannica (1994-2001): “Procrustes had an iron bed (or, according to some accounts, two beds) on which he compelled his victims to lie. Here, if a victim was shorter than the bed, he stretched him by hammering or racking the body to fit. Alternatively, if the victim was longer than the bed, he cut off the legs to make the body fit the bed's length. In either event the victim died… The "bed of Procrustes," or "Procrustean bed," has become proverbial for arbitrarily--and perhaps ruthlessly--forcing someone or something to fit into an unnatural scheme or pattern.”

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Paradox in Practice?
The Rhetoric of Psychiatric Rehabilitation

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Abstract

When psychosocial programs are scrutinized there is a tendency to pay attention to *either* formative intent *or* actual practice. What is lost in such dichotomized analyses is an appreciation of the discursive and theoretical transformations that occur as idealized goals are concretized into systematic practice. Using the rhetoric-of-inquiry framework (Foss, Foss, & Trapp, 1991; Nelson, Megill, & McCloskey, 1987) and the formative and practical texts of the Boston University model of psychiatric rehabilitation (Anthony, Cohen, & Farkas, 1990; Anthony, 2002), I argue that three paradoxical shifts occur as psychiatric rehabilitation's "rhetoric of intent" becomes a "rhetoric of practice." These shifts are identified and discussed, as are the implications for psychiatric rehabilitation participants specifically, and mental health care in general.

Keywords: psychiatric rehabilitation, psychosocial rehabilitation, psychotherapy research, schizophrenia, qualitative research, mental health services.

Introduction

As we anchor ourselves in the 21st century, we are increasingly aware of the social, fiscal, and familial problems that accompany mental illness. At the same time, however, mental health professionals are persistently thwarted in their attempts to develop thoroughly effective remedies. In spite, or perhaps because, of this, several hundred approaches to psychotherapy exist (Corsini & Wedding, 2000), pharmacological and other medical interventions are increasing in number and popularity (Burns, et al., 1999; Keen, 2000), psychiatric hospitalization remains a highly utilized treatment avenue (e.g., Clarke, Herinckx, Kinney, et al., 2000; Conte, Ferrari, Guarneri et al., 1996; Haywood, Kravitz, Grossman, et al., 1995), and community mental health programs continue despite funding challenges and low visibility (Stroul, Pires, Armstrong, & Meyers, 1998).

Interestingly, when any of these approaches are scrutinized (by contemporary observers or historians), there is a tendency to examine *either* formative intent (e.g., the approach's goals, stated and unstated, general and particular), *or* the specifics of actual implementation (e.g., does the program work, is it administered correctly, what external and internal forces affect application and outcome?). An example of the former critique comes from the antipsychiatry movement of the 1960's and '70s. Encompassing a diverse group of scholars including Szasz, Laing, Cooper, and even Foucault, this "group" questioned the intent of all psychiatric intervention, reframing the goals and activities of its practitioners as various forms of state (e.g., Szasz, 1961), social (e.g., Foucault, 1965), and familial control (e.g., Cooper, 1972; Laing, 1972).

Since the late 1970's, and characteristic of the latter style, evaluations of present and past psychiatric practices have generally become more limited in scope (Brown, 1994). Accepting benevolent intent and eschewing issues of power and control, scholars identified as "process," "outcome," "fidelity," and/or "evidence-based" researchers focus on the actual implementation of interventions in an attempt to answer questions including, "does psychotherapy work as well or better than medication?" (e.g., Seligman, 1995), "which type of intervention is best for which disorder?" (e.g., Nathan & Gorman, 2002), and "are clinicians applying interventions correctly, and if not, why not?" (e.g., Abrahamson, 1999; Crits-Christoph, Baranackie, Kurcias, & Beck, 1991; Luborsky, et al., 1999; Miller, Luborsky, Barber, & Docherty, 1993). This last question, accompanied by the pressures of managed care, has led to an interest in standardizing the activities of practitioners, culminating in an increasing number of manualized approaches (Scaturo, 2001; Beutler, 2000; Bond, Evans, Salyers, Williams, & Kim, 2000; Chambless & Ollendick, 2000; Sperry, Brill, Howard, & Grissom, 1996).

What gets lost in these dichotomized analyses is an appreciation of the theoretical and discursive transformations that occur as an approach's formative intent is translated into systematic practice. Specifically, one has a difficult time determining whether the assumptions that structure a psychiatric approach's goals are consistent with those structuring its interventions. We tend to assume such consistency exists, but are we justified in this? After all, psychology and psychiatry's general unwillingness to examine their underlying assumptions, not to mention the logical consistency of their theories and interventions, is well noted by the more philosophically inclined (e.g., Miller, 1992; Wallace, Radden, & Sadler, 1997). Still, resistance aside, such examination seems warranted from a scholarly perspective. Further, it may have particular import for clients and practitioners who are brought into programs of care based upon the strengths of formative intent (e.g., articles and chapters outlining the programs goals and points of emphasis), but whose experiences run counter to their expectations (e.g., Strawbridge, 2002; Beutler, 1997).

Exploring the possibility that assumptions can shift, what follows is a textual analysis of a popular and well-documented program, the Boston University approach to psychiatric rehabilitation.[1] Developed by William Anthony (e.g., 1980, 2002) and colleagues (e.g., Anthony, Cohen, & Farkas, 1982, 1990), it is an apt and potentially illuminating choice for the following reasons.

First, the BU approach is impressive for its breadth of focus. Designed for persons with severe psychiatric disability [who] have diagnosed mental illnesses that limit their capacity to perform certain functions … and …certain roles" (Anthony et al., 1990, p. 4), this form of psychiatric rehabilitation attempts to provide these individual with "those physical, emotional, and intellectual skills needed to live, learn, and work in his or her particular environment" (Anthony, Cohen, & Cohen, 1983, p. 69). Such a broad focus means that many aspects of life and living are addressed – a valuable asset when assessing whether and how assumptions change as a program moves from intent to practice.

Secondly, the BU approach is well established in both the literature and the field. In the literature, we see Anthony develop this approach in the late 1970's and early 1980's, comprehensively articulating it in his text, *The Principles of Psychiatric Rehabilitation* (1980), updating it in *Psychiatric Rehabilitation* (Anthony, Cohen, & Farkas, 1990; Anthony, 2002), and elaborating upon it in a variety of articles and chapters (for a listing of articles published by Anthony and colleagues since 1990, see Center for Psychiatric Rehabilitation, n.d.). Its tangible presence in the field is also noteworthy. Indeed, over the past three decades it has become increasingly popular in publicly funded mental health facilities and beyond, frequently emerging as the dominant form of non-medical treatment (Anthony, 2002; Anthony, Cohen, & Kennard, 1990; Cook & Jonikas, 1996; Lamb, 1994; Lavender, 1995; Prendergast, 1995; Hughes, Lehman, & Arthur, 1996).

Finally, it is an approach connected to practices intended to be highly explicit, even transparent. From its early beginnings (Anthony, 1980) to its latest update (Anthony, 2002), its founders and practitioners have gone to great efforts to operationalized how its philosophy is to be enacted in practice. For example, in Anthony's (1980) first full-length text, discussions of the approach are often accompanied by case examples intended to illustrate and instruct the reader in how to recognize and enact the particulars of the rehabilitation process (e.g., pp. 33-34, 51-53, 62-63). These efforts culminated in the creation and dissemination of three multimedia training packages, each corresponding to a specific phase in the rehabilitation process:

1) Setting an overall rehabilitation goal training technology (Cohen, Farkas, Cohen, & Unger, 1992)
2) Functional assessment training technology (Cohen, Farkas, & Cohen, 1992); and

3) Direct skills teaching training technology (Cohen, Danley, & Nemec, 1992).

In the following analysis I examine the consistency of the assumptions that structure the participants and processes of psychiatric rehabilitation. Through examining the language of psychiatric rehabilitation, I argue that three paradox-producing shifts emerge as its formative intentions are translated into practice. Finally, I put forth some tentative thoughts on the implications of these shifts, for both the participants of psychiatric rehabilitation specifically, and mental health care in general.

Perspective, Materials, and Method

The Perspective: Rhetoric-of-Inquiry

The conceptual perspective for this analysis comes from a type of scholarship known as "rhetoric of inquiry" (Foss, Foss, & Trapp, 1991; Nelson, Megill, & McCloskey, 1987). This multidisciplinary approach has been used to examine the scholarly and applied practices of disciplines including mathematics (Davis & Hersh, 1987), anthropology (Rosaldo, 1987), and psychology (e.g., Eaton, 1999; Madigan, Johnson, & Linton, 1995; Sarbin, 1998; Shotter, 1991). Defined more by a particular attitude towards language than a specific methodology, the rhetoric of inquiry approach rests on the assumption that how language is used reveals a great deal about what that scholar or perspective values and/or assumes, even when there is the claim of being value-free or value-neutral. Furthermore, understanding how these values are put into action can provide clues as to how inquiry (scholarship) or application (technology) actually proceeds, including where problems lie and how they might be corrected. In the words of John Nelson, Allan Megill, and Donald McCloskey

(1987), "within particular fields, rhetoric of inquiry shows what we are really doing and how to criticize it ... Across different fields, rhetoric of inquiry shows what others are doing and how to learn from it" (p. 17).

Because there has been little critical, theoretical analysis of the BU approach's structure or process, analyzing its rhetorical practices presents itself as a logical starting point (Lilleleht, 2002; for a conceptual analysis for psychosocial rehabilitation as a whole, see Estroff, 1995). Indeed, identifying and understanding the consistent or changing nature of psychiatric rehabilitation language may be an important precursor to analyzing the specifics of lived rehabilitation experience (e.g., through ethnographic or phenomenological research). It may also be a useful aid in interpreting studies that focus on the efficacy of rehabilitation training and practice in general (e.g., quantitative and qualitative outcome, process, and/or fidelity research; e.g., Bond et al., 2000).

Materials

Psychiatric rehabilitation produces two types of texts: formative and practical. Formative texts include full-length books, chapters, and/or articles explicitly concerned with the description, philosophy, and intentions of psychiatric rehabilitation. Although these texts can describe specific practices (e.g., Anthony, 1980), their primary purpose is to present comprehensive and/or specific descriptions of what psychiatric rehabilitation is and seeks to do, as opposed to training readers in the specifics of its "technologies" (see Anthony et al., 1990, pp. 88-91, for a discussion of psychiatric rehabilitation as a human technology). Similarly, while psychiatric rehabilitation's practical texts may briefly describe intent and/or philosophy, this second set of texts is primarily focused on training mental health professionals and paraprofessionals to engage in its many technologies (Rogers, Cohen, Danley, Hutchinson, & Anthony, 1986).

Given the textual nature of this analysis, it is important that both formative and practical materials represent the psychiatric rehabilitation oeuvre. To that end, formative books and chapters are chosen for analysis when they: a) include Anthony as an author; and, b) represent current writings in the area of psychiatric rehabilitation; or c) possess archival importance, as indicated by their being repeatedly cited in more current materials (e.g., Anthony, 1980). Formative articles published in professional journals are selected if Anthony has authorship status, and the journal is recognized within its field as being scholarly and rigorous (e.g., *Schizophrenia Bulletin* for psychology and psychiatry; *Psychological Bulletin* and *American Psychologist* for psychology; *Rehabilitation Psychology* and *Psychiatric Rehabilitation Journal* for rehabilitation).

Practical texts come from the Center for Psychiatric Rehabilitation's multimedia training packages (Cohen, Farkas, Cohen, & Unger, 1992; Cohen, Farkas, & Cohen, 1992; and Cohen, Danley, & Nemec, 1992). Available to any interested professional or institution, these packages represent one major way psychiatric rehabilitation technology is disseminated. Trainers use these packages to structure training sessions with practitioner trainees, while trainees and practitioners use them to structure the rehabilitation process with clients.

Method

Using the perspective provided by rhetoric-of-inquiry scholarship, I examine the language of psychiatric rehabilitation's formative and training texts. In doing so, I attend to both what is written and assumed about rehabilitation participants, and how the rehabilitation process is described and reproduced. For example, within and across texts, what emerges as psychiatric rehabilitation's legitimate foci? That is, *which* aspects of human experience (usual and unusual) receive attention, which are ignored, and does this remain consistent? Regarding the rehabilitation process, *how* is this described and ultimately recreated? For example, given that trainees and clients alike are taught to develop their skills through verbally mediated exercises, to what extent and in what way are these verbal interactions structured? Is the level of instruction great or small (are there many rules guiding participants' speech/writing, or just a few)? Is there an emphasis on specialized terminology or ordinary language? Are discussions to follow any particular rhetorical style (e.g., denotative or connotative, metaphoric or operational, dialectical or propositional)?

All texts are analyzed for the presence and absence of statements and styles that shed light on these questions. Attention is paid to key phrases, repetition, and consistency (or lack thereof), as well as to the use of instruction, specialized language, and rhetorical style. Repetition (verbatim or in terms of essential content and/or style) across texts is taken as an indication of importance, and is noted in the analysis. In many respects the method used is similar to grounded theory (Strauss & Corbin, 1994). For example, the interpretive approach is flexible, and there is a reliance on "inductive strategies for collecting and analyzing qualitative data" with an emphasis on developing inductive theories as a result of the analysis (Charmaz, 2003, p. 82). There are, however, significant differences. For example, texts instead of interviews provide the qualitative data, and there is no formal coding strategy. Similarly, although the emphasis is always on language, this analysis is not a form of semiotics, as it does not utilize any formal word/phrase counting methodology. As such, it cannot make any definitive statements about importance or centrality from a quantitative perspective. Instead, my approach is much more interpretive, and therefore tentative. I am most interested in examining whether and how rehabilitation language (and the basic assumptions embedded within) changes or remains the same as intention takes action.

Results: Paradox

Comparing psychiatric rehabilitation's formative and practical texts reveal three paradoxical shifts. Regarding psychiatric rehabilitation participants, a paradox emerges which, for the sake of discussion, I term "divided integration." Regarding the rehabilitation process, two more paradoxes are identified: "dependent independence" and "unfamiliar familiar language."

A Participant Paradox: Divided Integration

Throughout psychiatric rehabilitation's formative texts, there is an intertwined emphasis on integration and skill development. Integration is one of the overarching goals of the psychiatric rehabilitation process; skill development is one way of achieving this goal (resource development is another; Anthony, 2002; Anthony et al., 1990). Together, these represent psychiatric rehabilitation's holistic and pragmatic image of itself and its participants. It is an approach that seeks to develop skills in un- or underskilled persons with mental illness, as well as their caretakers (professional or otherwise; Anthony et al., 1990). Further, these skills are not developed for their own sake, but for the purpose of integrating the individual into her or his community of choice. Paradoxically enough, however, the training manuals employ a rhetorical style and set of teaching practices that emphasize division and reduction. This emphasis is so strong that it becomes difficult to appreciate how any form of integration, be it of a set of skills or of an individual and community, might be achieved. What follows is a tracing of this paradoxical situation.

As one learns from its formative texts, the presence or absence of skill is a defining feature of those who participate in psychiatric rehabilitation. For example, in his first comprehensive text on psychiatric rehabilitation, Anthony (1980) instructs readers that "the main activity for practitioners is to systematically diagnose and teach the disabled helpee the skills necessary to live, learn, and work, while the main activity for the helpee is to perform the skills necessary to live, learn, and work" (p. 30). This can only be achieved through a skills-training approach in which "the rehabilitation diagnosis, as opposed to the traditional psychiatric diagnosis, attempts to identify those specific patient skill deficits that are preventing the patient from functioning more effectively in her or his living, learning, and/or working community" (Anthony, 1977, p. 661).

Thus, in psychiatric rehabilitation, clients are not to be understood in terms of symptoms, internal conflicts, or even crisis behaviors, since "psychiatric diagnosis does not predict rehabilitation outcome … diagnostic labeling of psychiatric patients does not provide relevant information about their rehabilitation potential, … [and] inpatient and outpatient interventions that follow psychiatric diagnosis have little impact on rehabilitation outcome" (Anthony, Cohen, & Cohen, 1983, p. 68; see Anthony et al., 1990, pp. 93-99; Anthony, Rogers, Cohen, & Davies, 1995, p. 353). Instead, the individual is conceptualized according to personal abilities and environmental needs (Anthony, 1977; Anthony, 1980; Anthony & Farkas, 1982; Anthony, Cohen, & Cohen, 1983; Anthony, Cohen, & Farkas, 1982, Anthony et al., 1990).

In order to be included in the psychiatric rehabilitation process, these abilities and needs must facilitate the person's integration back into the living, working, and learning communities of choice. Statements supporting the goal of integration are many, and include the following: "the goal of a rehabilitation approach should be to provide the disabled person with the … skills needed to live learn, and work in the community" (Anthony, 1977, p. 660); "practitioners of rehabilitation conceive of their goal as restoring the helpee's former capacity to function in the community, or, as reintegrating the helpee back into the community" (Anthony, 1980, p. 25); " the goal of psychiatric rehabilitation is to assure that the person with a psychiatric disability possess those physical, emotional, and intellectual skills needed to live, learn, and work in his or her own particular environment" (Anthony, et al., 1983, p. 70); "rehabilitation tries to open the doors of the community and help people develop a prescription for their lives" (Anthony et al., 1990, p. 2; see also: Anthony, 1982, p. 62; Anthony, 1992, p. 165; Anthony & Liberman, 1986, p. 542; Anthony, Cohen, & Farkas, 1982, p. 85; Anthony, Cohen, & Vitalo, 1978, p. 365; Anthony, Kennard, O'Brien, & Forbess, 1986, p. 249; Cohen, Anthony, & Farkas, 1991, p. 184; Rogers, Anthony, & Jansen, 1988, p. 11).

Identifying, developing, and assessing needed skills becomes the means by which participants come to live more integrated, fulfilling lives. Indeed, in the concluding chapter of their 1990 text, Anthony and his colleagues give voice to the holistic and admirable need to "envision a mental health system that does not define people who use the service by labels, but sees them first and foremost as people" (Anthony et al., 1990, p. 221).

As client and practitioner move to psychiatric rehabilitation's manuals of practice, this emphasis on integrative skill development continues. Interestingly, however, these manuals pursue skill development using a rhetorical style and set of teaching practices that are highly *reductive,* with a strong emphasis on *division* for the sake of observation and measurement. Thus, while the formative texts repeatedly speak of "the skills needed to live, learn, and work in one's environment of choice" (a relatively holistic goal that emphasizes integration of person and place), the training manuals teach participants to identify, divide, subdivide, and evaluate every component of any relevant skill.

For example, wanting to live at home might be divided into the "critical skills" of "disagreeing with sister", "spot-shopping", "choosing friends," "conversing with Dad about topics that interest him," and "budgeting paycheck" (Cohen, Farkas, & Cohen, 1992, "Reference Handbook – Listing Critical Skills," p. 8). These critical skills are identified and assessed through a series of language-based exercises in which client and practitioner do three things: a) "infer behavioral requirements" (that is, what skills does the client need to live at home, from the perspective of the people at home); b) "specify personally important behaviors" (that is, what skills does the client think she should have to live at home); and c) "analyze critical skill strengths and deficits" (which of these skills does the client have or need) (Cohen, Farkas, & Cohen, 1992, "Training Module – Listing Critical Skills," p. 8).

While these three steps help one identify relevant skills, a skill can only be considered critical after client and practitioner determine that it satisfies six criteria. Specifically, the skill must be *behavioral* ("they appear in the form of actions capable of being seen or heard by others," Cohen et al., 1992, "Training Module – Introduction," p. 11), *purposeful* ("require an understanding of the relationship between the performance of behaviors and the benefits obtained," p. 15), *generalizable* ("can be used with different people, in different places, and usually in different situations. There may be specific circumstances in which a person needs to use a particular skill, but the skill can always be used in other circumstances," p. 15), *compound* ("composed of both knowledge and behavior…the ability to do a set of actions - i.e., perform an operation - according to both a body of knowledge about what actions to do, why to do the actions, and when to do them," p. 15), *standardized* ("mastery can be determined on the basis of comparison of actual behavior with ideal behavior," p. 15) and *stable* ("only evidenced in multiple observations of behavior," p. 16).

In and of itself this level of specificity might serve a useful purpose. It certainly encourages both client and practitioner to focus on readily observable and seemingly pragmatic aspects of human existence (individual and environmental), and to do so in a systematic way. The problem, however, comes with the next level of division. Each of the three steps necessary to identifying critical skills (i.e., inferring behavioral requirements, specifying personally important behaviors, and analyzing critical skill strengths and deficits) requires successfully completing another set of substeps.

For example, in order to adequately "analyze critical skill strengths and deficits," the third step in developing the list of skills that are to be the focus of the rehabilitation process, client and practitioner move through three specific substeps: 1) "brainstorm the skills needed to produce essential behaviors;" 2) "choose the critical skills;" and 3) "estimate the client's functioning" (Cohen et al., 1992, "Reference Handbook – Listing Critical Skills," p. 42).

Furthermore, one accomplishes each of *these* substeps by completing an even smaller set of activities (sub-sub-steps). For example, in order to engage in "brainstorming," practitioner and client are instructed to "ask the question 'what are the skills the client needs in order to perform the listed behaviors?'" (Cohen et al., 1992, "Training Module – Listing Critical Skills," p. 32). Although reasonable in and of itself, even this does not remain an undivided question. Indeed, asking the question properly involves four things (Cohen et al., 1992, "Training Module – Listing Critical Skills"):

> 1) "trying to list all the possible skills needed for the particular client to produce the behavior…"
> 2) "further exploration of [the behavior] to discover underlying skills …"
> 3) "thinking about the 3 types of skills – physical, emotional, intellectual – in order to generate skills…"
> 4) "thinking about the preparatory skills needed 'Before' performing the behavior, the execution skills needed 'During' the behavior, and the monitoring skills needed 'After' the completion of the behavior" (pp. 32-33).

Through utilizing language and constructing experiences that emphasize multiple levels of division, psychiatric rehabilitation's training manuals seem to reflect the assumption that, when it comes to its participants, what counts are those aspects of experience that can be reduced to their most basic, rehabilitation-specific level. This stands in direct contrast to its rhetoric of intent, which focuses on integration (of skills into the rehabilitation goal, of person into her environment of choice). And the possible results of this divisive discourse? The person's original intent, goal, desire (be it the practitioner's desire to teach her client a productive set of skills, or the client's desire to live independently) is in danger of becoming lost in a plethora of steps, substeps, and sub-sub-steps.

A Process Paradox: The Dependency of Independence

The second set of paradoxical shifts emerges when one examines how the psychiatric rehabilitation texts structure the interactions that make up the rehabilitation process. On the one hand, psychiatric rehabilitation's formative texts speak of a process that emphasizes independence and autonomy. For example, there is repeated emphasis on integration into the community "given the least amount of support necessary from agents of the helping professions" (Anthony, 1977, p. 660; Anthony, 1980, p. 30; Anthony & Liberman, 1986, p. 542; Anthony, Kennard, O'Brien, & Forbess, 1986, p. 250), "with the least amount of ongoing professional intervention" (Anthony, 1992, p. 165). Although Anthony and his colleagues do stress that "dependence is not a dirty word" (Anthony, 1982, p. 64; Anthony et al., 1983, p. 75; Cohen et al., 1991, p. 189; see also Anthony et al., 1990, p. 68; Farkas, Anthony, & Cohen, 1989, p. 10), their formative texts consistently present psychiatric rehabilitation as a program through which some degree of personal independence can be achieved.

The training manuals, however, utilize discursive style that encourages, indeed insists on, a very high level of dependency. Indeed, as the examples in the previous section suggest, given the level of division and detail involved in the rehabilitation process, it is hard to imagine how this could not be the case. One need only peruse the manuals (remembering that they are intended to parallel the process that occurs between client and practitioner), to realize how minutely the language and actions of all participants are structured. Across all phases of the rehabilitation process, the training manuals instruct trainer, practitioner, and client in precisely what, when, why, and how to speak and behave within the rehabilitation context. These instructions, presented as scripted dialogue, direct both the types of activities one engages in, and the content of these activities (e.g., Cohen, Farkas, & Cohen, 1992, "Training module – Coaching the client," p. 16). Indeed, across all training manuals, participants are told when to ask questions, make specific points, explain an issue, discuss, and tell what will happen next.

One is left wondering whether, given the scripted presentation of these instructions, participants might feel the need to follow and repeat them in a verbatim manner. At the very least, this degree of structure leaves little room for independent, spontaneous, creative thought or behavior. And the question arises as to whether such thought or action, being unregulated and unsystematic, might be considered or source of error or difficulty.

From a textual perspective, then, personal independence appears to be the promised result of a process that is so structured and systematically detailed that it encourages significant dependency. Up to a point, this does not necessarily pose a problem. After all, human beings are social, dependent creatures. We do tend to need each other, particularly when we are in any type of distress. The difficulty, or paradox, of psychiatric rehabilitation is that its formative texts promise reasonable independence as the end result of processes that are not only dependency inducing, but also provide no way of diminishing this intense reliance (on the trainer, the manuals, or the practitioners). Thus, independence runs the risk of existing more as a promise than a lived-reality. How could it be otherwise when there is no transition, no guide for moving out of the intense dependency of the rehabilitation process, and into the relative autonomy of the non-rehabilitation world?

Another Process Paradox: Unfamiliar Familiar Language

A final paradox emerges when one examines how language changes as psychiatric rehabilitation's rhetoric shifts from formative to practical. Interestingly and consistently, both sets of text avoid using technical terminology in favor of non-specialized every-day language. This choice seems intentional, and may reflect psychiatric rehabilitation's desire to be accessible to a wide-ranging audience (e.g., Anthony, 1992, p. 166; Anthony, Cohen, & Cohen, 1983, p. 77; Anthony, Cohen, & Farkas, 1988; Anthony et al., 1990, p. 129-147; Anthony, Cohen, & Kennard, 1990; Cohen, Anthony, & Farkas, 1991, pp. 199-200; Farkas & Anthony, 1989; Rogers, Cohen, Danley, Hutchinson, & Anthony, 1986).

This avoidance of technological language may also reflect psychiatric rehabilitation's oft-cited preference for practice over theory. We see this preference in the directive that "the rehabilitation practitioner's interest in the issue of causation [regarding skill deficit] is at this time more a theoretical than practical concern" (Anthony, 1980, p. 30). We also see it in the explanation that "psychiatric rehabilitation practice uses a variety of techniques based on functional effectiveness rather than theoretical allegiance" (Cohen, Anthony, & Farkas, 1991, p. 188). Indeed, the deliberate use of familiar language, especially in the formative texts, seems to be a reminder that psychiatric rehabilitation is tied to no underlying theory of mental illness, and therefore has no need for specialized terminology (Anthony et al., 1990, p.66).

Once again, however, as formative intent moves to practice an interesting shift occurs in the program's rhetoric. Although its training manuals never rely on specialized language, they are written in a highly positivistic manner (indeed, the above examples serve as excellent illustrations). That is, the language of these manuals embeds participants in way of thinking, writing, and speaking that attempts to be completely visible, totally operational, stripped of all inference and metaphor. In doing so, the training manuals essentially create a discipline-specific language by imbuing the most general, commonly used words with rehab-specific meanings.

For example, the word "skill" becomes "Skill", a term requiring twelve pages of text to define it, and numerous exercises aimed at assessing the degree to which its user has internalized its "proper/official meaning" (Cohen et al., 1992, "Training Module – Introduction," pp. 10-21). Furthermore, whenever you are discussing behaviors in relation to a particular skill, you must define them according to a very clear set of rules. Specifically, these discussions must utilize words that are *integrated* ("describe the unified performance of the individual actions that make up a skill"), *interchangeable* ("are consistent with the skill name"), *fresh* (so that you "use words other than the skill name"), *brief* ("use as few words as possible"), and *clear* (so that you "can be easily understood by the client") (Cohen et al., 1992, "Reference Handbook – Describing Skill Use," p. 13).

Other language rules presented in the training manuals address the structure of discourse. For example, in discussing when to use particular skills with your client (referred to as "describing circumstances"), you are instructed to use the "when (situation), with (people), at (place)" format. Additionally, you must make sure that "circumstances are stated beginning with the word 'Before,' 'During,' or 'After'"(p. 17).

Thus, although the words themselves retain their superficial simplicity, the familiar becomes unfamiliar as implicit, connotative meanings are replaced by highly operationalized, rehabilitation-specific meanings. This transformation seems to rest on the assumption that there is more to the rehabilitation process that meets the eye. Indeed, it implies that there is a level of complexity for which one must be trained, a degree of instruction one must receive in its entirety, and an amount of rehab-specific exercise to experience in order to become an effective rehabilitation participant.

Discussion: The Paradox of Practice

A paradoxical communication is one that contains two messages which, taken separately, are logically consistent and meaningful. When taken together, however, they stand in opposition to one another, creating an impossible, if not absurd situation. Respond to the first message and you negate the second; respond to the second and you negate the first. Joseph Heller's *Catch 22* (1955/1996) is perhaps the most widely recognized literary tribute to the paradox. Within psychology, researchers including Watzlawick (1976; with Beavin and Jackson, 1969) and Bateson (with Jackson, Haley, and Weakland, 1956), have studied this form of communication in relation to schizophrenia, depression, and other forms of emotional and behavioral "maladjustment." And George Kunz (1998), using the work of Levinas, has examined some of the existential paradoxes embedded in contemporary psychology as a whole.

The problem with paradox is that it renders straightforward action and reaction, thought and emotion, quite difficult for the person to whom the communication is directed. To be on the receiving end of a paradoxical communication is to find oneself at best confused, and at worst, in a state of intellectual, emotional, and/or behavioral paralysis. It is my hypothesis that both possibilities must be considered when psychiatric rehabilitation intent stands alongside its manualized form of practice. In other words, the paradoxes of divided integration, dependent independence, and unfamiliar familiar language all have the potential to affect the lived experiences of psychiatric rehabilitation's participants (be they trainers or trainees, practitioners or clients). Furthermore, while this structuring may ultimately enhance the development of the approach (e.g., resulting in a highly systematic, operationalized set of practices), it may be less than beneficial for its designated participants. If this proves to be the case, it would not be novel. Rather, psychiatric rehabilitation would join ranks with other social practices where benevolent intent falls victim to the demands necessitated by program survival and success (e.g., Leyerle, 1994; Spitzack, 1990; Parker, Georgaca, Harper et al., 1995; Caputo & Yount, 1993; Scull, 1989).

Consider, for example, the paradox of divided integration. Although clients and practitioners enter the rehabilitation process intending to learn skills that will allow them to successfully integrate into environments of their choosing (and, by extension, allow practitioners back into professional positions of efficacy and respect), this very process risks reducing and dividing lived experience to a potentially irreparable degree. How might this be experienced by someone like the anonymous author BGW (2002), who feels that his "delusions arise from … overanalyzing and articulating ideas" (p. 748); who, in the process of fixing something to eat "would get so tangled up in so many obsessions and compulsions that I could never finish making a meal, usually barely even started it" (p. 750)? Or by someone like Anne (Blankenburg as cited in Sass, 2004) for whom "everything is an object of thought" (p. 307), who speaks of experiencing the world "from somewhere outside the whole movement of the world" (p. 306); who, in the words of Sass, is "unable to stop thinking and questioning the most commonplace facts or axioms of daily life" (p. 307)? Or by Renee (Sechehaye, 1979), who experiences the faces of others (in this case, her analyst) as an amalgam of disconnected, objectified features, "separated from each other: the teeth, then the nose, then the cheeks, then one eye and the other," with this disconnected "independence inspire[ing] such fear [that it] prevented my recognizing her even though I knew who she was" (p. 51)? As evidenced by the rhetorical practices of its training manuals, psychiatric rehabilitation's penchant for reduction and division takes whole behaviors out of their lived and largely prereflective contexts and places them under the specialized rehabilitation gaze. All participants and their actions are divided and subdivided, transformed into thoroughly visible part-entities, and given rehabilitation-specific values and expectations. Ironically, in doing so psychiatric rehabilitation may inadvertently and eerily echo some of the pathological experiences it makes such efforts to ignore. This raises several questions. Should psychiatric rehabilitation pay more attention to the phenomenological experiences of its participants (abnormal and otherwise)? Does the approach share anything more in common with the schizophrenic lived-world (in terms of historical and/or cultural factors that might underpin both; e.g., Sass, 1992; Lilleleht, 2002)? And, regardless, is it possible that rehabilitation practice (in contrast to its overt intent) is more focused on teaching participants the skills necessary to continue the rehabilitation process, than on helping participants acquire skills necessary for personal and community integration?

Similarly, the paradox of dependent independence raises the question of whether autonomy (in clients and practitioners) is really desirable after all. Such ambivalence is nothing new, as North Americans (sharing, to some extent, a cultural identity built around an odd mix of rugged individualism and rigid conformity; Bellah, Madsen, Sullivan, et al., 1996) have long struggled with how to control the "deviants" among them, and when, if ever, to set them free or render them responsible (Grob, 1994; Rothman, 1990). In their formative texts, psychiatric rehabilitation authors acknowledge some of this ambivalence, taking the common-sense position that some dependence is necessary if skills are to be taught, and personal choices about living, learning, and working, are to be achieved. However, in creating training manuals that utilize a rhetorical style almost obsessive in detail and lockstep in structure, might it not become difficult for participants to actually achieve independence from the rehabilitation process? If so, how might this be negotiated by someone like Jordon (1995), haunted by "one particular friend, the Controller" who demands more and more of her time listening to his demands such that her own "thinking become more and more fragmented" (p. 502). Or by the person who finds "emotions tremendously complex, and [is] quite acutely aware of the many over- and undertones of things people say and the way they say them … [such that] I have difficulty handling situations that require me to be too artificial or too careful" (Hatfield & Lefley, 1993)? Is it possible to successfully negotiate such structured relationships if yours is a lived-experience acutely sensitive to and disabled by such structures? And for those of us less affected by such structured and structuring relationships, might this lead us to wonder whether independence exists more as an illusion, a technique to keep the participants engaged, motivated, and productive *within* the rehabilitation process? At the very least, one is left feeling that the manual-based practice is running counter to its formative intentions.

This brings us to the paradox of unfamiliar familiar language. Although participants will not find themselves confused by unfamiliar terminology, as they enter the training and practice of rehabilitation, familiar words do start seeming strange. Again, this bears an eerie similarity to how some people with schizophrenia describe their own relationship with language. Consider Artaud (as cited in Sass, 2004) for whom "all languages go dry, all minds parched, all tongues shrivel up" (p. 312). Or Renee (Sechehaye, 1979), who describes her experiences of everyday objects as follows: "I said 'chair, jug, table, it's a chair.' But the words echoed hollowly, deprived of all meaning; it had left the object, was divorced from it, so much so that on one hand it was a living mocking thing, on the other, a name, robbed of sense, the envelop robbed of content" (p. 56). Just as Renee's focus on the words themselves render their lived meanings elusive and even mocking, the rehabilitation manuals' numerous language exercises render implicit meaning excruciatingly visible. And as each word is given its own rehabilitation-specific meaning, it loses its connection to the larger, non-rehabilitation world. Might this distance/disconnection inhibit the ability to communicate, to talk, with any ease? Even worse, to what degree might it render participation excruciatingly difficult for someone whose "own inadequacy to use language to express what lies buried so deeply inside me, even when I am lucid, makes words a curse that blocks the proverbial light within the tunnel, and I am alone with my darkness" (Ruocchio, 1991, p. 358); and for whom "with each uncommunicated experience, the darkness grows" (p. 358)? If one takes these language exercises seriously, rehabilitation participants may no longer be able to talk with one another without a great deal of pre- and post-reflection, observation, and practice. In this way, speaking, reading, and writing may become more exercises in rehabilitation membership than acts of interpersonal, integrative communication.

Conclusion

But what, one might ask, are we to do with these paradoxical shifts? And what are the implications for mental health care in general? Regarding the first question, one possible solution would be to give preference to one set of assumptions over the other. Thus, we could choose to take either psychiatric rehabilitation's formative texts *or* its manuals of practice as being truly representative of its developers' beliefs about mental illness, and their goals regarding their participants. This, however, would be fairly problematic. After all, psychiatric rehabilitation is bound by both sets of texts (some of which are authored by the same people; e.g., Cohen and Farkas), just as Heller's Yossarian is bound by two sets of consequences (told that he can get out of combat if he asks to be grounded for psychiatric reasons, but that making this request is itself proof of his sanity; 1955/96).

Perhaps, then, we must accept the meaningfulness of both sets of assumptions, and test out the degree to which the expected outcomes occur in actual rehabilitation practice, and how rehabilitation participants (client and practitioner, trainee and trainer) deal with them. Indeed, the capacity to identify such situations and their consequences may be particularly important in psychiatric rehabilitation because – to the extent that paradox does produce paralysis – there is the possibility that those closest to the paradoxes may be the least able to articulate them (even when reacting to them). If this is the case, perhaps this analysis can assist in creating a roadmap for more experience-near research. In short, this analysis should be considered a beginning and not an end. Indeed, it would be more than a little ironic if this text-based, somewhat disembodied method were to produce the final word on what appears to be a potentially fragmenting and disembodied experience.

Regarding the more general question of relevance, although this analysis concentrates on one specific approach to psychiatric rehabilitation, its results raise questions about manualized treatment in general. At the very least, this analysis suggests that certain important transformations can occur as formative intentions are translated into behavioral practice. There are, after all, different pressures and constraints affecting both the development of a psychosocial program's philosophy of care and the formalization of its practice. And it is not unreasonable to expect that these pressures might find their way into its formal rhetoric. Nor is it unreasonable to hypothesize that such pressures could potentially produce important, although possibly unrecognized, differences between what clients and practitioners are inspired to do, versus what they are instructed to do. This gulf, or rather this strange confluence of diametrically opposed influences, has one set of implications for the participant (e.g., confusion, paralysis, anger) and another for the historically minded observer (e.g., confirmation regarding the self-perpetuating nature of disciplinary power, and the contradictory goals of psychiatric practice). Both implications are potentially significant, and both might be better understood when taking seriously what some consider "just rhetoric."

Notes

In choosing to examine the Boston University approach, I am aware of Anthony's (1994) statement that there never was a "B.U. model" (p. 169). Although Anthony prefers to define the Center's work as an "attempt to develop various components of the philosophical, empirical, and technological foundations of the field of psychiatric rehabilitation," (italics mine, p. 169), his refutation is not consistent with the fact that this approach does maintain a specific philosophy (e.g., Anthony, Cohen, & Farkas, 1982) connected to specific sets of practice (e.g., Cohen, Farkas, Cohen, & Unger, 1992; Cohen, Farkas, & Cohen, 1992; Cohen, Danley, & Nemec, 1992), which can be differentiated from other forms of psychiatric rehabilitation (e.g., Corrigan, 2001; Stein & Test, 1980; Liberman & Foy, 1983).

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Love among Couples Diagnosed with Schizophrenia

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Abstract

This qualitative study aimed at finding out what the experience of love and being loved meant to couples both diagnozed with chronic schizophrenia in and out the mental health clinic and the impact of such a relationship in their psychosocial functioning. The sample included ten heterosexual couples treated with second generation“atypical” antipsychotic drugs. Our primary research tool the in-depth semi-structured focused interview usually conducted with each one of the 20 partners separately. Content analysis of the interviews indicated that the actions partners engaged in to express their love were circumscribed by the rules of the institution, the partners’ ethnicity and religion, and their level of sexual freedom.

Yet, despite those constraints, the experience of love enhanced motivation and the desire to come out of social and emotional isolation and become aware of the loved partners needs and emotions. Love gave research participants the strength to escape despair, to take care of themselves, to hope and plan for their future. No longer in a world of their own, couples requested some privacy and physical space in which they could be intimate in the institution or half-way house. Other ethical issues addressed in this article are (1) the right to privacy and intimacy and (2) mixed couples, Jewish and Arab, transgressing the normative constraints imposed by tradition and religion, (3) separation, and (4) being financially taken advantaged of. Guidelines are proposed to accommodate the emerging needs of heterosexual couples diagnozed with schizophrenia in love within an institutional framework.

Background

Bertrand Russell (1929), and later Eric Fromm (1957), and Buber (1958), saw in love much more than lust and the desire for sexual intercourse. Love was the principal means to transcend loneliness in existence through the union with, and concern for, the loved person. The current study examines the experience of being in love and being loved meant to heterosexual couples both diagnosed with chronic schizophrenia and the impact of such love on their socioemotional functioning.

Since Plato’s symposium (2001) several taxonomies of love have been formulated with the emphasis on reciprocity and caring and the development empathy (Rubin's, 1973 ; Selman, 1980; Sternberg & Grajek’s. These components enable each one of the partners in a couple to go beyond a self-centered egocentric perspective in order to see things from the perspective of the loved partner (Selman, 1980). Ceasing to focus uniquely on their own self, the partners in love become transformed as they reflect to one another their own needs, feelings, and emotions.

Awareness of self and others’ needs and feelings has historically been considered to be lacking in person diagnozed with schizophrenia. These persons been described as confused about their own identity, losing ego boundaries, and as having difficulty in adopting a third-party perspective (Carini & Nevid, 1992; Harrow & Quilan, 1984). They typically exhibit reduced emotional responsiveness characterized by apathy, anhedonia, and blunted affect (Herbener & Harrow, 2002). Although they have the capacity to feel different emotions, they seem to have difficulty expressing and perceiving those emotions. At times, persons diagnozed with schizophrenia also exhibit inappropriate emotional responses (Penn, D.L. Combs, D.S., Ritchie, M., Francis, J., Cassisi, J., Morris, S. & Townsend, M., 2000). Their cognitive, social, and emotional skills have been described as deficient and characterized by looseness of association, distractibility, and inability to pay attention to and pick up interpersonal cues. Such deficiencies usually impair interpersonal communication, and lead to social withdrawal, lack of social interaction and stigma (Asarnow, Carlso, & Guthrie, 1990; Elkins, 1992; McGlashan, 1986; Grillon, 1990; Penn, Comb & Mohammed, 2001; Penn, Kholmaier & Corrigan, 2000).

While antipsychotic medications have been effective at reducing positive symptoms such as hallucinations and delusions only the advent of atypicial antipsychotic medications was able to alleviate those negative symptom related to cognitive and emotional impairments exhibited in schizophrenia (Bilder, R. M., Goldman, R. S., Volavka, J., Czobor, P., Hoptman, M., Sheitman, B., Lindenmayer, J., Citrome, L., McEvoy, J., Kunz, M., Chakos, M., Cooper, T. B. Horowitz, T. L., & Lieberman, J. A. 2002; Kane, J. M., Marder, S.R. Schooler, N.R., Wirshing, W. C. Umbricht, D., Baker, R. W. Wirshing, D. A., Safferman, A., Ganguli, R., Mcmeniman, M., & Borenstein, M., 2001). Once treated with such atypic antipsychotic medication persons diagnozed with schizophrenia were found to be better able at monitoring the cues that guide and shape ongoing interactions. Consequently the inappropriate and eccentric affective responses that used to interrupt the flow of mutual expectations and disrupt interpersonal communication greatly diminished (Heinssen & Cuthbert, 2001; McGlashan, 1986; Samem, Kring, & Kerr, 1996). When added to medical treatment, staff’s accessibility, and acceptance, social skill training, and rehabilitative techniques were found to ameliorate schizophrenics’ interpersonal skills and change distorted and anxiety-producing schemata of attachment relationships thus allowing them to come out of their social isolation (Bengtsson-Tops & Hansson, 1999; Heinssen & Cuthbert, 2001; Nisenson & Berenbaum, 1998). As a result, the natural propensity for attachment and love relationship among these persons emerges in and out of the mental health clinic.

The development and maintenance of a love relationship among couples, both of whom were diagnosed as chronic schizophrenic, has rarely been studied. The reason for this neglect may be related to the fact that such a relationship was often assumed to be nonexistent. This topic is, however, of great significance to the field, since to love and feel loved by another person requires self-awareness and awareness of the other, as well as mature emotional and cognitive capacities for empathy and interpersonal communication (Erikson, 1959; Kohlberg, 1969). The goal of this qualitative research is, therefore, to discover what the subjective experience of loving and being loved meant to chronic persons diagnozed with schizophrenia at different stages of their love relationship, and the impact of such a relationship on each one of the partners' mental health, and socioemotional functioning.

Method

Sample Description

The sample included 20 heterosexual partners in a love relationship. Each one of the partner was diagnosed as chronic schizophrenic by two ward psychiatrics using Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association, 2000). All members of the couples were treated with second generation "atypical" antipsychotic drug [1] They were all enrolled in verbal and nonverbal interpersonal and motor skill training. Some of the couples also worked outside of the institution in a rehabilitation factory specially designed for them. Five of the couples lived in a mental-health institution, a sixth lived in assisted living and would come to the institution only during the day. The remaining couples resided in the community in half-way houses for the mentally ill. Most of the couples had several times been hospitalized in a in patient mental-health institution located in Northern Israel. Except for one couple in which the female was 8 years older, females was younger than their male partner. The age range of female partners was 28 to 38 years, Mean=33.5, Median=35. The age range of males was between 22 to 60 years, Mean=43; median=45. The widest age difference between a male and a female partner was 25 years. In seven out of ten couples both partners were Jewish. Two other couples were ethnically mixed, with the female partner being Muslim and the male partner Jewish whereas in the last couple both partners were Muslim.

No requirement was placed on the length of relationship, which was found to vary from one month to five years. In many cases, the partners knew each other either from the mental health institution or their place of work several years before they had become a couple. Six out of the 20 members in the couples had previously been married or had had a close relationship with another partner in the past. Although four participants had children from a prior marriage, only male and one female were regularly visited by them. One of the females in the sample had seven young children whom she has lost touch with. For cultural reason no family member brought the children to visit. The purpose of the research was explained to the research participants prior to obtaining their consent. Confidentiality and anonymity were guaranteed; all names and identifying information were replaced by pseudonyms.

Procedure

The in-depth semi-structured focused interview was chosen as the most appropriate research tool to examine what the experience of love and being loved meant at different stages of the relationship. Focused interviews have been viewed as a "directional conversation that elicits inner views of respondents' lives as they portray their worlds, experiences, and observations" (Charmaz, 1991, p. 385). Questions included in the interview guides aimed at exploring the degree to which interviewees were aware of their own needs and feelings, and of those of their partners, what were the cues particants relied on to express their love and understand that they were loved. Additional questions inquired about the *raison d'être* of the love relationship, its costs and benefits, the needs it satisfied, and the support it provided. Questions regarding physical attraction and sexual intercourse were included. Questions were asked about the extent to which the love experienced had influenced the partners' daily living and future plans.

The interviews, which lasted two to three hours, were conducted at the partner's place of residence, either in the mental health institution, or the half-way house. For eight out of ten couples, each one of the partners was interviewed separately. The remaining two couples were interviewed together due to the inability of one of the partners to communicate in Hebrew. All the interviews were conducted in Hebrew, except for one which was conducted in Arabic. To allow for the interviewee's narrative to flow naturally, the interviewers (one male and one female) kept interference to a minimum and waited until the end of the narrative to inquire about topics appearing in the interview guide which had not been addressed by the research participant. Participant comportment and nonverbal expressions were also noted.

Analysis

Content analysis of interviews was, therefore, chosen as the most appropriate research tool to analyze the experience of such close relationships. (Brunner, 1990; Coles, 1989; Denzin, 1989; Holsti, 1969; Richardson, 1990). The analysis followed the constant comparative method (Glaser & Strauss, 1967; Strauss, 1987). Interviews were transcribed and repeatedly listened to while reading the transcript. Then, each interview was deconstructed into core themes and compared to other interviews for similarities and differences. Comparisons and contrasts allowed to inductively infer composite themes that reflected the participants' shared practice and common meanings (Lincoln & Guba, 1985). The researchers were not interested in establishing the accuracy of the participants' answers, but in finding out the participants' subjective truth, the truth the participants perceived, interpreted and communicated at the time of the interview (Gergen, 1980). Partners' accounts of their love relationship were, therefore, supported by autobiographical information and direct quotes from the interviews (Stiles, 1993).

Findings

As residents of a mental health institution or half-way house, all the research participants, except for one couple residing in the community, were not concerned with paying the bills or cooking. Their basic needs were taken care of, they had plenty of time to be with each other, socialize, and fall in love! In the words of Hanna, who lived in a half-way house,

Here we do not have to worry about anything. Your meals are scheduled, your food is on time. You can shower, you have a room. We have here everything. So we have love and love is much more sweet like that, with more concern, with compliments, with love. Love with sweetness.

Proximity in space was an essential criterion to initiate a relationship. It allowed each one of the partners to read and understand the other partner's cues expressing interest and/or to feel personal attraction. For instance, Dany who for eight years had been seeing Osnat going through the revolving door of the institution but never approached her, until they sat, next to each other on a bench. Dany remembered: "It was in the canteen, she sat next to me and smiled at me. I understood she wanted me!" Tony also told us how Linda had attracted him: "She came to me. I was in Unit 2. She came to the window and brought me pizza and other food!"

Physical Appearance and Attraction

For some partners, physical appearance was an important issue, for others it was not. In the former case, both partners were aware of each other desire. For instance, Dany was seduced by his girlfriend Osnat's appearance, "She is tall and thin, she is like a model! She is funny, she is energetic!" By contrast, Osnat was repelled by Dany's weight:

He has a nice looking face, the problem is his body. Is it possible to help him?; to explain to him about the food he eats. Even his sister calls him 'fatso.' I want a man who is athletic. He would be happy if you could help him lose weight.

Dany who was interviewed separately, was fully aware of Osnot's conerns: "She [Osnat] is not happy with my body!" Sam had similar complaints about his girlfriend Rina. While describing characteristics of the ideal woman, Sam explained,

I love her delicate face, a very beautiful face, and her nose and her lips! To tell you the truth, her face is beautiful, but her body is a catastrophe!….I love a woman with class, very intelligent, very delicate, this is the woman I love! I do not love her face or her body… I love her style! (Sam)

Rina was perfectly aware that Sam was not satisfied with her obesity. In her own words, "He does not want me to eat too much, because it is not healthy for the heart (Rina)."

For two other couples, having no teeth or being overweight was of no concern to them. For instance, Barry who during all the interview had been complaining that Natalie, his girlfriend, had not showered for two days and who was disturbed by her body's odor, never commented on her heavy appearance. He just wanted her to take a shower! [2] Vadim, remarked that beauty was in the eyes of the beholder when he described his girlfriend "She has long hair brown black hair. To me she looks beautiful, to another person she might not."

Personal Qualities

Female participants often mentioned the comfort, support, and protection their partner gave them. The way their partner treated them and his largeness were additional reasons for loving them. In the words of Rina,

He is good, he behaves nice to me, he protects me. He is not cheap, he bought me presents… He gives everyone cigarettes and does not ask from anyone anything!… He is the most loyal of all men I know! Only on him I can count. He is a great guy!

Similarly, Fatana loved the serenity of her male partner. It did not bother her that her partner had no teeth and had been an alcoholic. For her "to love is to love a person with all his drawbacks, to understand him, and be patient!" In contrast, Mustafa had found in Yisha the perfect mix of internal and external beauty. In his own words,

Look at her beauty, her softness and her kindness! Is there anything better than that! Who wants more? Who could find anything more beautiful than that? We love each other [Yisha smiles].

Outward Expressions of Love and Affection Holding hands, kissing and hugging, and saying "I love you!", were the many ways partners expressed their love and conveyed to one another their feelings. In the words of some of the participants:

She tells me she loves me with a kiss. She says 'I am crazy about you!' or only kisses me. I also tell her I love her! I feel we are a couple. I even called ERAN [the emergency hot line] to tell them that I had a girlfriend. It is good to be with her. She is beautiful! I am ready to give her anything…. I want to live with her all my life (Dany).

She gives me everthing! She gives me love, she gives me a good heart. She kisses me…. She hugs me (Barry).

Presents: Love was also expressed by giving presents and seeing the joy the partner experiences. In the words of Sam,

Love is the greatest word in the universe! But what is love?… I will tell you! I saw a pair of pants and I bought it for her. When I saw the joy on her face it was for me all the world!

Dany told us about the very special present he had given to Osnat. It was an underwear that he had purchased long ago for his imaginary model girlfriend who had now become a reality. Dany recounts,

Once I went to the store [lingerie store] and told them that I had a girlfriend who was a model and wanted to buy an underwear. I did not have a girlfriend then. I gave it to Osnat.

Inward Signs of Love

Being loved and loving made the partners feel good!

He tells me:" Come !" and gives me a big hug. His hug and love give me a warm feeling (Osnat).

He gives me a good feeling, he appreciates me (Rita).

Escape from Loneliness, and Depression

For all the participants, love provided an escape from despair and isolation. To love was no longer to be alone; it was to be together. In their own words:
When we are together and listen to the music I feel like a couple. To be a couple is to be together. Without a girlfriend, it is only one world. With a girlfriend, it is two worlds (Dany).

I was alone! To live alone is not the same. I have also lived alone. It is not good to live alone! It is terrible! *A person alone is like a blind man*. [italics added for emphasis]. It is not good to live alone! (Ed).

After recanting about his mother divorcing his father and leaving for Germany, his father abandoning him and his first girlfriend suddenly dying of an overdose of Vodka, Barry told us how much his present girlfriend, Natalie, had helped him. He recounted,
I was alone, I stayed alone, I was lonely. This is why I get depressed. With Natalie I am less lonely, I have someone with me. I go away from depression.

Awareness of One's Own Needs and Those of One's Partner

Being in a romantic relationship made the participants concerned about their own appearance, which they had previously often neglected. In their own words,

> When I did not have Natalie I did not want to take a shower or comb my hair. I had mental depression; I was neglecting myself (Barry).
>
> When you live with someone you want to be clean and orderly; you want to change clothes! (Ed).

Similarly, destructive behaviors were rejected as no longer needed. For instance, once in a relationship with Waffa, Vadim no longer needed to drink

> I drink when I do not feel good. She makes me feel good! When she comes I dress nicely and put on perfume. When I was drinking I was neglected. I was not okay!

Awareness of the Partner's Needs

To love was to be aware and to take care of one's partner's needs. Dany and Osnat would obtain a pass from 1pm to 6pm to go to the apartment that Dany shared with his mother. In his room, Dany helped Osnat relax while listening to music. In the words of Osnat,

> He puts music, he helps me relax. We sleep together in the afternoon. He likes music, quiet music like me (Osnat).
>
> Dany echoed Osnat's sentiments,
>
> If she wants me to make coffee, I make coffee. If she wants me to bring her a slice of bread with spread cheese, I bring it to her.

Sam and Mustafa perceived themselves as knights protecting their "ladies" from evil figures around them. In the words of Sam,

> She needs someone to protect her from all these dogs! She is too easy! She runs very easily to men. Anyone throws a good word at her and he buys her. I just leave and they all jump on her.

Speaking about his girlfriend's husband, Mustafa explained.

> He does not help her, worry for her or take care of her. I do anything for her. Yesterday he came to visit her, but did not bring her anything. I want to help her. I want to do everything for her. Her husband does not give her a shekel [equivalent of 21 cents]. He takes all of her Biteuch Leumi [social security].

For Waffa, to take care of Vadim was to cook the food he liked: "I know that Russians love fish, and Kaviar, so I cook fish with potatoes, it tastes good. He likes it."

Participation in Joint Activities

When in love, partners wanted to share their recreational activities. In the institution this meant sitting on the grass, talking, holding hands, eating together, and at times buying ice cream at the minimarket nearby. In the words of Mustafa,

> We eat together. The kids bring food and things, and we eat together. Then I go to rest a little and then I go back to her. We also eat breakfast together. I do not work or anything. I can be with her all the time.

The one couple who lived in assisted living and came daily from 7:30 am to 1 pm to the institution, was much more autonomous and could engage in a wider range of activities. Ed recounts,

> We cook together, do the laundry, shop together. We do everything together! I prepare the food, she cooks it. I cut the potatoes; she fries them. We hang out together, we go out to restaurant, we take care of the dog together.

Sharing Problems and Worries

The extent to which the partners shared problems and worries depended on their personal idiosyncracies. Some of the partners felt the need to share. Similarly, some of the partners more than others were better at listening, and at focusing on their lover's needs. For instance, while Dany and Andre listened at length to their girlfriend's concerns, they were less able to share their own feelings. In their own words,

> She does not keep things inside, she says it, she gets angry. I shut up and keep quiet. There are things I want to tell her, but I do not. I do not know if she can take it (Dany).
>
> I keep everything inside. I do not tell anyone! She shares with me her feelings and thoughts. I listen to her and try to help her, and answer her, but what I feel, how I feel, she does not know! (Andre).

Barry, on the other hand, felt no need to share his problems with Natalie. The social worker would fulfill that purpose. With Natalie he spoke of love. In his own words,

> I do not talk about my problems. I talk to her about love. I talk to her about what is good in my soul! About my problems, I talk to Olga, the social worker.

The capacity for empathy and sensitivity for the partner's suffering were best captured by one of the research participants, Ed. Ed was stayin up all night to be there for his girlfriend Linda who worried about her sick father.

> **Ed**: Yesterday she did not sleep all night! She is a little worried, her dad is sick!
>
> **Interviewer**: How do you know that she is worried about her dad?
>
> **Ed**: She calls him on the phone!
>
> **Interviewer**: Does she tell you she is worried?
>
> **Ed**: No, I hear her voice on the phone. So I know.
>
> **Interviewer:** And when she does not sleep, do you sleep?
>
> **Ed:** No, we both stay up and watch the TV show "Life of Love".

Expressing Negative feelings

Love led partners to experience negative feelings such anger and jealousy. Sam and Andre were experiencing these feelings because of the rumors they heard circulating about their girlfriends' unfaithfulness. In their own words,

> **Sam:** They try to flirt with her. She had many boyfriends in the half-way house, not only one— four.
> **Interviewer:** How do you feel when other men talk to her?
> **Sam:** I am jealous. It makes me mad, because she is not guilty. He takes advantage of her.

As the interview progressed, Sam also revealed that he had hit his girlfriend, who was now fearing him.

> I like to be with her, but I think she is a little scared of me. A couple days ago I hit her. She is okay. She always asks me if I want to be alone, if she disturbs me. I tell her "Enough! Do not feel that I do not want you or reject you!"

Maia, Andre's girlfriend knew that he was angry because she had kissed someone else. She noted that "There is here another guy who is crazy about me. He all the time looks for me! I would not say that in front of Andre, because he is very jealous."

Future Orientation, Love, and Personal Strengths

Each one of these romantic episodes, unique in its autobiographical details, progressed along a timeline. Some of the partners, at the beginning of their love relationship, were still unsure of their love and therefore, could not enjoy the psychological security that would have allowed them to escape loneliness. For instance, Andre, 22 years old, was still feeling depressed even though had a girlfriend, Maia 30 years old, whom he had met three months ago. In the words of Andre,

> I am a little depressed. My life here is empty. I want to be home, to find a job and live my life.…Maybe we will live together. I am not sure.

Comparing past and present relationships, Andre did not feel for Maia the same love he had felt when he was 16 years old. He recounted,

> I loved her so much. I was a little kid and until today I still love her! I do not yet feel those things for Maia. I do not know if it is serious, I have to live with her and see. I want to see how she is at home, her nerves, see everything, then decide maybe if she will fit me. If I love her, I will marry her.

In contrast, the partners who were deeply in love had acquired the strength and motivation to plan for the future. Barry's future plans were very clear— He wanted to spend his life with Natalie! "I want to marry Natalie, I am big already! Thirty-five years old! I want to live with her—that's it."

> To achieve this goal, Barry had applied for subsidized assisted living and was on a three-month waiting list. Barry was also planning to have children: "I want a boy and a girl" (Barry).

Similarly, the love Waffa had for Vadim had given her the strength to think about finishing her bachelor's degree. In her own words,

> I love him. Without him I was desperate, now I have hope. I do not want to be in the hospital. It destroys your confidence. I want to work, to study, to have fun. I want to go back to school. Studying is important. It gives you confidence and dignity. I want him to be released from the hospital. I want him to work, that we have a life, a home, and money!

Despite some disassociative thinking, and inappropriate laughter Osnat also shared with us her plans for the future as she explained:

> You cannot climb a ladder all at once, you will slip! [laughing] I like to joke!
> [Three sentences later she explained]
> Me and Dany love each other terribly. We have decided on a wedding date January 10th next year, and the place of the wedding. I want a wedding without a dress and without guests because they drive me crazy (Osnat).

In the case of ethnically mixed couples, love also gave the partners the courage to fight a desperate battle against religion and tradition. For instance, Vadim, a Russian Jew, was ready to convert to Islam to marry Waffa. In Vadim's words, "On the paper it will be written that I am an Arab. But in my heart, I will stay Jewish!" Waffa, Vadim's girlfriend, was full of apprehension. She feared that even a conversion would not suffice. Waffa knew she could have a civil wedding in Cyprus which would be recognized de facto Israel since none is performed in Israel. However this alternative was a solution for her since she did not want to have trouble with her family. Her parents had died, and her uncle had already rejected one of the students who proposed to her. She remembered, "They sat and drank and then he kicked the guy out. I became sick." Now she was scared to approach her brother. She exclaimed: "They will not accept the marriage!"

Mustafa and Yisha, both Muslims, and already married, were deeply in love and dreamt about an impossible future together**.** The fact that Mustafa was married did not represent a problem, since according to the Muslim religion men are allowed to have up to four wives. Mustafa reported that

> **My wife will go crazy if get married to her. But I do not care. I was living alone. I cannot live with my wife! My children know her and love her very much. They respect her very much. I told them I want to marry her.**

However, a different destiny awaited Yisha outside the institution. Death and bloodshed were the price unfaithful Muslim women had to pay, as family members avenge the honor of their family through murder. One of the interviewers reminded Yisha of these facts while speaking in Arabic, since she did not understand Hebrew. Yisha's face immediately became sad and stern. Mustafa switched from Hebrew to Arabic to clarify his intentions to Yisha. In case she does obtain a divorce, they would remain forever in the insitution. Mustafa explained that

> I want to speak in Arabic so she understands where we are going. We shall talk to him [her husband] and ask him to divorce her. We shall get married, '*in sha Allah'* (if God pleases). If her husband leaves her or divorces her, we shall get married. If he does not let her, we shall stay here. Here we are with one another. Maybe rather than killing her, God will take his soul instead!

Coping with Separation

At times, the future meant being temporarily separated from each other. Osnat and Dany had planned to get married, yet, Osnat was about to leave to a half-way house located 2 hours from the insititution where both partners presently resided. Dany's script of the separation was unclear. He told us that he would travel by bus to go and visit Osnat and maintain phone contact with her. When addressing the eventuality of a permanent separation, Dany explained that he would be sad for one or two weeks, call ERAN (the emergency hot line), and forget about it!!

Similarly, Sam seemed quite detached when facing a hypothetical separation

> When I leave a place, I detach myself from it. It is my defense mechanism! Without wanting to detach myself, I detach myself! I find something more interesting to do! I look forward, not backward. Sick people have to understand that here it is not their house! What is love? Far away from the eyes, away from your heart! What do you want me to feel? That day and night I think about her because I love her? I love many things! I also love cigarettes! If I do not have any I go crazy!

Separation had become a reality for one of the participants at the time of the interview. Heartbroken, Itzak (53 years of age) was longing for his beloved girlfriend, Lisa (38 years), who for the past three weeks had stopped coming to the half-way house in which he resisded. Lisa was upset with him because he had refused to give her 300 shekels [about 65 US dollars]. Repeatedly squeezing his neck as if he strangulating himself, Itzak explained that he had been warned that Lisa was only after his money but he disagreed:

> Since the time she came and asked me for 300 shekels and I did not give it to her, she stopped coming. I simply did not have money in my pocket! I could not give it to her. Since then she did not come… I know her from a long time! I want her! I love her…. I know her, but I did not have money, so she got mad at me! She is a good girl, a good soul! She will come back!
>
> **Interviewer:** Does she take advantage of you financially?
>
> **Itzak:** She does not take advantage! For a girl you do everything! [Itzak knew she was seeing other men] This girl goes one time with this guy, another time with that one. [Yet, she showed concern for him] She also washed my laundry and put it in my room!
>
> Longing for Lisa, whom he had known for so many years, Itzak continued,

> I love her, so I give her! She will come back! We shall be friends! Every man wants a woman! She hugs me and kisses me. She makes me feel good! She makes me feel love!

Listening to this sad tale made the researchers wonder whether Itzak was really being taken advantage of, or simply exchanging money for kindness and an illusion of love many "healthy" people were also ready to pay for!

For one of the women, the love relationsihp had turned into a nightmare! Nava, a 36-year old Muslim woman, had fallen in love with a Jewish man while in the institution. Once released, the couple had eloped to Cyprus to get married. Nava up to this day never revealed to her brothers she had been married, and divorced. Nava's romantic relationship lasted four years. However, once out of the institution, her spouse stop taking his medication. The relationship rapidly deteriorated. In her own words:

> He played it cool in the institution! In love! When we went out he stopped taking medicine. He also cheated the doctors. He told them "I take the medicine! I feel good, I love my wife!" He told me:" The doctor did not give medicine." But, I knew that he was lying.". Before the wedding, everything was okay! He used to sleep with me, but after he cheated on me. I saw him kiss a woman on the lips! I told him: "What is this?" He said: "She kissed me!" In 1997 we got married…the social worker arranged that I work as a cleaning woman. I gave him all my money and did not buy anything for myself. He spent all the money on his friends, to buy cigarettes and beer for them. When I told him "It cannot continue like that!" arguments started! the problems started!"

Nava had lost all illusions about love! She reported that,

> He told me "I will protect you! I love you! Nonsense! I do not believe in love! I do not want to fall in love! Love is blind! It disappoints you!

Falling out of love all that Nava now wanted was to be independent. She told us:

> I do not want men who tell me what to do, who decide for me what to do! I want to be divorced, free with myself! I want my own home. I only look for a guy to speak with, to spent time with! They make me feel good. I do not care what other people say!

Sex and Lack of Privacy

Love relationships were not always consummated in sexual intercourse. The level of sexual intimacy of the participants had reached was usually determined by the level of religiosity and sexual freedom of the female partner. Five of the ten couples did not have sex based on cultural and religious grounds. The female partner was the one who set the limits concerning how far she was willing to go by either wearing traditional clothes or indicating outright to her partner that sex was not the right thing to do outside of marriage. Osnat, who was 28-years old, stated "We love each other, but with limits! What I like about myself is that I watch myself."

For Mustafa and Yisha, the Muslim couple, sex was out of question. Yisha was religious. She was wearing a white scarf on her head. When asked about sex, Mustafa exclaimed:

> No! It is forbidden! She is religious!… She prays! It is forbidden! It is a sin . But God will help us.

The male partners complied with their girlfriend's request. For instance, Osnat went to Dany's apartment in the afternoon and layed *next to him* in bed while listening to music. Yet Dany never took advantage of the situation to force sexual intercourse on her. Vadim, a Russian immigrant, also respected his girlfriend's wishes, when he explained:

> Vadim: **Only kisses, no sex, until after marriage**
>
> **Interviewer:** This is what she wants?
>
> **Vadim:** Yes!

Nevertheless, the limits set by the female partners did not prevent male partners' from fantasizing about better days! When asked: "Why is it good to be together?" Vadim replied: "Because of sex!" Similarly, Dany who never had a girlfriend before expressed the same longing for sex:

> Dany: To love! To get married! To have sex! To tell you the truth, after many years you can have a lot of sex!
> Interviewer: Do you like sex?
>
> **Dany:** Of course, every man likes sex.
>
> **Interviewer**: Does she give you sex?
>
> **Dany:** *Yes! In the future*! [Italics added for emphasis]

For those female partners who were sexually liberated, sex was a natural thing when you are in love. In the words of Rita,

> A boyfriend is something natural! If a woman does not have sex with a man it is not worth it!! I did not have sex for 15 years….. A woman who has a boyfriend and has sex loses weight. A boyfriend is good for your soul, except those who hit….the truth is that we did not have sex…but here and there!

For Maia, to have sex was a way to achieve serenity:

> Without sex there is no bond, no communication, no hugging and kissing… and they are the moments when your partner is calm and you are calm and you enjoy doing things together. You go on the grass and drink coffee together, we sit in canteen or we look for something to do together.

Making love was not easily accomplished within the narrow confines of the institutional framework. Whether in the half-way house or in the closed institution, there was no physical space allocated for couples to be intimate with each other. The staff seemed to close their eyes and ignore the issue, while fully being aware of the existence of those relationships. Maia recalls that

> The female doctor said: "How was it! Or watch yourself! People have a big mouth! But they do not make problems! It's like there is no law that says not to have sex in the hospital"

Andre explains that everyone finds a corner of his own to have sex. Mattresses have been placed in all kind of "secret places" for that purpose!

> It is allowed, but not in….In the institution, I do not know! In the rooms it is forbidden. You have sex where you find a place. There are places where there are mattresses, you can go there.

Nava told us about a greenhouse in the mental institution called "the agriculture," which was the most popular place to have sex. She explained:

> I go with them to the agriculture [a greenhouse]! There is there a "suite" between the trees! There is a mattress and a bed that the guys have fixed!…But there is another place and no one knows about it!

The lack of privacy, whether in the institution or half-way house, was a major problem encountered by those couples who wanted to be intimate with each other. Maia explained how difficult it was to find privacy "We have to look all the time for a place." When asked about the greenhouse, she exclaimed:

> **Maia:** No! Out of the question! Imagine that everyone would come to the agriculture. It would end being a very cheap place. To be discreet is the nice part about it.
> **Interviewer**: What would that be like?
> **Maia:** I would have liked that they give us a private place to sleep together. Its like a prison here!

Barry, who lived in a half-way house, also had to confront institutional rules that prevented him from being intimate with Natalie. Even though Natalie had her own room, it was against the regulations to spend the night together. In Barry's words,

There is an hour where everyone has to go to sleep. At 11 pm we have to go to our room. If I stay they make me go up. The night guard yells and tells me go to sleep!

> Barry expresses his feelings concerning the lack of privacy,

> **Interviewer:** Are you lacking anything here?
> **Barry:** I lack being alone, that they do not watch us all the time.
> **Interviewer:** You mean privacy?
> **Barry:** Yes! There is no privacy here! If I had a home we would feel closer. Here you cannot do anything, sleep together, kiss or pet. They see everything.

> Female partners revealed problems related to sexual intercourse such as vaginal infection, pregnancies, and abortions. In their own words,
> I have a sexual problem….I am ashamed to tell you! It is always itching down there (Osnat).

> It is forbidden to have sex. I am itchy. I have to go to the doctor to be checked! (Rita).

Discussion

This qualitative study aimed at examing what the experrience of love and being loved meant to heterosexual couples both diagnozed with schizophrenia who resided in the mental health institution or in the community mental health setting. Content analysis of in-depth semi-structured focused interview were conducted with each member of 10 heterosexual couples treated with "atypical" antipsychotic drugs. Despite some looseness of association, and eccentric affective responses, research participants told us clearly what the experience of being in love meant to them.

In the participants' love relationship, each unique in itself, emerged all the nuances and shades of feelings of love and affection, jealousy, and anger. The importance of the proximity and attractiveness in initiating a love relationship has also been indicated in previous research conducted with healthy couples (Berg & Mcquinn, 1986; Hatfiled & Traupmann, 1980; Walster, Berschied & Walster, 1978). (Berg & Mcquinn, 1986; Hatfiled & Traupmann, 1980; Walster, Berschied & Walster, 1978). For most of the interviewees, the benefits of a love relationship far exceeded its costs. For most of the interviewees, the benefits of a love relationship far exceeded its costs. To the research participants to love meant to feel good, to receive and give affection, to become aware and take care of one's needs and those of the loved partner. To love meant wanting to be with the other and doing things together. To kiss, hug and have sex or dream about it were included in the experience of love and so was the feeling that someone is there when you needed him or her. To love meant no longer being alone, or depressed. The experience of love allowed research participants to come out of social and emotional withdrawal while focusing on their partners' feelings and wants. Love gave the purpose and meaning to lives of the research participants. Together, they had the strength and courage to look toward the future, to have their own apartment, to get married, and for some to plan on having children.

The findings of the study indicate that once negative symptoms related to cognitive, emotional, and social skill deficiencies were ameliorated by "atypical" antipsychotic medication such as Clozapine, persons diagnozed with schizophrenia' natural capacity for love and attachment emerges (Bowlby, 1969). Love in turn improves motivational deficit, sharpens attentional and socioemotional skills. Partners in love exhibited various of degree self-awareness and awareness for each other's needs and feelings as well as empathy. No longer withdrawn in a world of their own, the couples in love planned a future in which they could love and live together

Aside from capturing the subjective experience of the respondents, this study identified concrete problems arising in the institutional framework that must be addressed to accommodate for the emerging needs of schizophrenic couples. Research participants' most pressing needs for privacy and intimacy conflicted with the very norms of the asylums and those of the institutional framework (Goffman, 1964). Yet, residents need priviacy, love, and to make love with dignity. Leaving old mattresses throughout the institution in clandestine places, allowing the residents to find "secret places" to make love, and pretending that staff is unaware of this practice, is far from effective hospital administration. Therefore, a separate unit for couples and other institutional arrangements could be established.

This study clearly shows the beneficial impact of loving and being loved on the motivational, and socioemotional functional of persons diagniozed with chronic schizophrenia. Mental health professional must, therefore, recognize and reinforce love relationships as one of the best indicators of recovery.

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Endnotes

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[1] The second-generation atypical antipsychotic medication most often used by the psychiatrist were Risperidone, Olanzepine, Quetapin, Zyprazidon.

[2] At the end of the second interview, the researchers saw Natalie coming down the stairs with wet hair, and another dress. Barry was smiling—she had taken a shower!

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Recovery from Severe Mental Illness: The Lived Experience of the Initial Phase of Treatment

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Abstract

Purpose: This hermeneutic phenomenological study examined the lived experience of persons recovering from serious and persistent mental illness (SPMI). The study reports results from the first six months of treatment and is part of a two-year longitudinal study. Method: Forty-four adults with SPMI referred to county case management services were recruited for the study. A semi-structured interview was conducted for 1-2 hours to elicit client narratives of their experience in recovery. The interviews were transcribed, read, and coded to cluster thematic aspects in each case and across cases. Atlas-t was used to recode transcripts and retrieve quotes to dimensionalize each essential theme. Transcripts were reread for confirming and disconfirming evidence for each theme. Results: Five themes were identified: 1) "life is happening around me" 2) striving for independence 3)"being in there with me" 4) pacing recovery and creating optimal challenge 5) the wish for meaningful community participation. Implications for Practice: Findings delineate critical factors in early stage recovery as identified by persons with SPMI. They highlight the need for clients to be an active collaborator in determining areas of therapeutic attention and emphasize the importance of relational factors in developing experiences of mastery and a more functional sense of self. Obstacles described by clients in early phase recovery provide new insight and meaning into problems of motivation and non-compliance in treatment. Findings suggest important areas for staff training and advocacy services.

Introduction

The recovery movement in mental health has developed as an emerging alternative model for mental health care and is now a guiding principle in the provision of mental health services (United States Surgeon General's report U.S. Department of Health and Human Services, 1999). Four qualitative studies have examined the process of recovery as experienced by consumers and developed stage models of recovery that identify unique dimensions and issues in the recovery process (Davidson & Straus, 1992; Baxter & Diehl, 1998; Young & Ensing, 1999; Spanoil et al., 2002. Models of recovery, derived from consumers' experience, can be valuable for understanding the issues, dynamics and person-environment interactions that promote or hinder recovery.

The initial phase of participation in psychosocial rehabilitation is particularly important in recovery. Consumers are often in crisis, experience little control and have few resources. Successful engagement in services may be complicated by the symptoms and disability of mental illness, by differences in goals between consumer and mental health workers and the complexity of mental health and social service systems ((Chinmen, 1999; Lang, 1999).

What do we know about the consumer experience in the initial phase of recovery? Baxter & Diehl (1998) describe initial phase issues of 1) the experience of crisis 2) a period of recuperation characterized by denial of illness, confusion and despair. Young and Ensing (1999) identify the importance of acknowledgement and acceptance of the illness as the major issue in the initial phase. Developing a desire to change, finding a source of hope and inspiration and a person to support them through the process are factors that facilitate recovery. Spanoil et al., (2002) describes the struggles of consumers in this stage: being overwhelmed by disability, trying to understand what is happening, confused, disconnected from self and others and experiencing little sense of efficacy. Davidson and Straus (1992) focus on the process of reconstructing a functional sense of self. The initial aspects of this process include 1) discovering the potential for a more active sense of self and 2) "taking stock of the self:" the process of evaluating one's strengths and weaknesses before attempting life changes.

While there are similarities among studies in the description of initial phase issues there are several limitations to this literature. There is little focus on the essential social and environmental contexts of recovery; the use of a single retrospective interview doesn't allow for examination of issues over time; the studies of recovery either describe the experience of consumers not currently involved in treatment or they fail to describe the important aspects of the treatment process and relationships.

The purpose of this study is to provide an empirically derived description of the lived experience of recovery of consumers participating in the initial phase of psychosocial rehabilitation. Specific aims of the study are to 1) identify the critical issues, tasks of recovery for consumers and mental health professionals in the initial phase of recovery 2) understand the significant interactions between person, illness, case manager, family and community that facilitate or hinder the process of recovery

Methods

Subjects

This study reports the results from the initial phase of a two year longitudinal study that is examining the lived experience of persons participating in psychosocial rehabilitation services. Subjects were recruited from Mental Health Resources, a non-profit mental health provider of services to persons with severe and persistent mental illness in St. Paul, Minnesota. In the initial phase, services included assertive community treatment teams and less intensive case management. A total of 60 subjects were consecutively referred to the study over a four-month period after their entry into Mental Health Resources programs. Inclusion criteria for the study were 1) a diagnosis of schizophrenia, schizoaffective, bipolar, chronic major depression, or substance abuse, 2) involvement in MHR for no more than four months, and 3) no evidence of a primary substance dependence diagnosis or organic brain syndrome. Five clients were excluded because of a primary diagnosis of substance dependence; five clients declined participation in the study; six clients were deemed too severely ill to participate in the study. Informed consent was obtained from the 44 subjects who participated in the study. The average age of subjects in the sample was 37 (SD = 10.57). The average length of illness was 18 years

(SD = 10.50). Of the total sample, 68% were female and 32% were male. Seventy-five percent of the subjects were Caucasian and 25% were persons of color. Moreover, 53% had a diagnosis of schizophrenia or other psychotic related disorders, 40% had a mood disorder diagnosis, and 7% had other diagnoses.

Research Method

A hermeneutic phenomenological paradigm guided the research approach. Hermeneutic phenomenology attempts to find, describe, and understand the individual's subjective experience by systematically determining the invariant components of a particular phenomenon, e.g. be-ing a person with severe and persistent mental illness (Giorgi, 1985; Giorgi, 1997; Davidson, 1997; Van Manen, 1990). Although phenomenological research seeks the essence of the experience, there is the realization that the interpretation of that experience is socially constructed by the participants themselves and co-constructed with the researcher. Data were collected through semi-structured interviews that were audio taped. Interviews lasted from one to two hours. The interview focused on five questions: What are your life aspirations? How does participation in MHR services help you achieve your goals? What do you do that helps you achieve your goals? What obstacles do you experience in recovery? What do you need that you don't have that would help you in recovery?

Themes were assigned and clustered based on a line-by-line and holistic reading of interview transcripts and accompanying materials as well as across-case comparisons. Essential themes were determined using the process of imaginative variation (Giorgi, 1985, 1997). Imaginative variation is a process whereby the researcher takes a concrete example of a thing, and imaginatively subtracts one feature, then another, discovering in the process which features are essential and which are not. A qualitative computer research program (Atlas-ti) was used to recode the transcripts according to the essential themes and retrieve the quotes to substantiate and describe the findings. Repeatedly reading and testing texts against proposed interpretations validated the findings.

Since qualitative research uses the researcher as the instrument of data collection and the center of the analytic process (Patton, 1990), it is necessary to establish mechanisms that hold the researcher accountable for the disciplined use of subjectivity. One method is for the researcher to be internally reflexive and forthcoming about his or her process (Armour, 2002). In addition to keeping an audit trail of raw data and a log of experiences, emotions, insights, and questions of the interviewer (DR), two consultants were used to monitor the influence of subjectivity on the data. The first consultant (WB) shadowed the interviewer and challenged the research process by independently listening to the audio taped interviews, writing reflections on the interviews, substantiating the determination of the essential themes, and reviewing the findings against the associated quotes from the transcripts. The second consultant (MP) was a specialist in hermeneutic phenomenology. She reviewed methodological procedures, essential themes, and descriptions of the themes.

Results

Five themes emerged from this study: life is happening around me, striving for independence, being in there with me, pacing recovery and creating optimal challenge, and wish for meaningful community participation.

Theme 1: Life is Happening Around Me

People in the study described a general sense that "life happens around them" and they were not participating in it. They experienced that they were "living at a different speed". Since "real life" or the life most people live happens at a quick pace, they cannot entirely keep up or fully meet life's demands. People described life as lacking structure and often they felt bored. The majority experienced major losses and felt disconnected socially, marginalized economically, and stigmatized by mental illness. Becoming ill took them away from other people and resulted in disconnection. People described the negative consequences of having become ill: dropping out of school, losing jobs and friends. Several people said that with more information some of these consequences could have been avoided. Many said they did not know how to “get into the system” when they initially needed guidance.

The loss of ones job, home, and important social roles leads to boredom and a sense of alienation. Many people spoke to their level of inactivity and the tedium it produced while at the same time they wanted to fill their time meaningfully. Several connected their boredom to a lack of money. Many said they had used sleep to fill up time, because they didn’t have enough money to do the things they would like to.

People also spoke to the experience of demoralization: worry, a sense of constricted options, discouragement, and an intermittent loss of hope. One person said, succinctly, “Sometimes, with this illness, you don’t feel like you have many options.” People expressed sentiments such as “projects seem to be impossible for me right now… [as are] little things like going to drug stores with your own prescription.”

Clients spoke strongly about the negative effects of provider turn over and the realities that providers often change, quit, or move. Provider turn over was reported for case managers as well as doctors, psychiatrists, and therapists. Respondents pointed out that they often had multiple providers which were confusing and there was a lack of integrated care. People pointed out that a short amount of time with many medical providers interfered with a sense of “being known”. Alternately, having a long-term provider gave them a sense of constancy. One woman described this well, saying, “I mean, with my doctor, I know her. And I know she’ll prescribe good drugs for me. But if I go somewhere else that I don't know, I don’t know if they’ll prescribe good drugs for me or not.” Finally people spoke to the brief tenures they had come to expect, especially in the social services.

Theme 2: Striving for Independence

Participants in the study described their aspirations and efforts to become more independent. This theme manifested in two ways: striving for independence and normalcy, and struggling with dependency and control. All clients expressed the desire for independence. One client spoke for many when he said “The main goal is to get back out into society and to become a productive member.” The stated goals are not ends in themselves. It is not a GED for the sake of a GED. Rather the goals are a means of achieving the prized objective of returning to a sense of normalcy and to their lives before they became ill. Many expressed a desire to 1) do what other people do and 2) return to a former sense of self: to finish school, return to work, and get back to participating in former interests. One person made this link between independence and a sense of normalcy explicit by saying, “One goal would be to actually get back into mainstream society…I’m actually like everybody else.” Another person defined independent as “being able to function just like other people do without Mental Health Resources.” When trying to define what is healthy or “normal,” several people spoke to seeking to emulate their friends who are well. One person summed up the issue this way: “Normal is doing what other normal people do.”

People also described their difficulties with being in a dependent role and often controlled by others. Although they expressed a strong, genuine desire to be free of government assistance, they also recognized that the lack of state or federal aid would put them in a financial bind. One woman summed this up: “I’m so sick of welfare and everything. I was off welfare for a year and a half and I ended up right back on it. I couldn’t make enough.”

Many desired to separate from parental supervision: “to live independently separating myself from my mom and dad; they’re over protective, and it’s hard to um, hard to separate myself from them.” Several people spoke to the loss of this sense of independence when they became ill. One respondent described getting ill as an infantilization. She said, “Then I became like a baby…I lost my independence; I lost my apartment.” Many described families who worried about them and the need to prove themselves both to their families and to providers. One man referenced the mental health system when he said, "You know how much, how many more years do I have to give you people…to let you know that I'm capable and able to set, to um, deal with life?" Another said, "It's like they take my control away to a point I don't like."

Theme 3: Being in There with Me

People saw their case managers as helping them by 1) being "in there with me" (i.e. having a significant alliance), 2) really knowing the client in a personal as well as professional way 3) providing supplemental functioning: instilling and holding hope when the client cannot, "keeping perspective," helping the client to structure, giving reassurance, providing information and encouragement – all within a deeply human and personal context. Clients report feeling known and cared for as people versus simply "clients."

The case manager was seen as someone who is "in there with me", as someone with information and access to resources who was on their side and invested in the person's success. Most people described having more of a personal relationship than a strictly professional alliance with their case managers. Many of them described their case managers as having gone above and beyond the call of duty in giving help. One woman tearfully described her case manager, though biologically younger than her, as a father figure: "When I'm lost, he comes and looks for me."

Others contrasted their case managers with psychiatrists, doctors, and county financial workers who often seemed rushed and over-focused on their disability while lacking a sense of concern for them as a person, apart from their symptoms. A few clients did not feel as connected to their case managers and spoke to a lack of alliance. One said, "I don't really feel like any … really do work with you." Others spoke to the availability of workers, "My case manager is a very nice woman, but she's hard to get a hold of" while others had conflicts with the case manager about treatment goals: "His goal is for me to stay on medication and keep seeing my doctor. But I don't want to stay on medications."

Among those who were dissatisfied, most spoke to the role of time – that if they had more time with their case managers, they thought they would feel more of an alliance with them. A few spoke of the difficulty of opening up to people and the challenge of turn-over among professionals. One man said, "I keep things very superficial, and there's a lot of things I won't open up to unless it's somebody that I [have] known…on a regular basis." Some desired to see their case manager more often, but couldn't due to high case loads. Poorer alliances were strongly associated with a perception the case manager was rushed, symptom oriented, and didn't really know the client as an individual.

The sense of being known and believed in was essential in successful working relationships. Clients felt that workers respected both their limitations and strengths. Clients spoke to the importance of "people who understand me" and "know me real well". One client described the relationship: "He knows me real well…he knows how to talk to me, and how I can understand things."

Most clients experienced their case manager as both caring and competent and took great comfort from this. Clients were able to borrow from the strength of the relationship. One person said, "I can call up and ask a question or say, 'Can you help me in this area?' It's very relaxing." Another stated, "It's very helpful to have an advocate that knows the system, knows it's screwed up and can (figure) this kind of stuff out…if I were doing it myself I wouldn't know where to begin."

The experience of "being known" by another was profoundly important. The case manager and other professionals who really "know" the person often compensate for the lack of being known by friends, family and children. Besides supplementing clients' own functioning by helping them maintain these behavioral changes, case managers served an important cognitive function, they helped clients "keep perspective" and test reality. Many clients talked about how their own thinking became easily clouded when they were depressed or too isolated and how case managers helped them to re-orient and think more clearly. Clients also talked about how easy it is, when on their own, to despair and how the case manager encourages them to remain hopeful and continues to believe in them and in what they can do. Case managers thus helped clients structurally. They offered concrete, external structure and psychological structure that helped people remain focused on their goals, hold onto hope, and think clearly.

Theme 4: Pacing Recovery and Creating Optimal Challenges: The Invisible Work of Recovery

Severe mental illness creates a situation in which it is difficult to trust oneself, one's perceptions and the assessment of one's abilities. Coping with such a situation entails repeated weighing and measuring, evaluating and assessing of the potential opportunities and risks of any step in recovery.

People defined several areas in which they are personally active in their recovery. These include contemplating change, pacing recovery, keeping routines, helping others, seeking spirituality and accepting their illness. Many people were clearly in a contemplative stage of change. While they were not yet setting goals or taking action, they were thinking about doing so in a very conscious, intentional way.

This process of contemplation involves ambivalence. People described this as a difficult process to manage, often fraught with fear and ambivalence. One man spoke about a fear of returning to work too quickly: "I mean, I worked full time before and done okay with it, but I'm a little afraid of it because I don't want to get too overstressed and have symptoms." One woman spoke to her own ambivalence: "Sometimes I'd like them to go a little faster, but then, the next day; it's like…oooh I have to could slow down".

People sought ways to achieve a greater degree of independence and to "get back to how they were" at a manageable pace. They sought to avoid being bored on the one hand or overwhelmed on the other. In essence, they worked to create an optimal degree of challenge for them to "get back to normal". The theme of maintaining a routine was a central issue. Many talked about feeling out of a routine and that it took work to develop one again. They expressed a sense that they had lost momentum. One man described the problem by saying, "When I'm sleeping, um, I don't have an alarm clock…so I just kinda sleep in…I just get up when I feel like it".

Those who were able to establish some routine experienced a sense of mastery and pride. One woman described, "I'm cooking again, and now I'm reading. I do floral arrangement, and you know I'm just starting to do the things I enjoy, you know, trying to get back into a routine." People described pride, even in the "small things." One man described his routine as "I go to my philosophy classes, and I go to church, and I pay all my bills on time. I like paying my bills." Many also spoke to maintaining a regular routine as quite a struggle and to their own vacillating between doing too much and doing too little: "Some weeks I do too much and then other weeks I fall behind, and then I get all disorganized." "It helps me to get up in the morning, but if I start falling behind and I get into a slump and I want to sleep all the time, or not do anything." All people experienced struggles with hope and despair because "it's (mental illness) so hard to overcome…"

Theme 5: Wish for Meaningful Community Participation

Many people spoke about their desire for more social connection and a greater experience of inclusion in the community. One person commented, "If you want health and wellness, you gotta have us be able to be in the community." People expressed the desire for a wider social network, and one they perceived as "normal." People enjoyed knowing the people in their building, being a part of a card club, displaying art, playing the piano, and just having friends.

Money and transportation were strong, recurring themes and were identified as significant obstacles that stood in the way of greater social involvement as well as independence. Many respondents, in fact, equated having more money and more easily accessible transportation as equivalent to having more meaningful engagement in the community and more independence, power, and agency. One man said: "Your destiny is controlled by a bus." People saw better transportation as a means to achieve more social involvement and access better jobs. Others emphasized the rigid requirements associated with financial assistance, disincentives to return to work such as losing insurance and housing assistance.

Discussion

These findings have several implications for training, practice and improving recovery-oriented services. The analysis of consumer narratives provides a picture of peoples' experiences from the beginning of psychosocial case management services to six months. The data of their experiences creates a map of critical issues and tasks for consumers and case managers that can be used in training and to improve case management services.

The development of goals in case management services raises several issues. The desire for increased independence is a priority for consumers and most people in this study saw work as a significant part of their recovery. The development of a range of work-oriented programs is clearly a necessary component of recovery-oriented services. Previous research has shown significant differences between provider goals that focus on medication and treatment compliance and consumer goals that emphasize practical daily needs, social activities in "normal" settings and work (Chinmen, 1999; Lang, 1999). These differences suggest that attention must be given to strategies that facilitate collaborative treatment planning and negotiation of conflicts regarding goals. From a psychological perspective it is important to understand the dynamics that may be involved in goal setting so that genuine personal goals can emerge not driven by stigma or as a way of proving normalcy.

The theme of "being in there with me" highlights the importance of the person-case manager relationship that is based on taking time and making genuine personal connections. While many workers may naturally utilize supportive therapy approaches and provide supplemental functioning, specific training in this area is a requisite for intentional, informed, and effective practice. (Novalis 1993; Kingdom & Turkington, 1991). Similarly, people need help in structuring their goals and activities. In order to be successful people need to avoid the extremes of under stimulation and over stimulation. It is important to discuss early in the process the mandate for structure and the roles providers and consumers will play.

The consumer's effort to pace recovery in the initial phase is in many ways the invisible work of recovery: contemplation, coping with hope and despair, acceptance of illness, and the development of daily routines. Understanding this invisible work can help providers to lessen their frustration and gain a different perspective of consumer resistance and other counter transference reactions.

The findings of this study identify several predictable issues that participants face in the initial phase of receiving case management services. Familiarity with these tasks can assist workers in developing greater understanding of the experience of recovery, setting realistic goals and evaluating progress. The need of consumers for a routine that maintains and creates therapeutic momentum, a sense of mastery and normalcy are a crucial aspect of pacing recovery. Podvall (1990) has described the development of daily routines and disciplines based on interests, e.g. crafts, music, and sports, as a "mark of sanity" that is a critical milestone in recovery and suggests ways workers can facilitate this development.

The sense of constricted social opportunities experienced by consumers and obstacles to greater participation in the community underscore the importance of multiple strategies necessary for change. On the direct practice level, providers can help consumers cognitively broaden their thinking about options, provide resources and suggest alternatives. Providers need to think outside traditional referrals and focus on informal, non-professional networks and activities. The Friends Program (1999) and the Partnership Project (2001) provide examples of empowering consumers in developing social groups and activities.

At the same time, consumer-led program development is needed to expand avenues to social support and community involvement through services such as peer support programs and friendship groups where consumers are paired up with volunteers, churches, or other community groups. Collaborative efforts between consumers and providers are needed to improve services for critical issues such as relapse prevention

(Davidson, 1997). Continued advocacy for protection of rights and increased resources for basic needs are essential aspects of recovery-oriented service highlighted by this research.

This study provides an example of a phenomenological method that takes the person's subjective experience as the organizing construct and allows for the integration of disorder, health, and recovery factors. To view illness in this context provides a deeper and more realistic understanding of the complexity of living with mental illness and offers a framework that delineates the relevant aspects of context, coping, and resources needed to enhance recovery-oriented services for persons with severe and persistent mental illnesses.

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Subjective Memory Complaints in Relation to Anxiety and Test Performance of Patients Recovering from Severe Acute Respiratory Syndrome in Hong Kong.

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Abstract

Memory problems have been reported during steroid administration. The existing literature suggests that many of these effects are transient and reversible. The purpose of the study was to explore the associations of subjective memory complaint with objective test performance and emotional state in recovering SARS patients.

Method:

Twenty-three patients aged between 20 to 34 were divided into 2 groups: those who reported trouble with their memory and those who did not. Cognitive functioning including general intelligence and memory was assessed using subtests of the Wechsler Adult Intelligence and Memory Scales and the Hong Kong List Learning Test. Mood was assessed using the Hospital Anxiety and Depression Scale.

Results:

No significant difference was identified between the two groups in cognitive test performance. Furthermore, results obtained did not suggest the presence of any systematic cognitive impairment in both groups. However, the group reporting memory trouble was found to significantly score higher on an anxiety scale.

Conclusion:

Results suggested the possibility of a relationship between anxiety and subjective memory complaint. Results also suggest that subjective memory complaints need to be assessed and treated in the context of the overall adjustment in individuals trying to recover from a sudden and severe illness. Specifically, psychological intervention may be needed to help patients to overcome their anxiety about their functional competence in the process of psychosocial rehabilitation.

Key Words: SARS, memory, subjective complaint, test performance, anxiety

Introduction

Severe Acute Respiratory Syndrome (SARS) is an acute atypical pneumonia believed to be caused by a previously unknown coronavirus and is responsible for the first pandemic of the 21st century (Peiris et al., 2003). Hong Kong, China, remains one of the most severely affected areas. With the infectious nature of this new disease, SARS can have many behavioral and emotional implications for recovering patients. After recovering initially in the physical sense, other challenges begin to surface. These include uncertainties about side effects of medication, longer-term effects of the illness, the ability to return to previous occupation and to handle interpersonal relationships. Uncertainty and stigmatization are prominent themes in the longer-term emotional adjustment in SARS (Maunder et al., 2003; Gorodzinsky, 2003, Au et al., 2004).

A treatment protocol including a combination of ribavirin and systemic steroids was adopted from the beginning of the epidemic and the protocol is currently being reviewed (Chan et al., 2003; So et al., 2003; Yuji, 2003). Memory problems have been reported during steroid administration. This ranges from mild problems in verbal memory to severe dementia. The existing literature suggests that many of these effects are transient and reversible (Brown & Chandler, 2003; Newcomer et al., 1999). However, some recovering SARS patients receiving outpatient follow-up care in our specialist clinic have continued to report a subjective sense of memory difficulties. So far, there is no published data on the cognitive functioning of recovering Severe Acute Respiratory Syndrome (SARS) patients who have received steroid therapy in Hong Kong. Thus, the purpose of the study was to explore the relationships between subjective memory complaint, objective cognitive test performance and emotional state for these patients.

Method

Subjects and Procedure

Twenty-three discharged SARS patients (aged between 20-34) were recruited from the Outpatient Clinic of Queen Elizabeth Hospital. The age group chosen was based primarily on the availability of local test norms for that particular age group which is also the primary reference group of the established Wechsler scales (Wechsler, 1981). At the time of their regularly scheduled appointments at the clinic, all patients of this age range were invited to an interview with the clinical psychologist. After briefly outlining the purpose of the assessment and obtaining written consent, patients were invited to complete self-administered questionnaires. All consenting patients were seen about 1 to 2 months after discharge from hospital. One patient did not turn up for the scheduled appointment stating that there was no need for assessment.

Demographic characteristics were collected through the questionnaire. Illness and treatment related information including medication was obtained from the medical record. For the subjective memory complaint, each subject was asked “Do you have trouble with your memory?” The answer “yes” or “no” was recorded. This one question has been previously proven to be a sensitive and valid method to assess memory complaint in Chinese-speaking population (Wang et al., 2000). Based on the response to this question, 12 patients were allocated to the group with subjective memory complaint (SMC+) and 11 were allocated to the group without subjective memory complaint (SMC-).

Measures

The Chinese translation of the Wechsler Adult Intelligence Scale-Revised (WAIS-R) was used to assess general intellectual functioning (Wechsler, 1981; Chan et al., 2000). As for testing of memory, the Hong Kong List Learning Test (HKLTT) was used to assess verbal memory (Chan & Kwok, 1999; Au et al., 2003) and the Visual Reproduction (VR) subtest of the Wechsler Memory Scale-Revised (WMS-R) was used to assess to visual memory (Wechsler, 1987).

The WAIS-R subtests administered included Digit Span, Arithmetic, Similarities, Picture Completion, Block Design and Digit Symbol. The selection of subtests was based on the seven-subtest short form version of

WAIS-R that has generally been found to be a cost-effective and accurate method to estimate overall intellectual functioning (Axelrod & Paolo, 1998). However, the Information subtest was omitted as the questions in the original American version were judged to be not representative enough for the local culture. In terms of the dimensions of the underlying abilities measured, Similarities has been found to load on the "verbal" factor. Block Design, Picture Completion and Digit Symbol loaded on the "perceptual" factor. Finally, Digit Span and Arithmetic loaded on the third factor termed "freedom-from-distractibility" of "attention/concentration" (Leckliter et al., 1986). The HKLTT yields measures of immediate recall of the auditory-verbal learning of a 16-word list over three trials. It also involves a delayed recall of the list after 30 minutes. Local norms are available for the chosen WAIS-R subtests and the HKLTT. Requiring the drawing from memory simple geometric designs that are each exposed for ten seconds, the WMS-R (VR) produced a score for immediate recall and a score for delayed recall after 30 minutes. There are no local norms for the WMS-R (VR). However, with its primarily non-verbal content, the culture loading is considered minimized.

Emotional state was monitored using the 14-item Hospital Anxiety and Depression Scale (HADS) to provide measures of anxiety and depression (Zigmond & Snaith, 1983). Each item is scored from 0 to 3. Total scores range from 0 to 21 for the Anxiety subscale and also for the Depression subscale. The HADS has been widely used to monitor mood changes in medical and neurological patients in Hong Kong (Au et al., 2002).

Data analysis

The WAIS-R yielded six raw scores, one for each subtest. The VR of the WMS-R yielded two measures: immediate recall and 30-minute delayed recall. For the HKLTT, learning over three trials was added up to form a total learning score. The HKLTT delayed recall was based on the number of words recalled after 30 minutes. The raw scores of the WAIS-R and the HKLTT were converted into percentiles according to the available Hong Kong Chinese norms (Chan et al., 2000, Chan & Kwok, 1999). The scores for the WMS-R (VR) were converted into percentiles according to the norms given in the manual. The HADS yielded scores for 14-items from which two independent subscale scores was calculated for Anxiety and Depression. Subjects were divided into two subgroups according to the presence or absence of subjective memory complaint. T-tests were performed to investigate group differences on emotional state and objective measures of cognitive functioning. The SPSS programs for Windows, Release 7.0, was used for all analysis.

Results

Demographic characteristics and medical information of the two groups are summarized in Table 1. The 2 groups are largely comparable in the variables described. However, the age was higher in the group with subjective memory complaint than the group without [$t(22) = -2.80$, $p < 0.05$]. Results on the WAIS-R, HKLTT and WMS-R (VR) are summarized in Table 2. Results on the HADS are summarized in Table 3. No significant differences between the 2 groups were identified in the objective test performance. Furthermore, the test scores for both groups are all in the normal range. As for the HADS, there were also no significant in terms of the Anxiety and Depression subscale scores. Again, the scores for both groups are in the normal range. However, the group with subjective memory complaint was found to score significantly higher in Item 3 [$t(22) = -2.35$, $p < 0.05$]. For this item, patients were asked to rate in what degree they "got a sort of frightened feeling as if something awful is about to happen". Higher scores on the item indicated greater anxiety.

Table 1. Demographic characteristics and medical information of the two groups: patients with subjective memory complaint (SMC+) versus those without (SMC-)

	SMC+ Group (n=12) **Mean (SD)**	**SMC- Group (n=11)** **Mean (SD)**
Age	30.92 (2.07)	26.92 (4.30)*

Sex		
Male	3	7
Female	9	4
Education	13.83 (2.79)	13.73 (2.61)
Employment		
Employed	1	1
Unemployed	11	10
Marital status		
Single	5	6
Married	6	5
Widowed	1	
Time since onset (days)	71.00 (12.64)	86.00 (21.95)
Time since discharge (days)	43.67 (16.85)	56.10 (21.31)
Period of hospitalization (days)	27.18 (12.24)	27.80 (17.00)
Need for Admission into Intensive Care Unit		
Yes	2	2
No	10	9
Need for Intubation		
Yes	3	2
No	9	9
Prenisolone equivalence (mg)	2059.08 (1045.13)	1840.86 (1006.50)

*p < 0.05

Table 2. Objective test performance of the two groups: patients with subjective memory complaint (SMC+) versus those without (SMC-)

	SMC+ Group (n=12) **Mean (SD)**	**SMC- Group (n=11)** **Mean (SD)**
Wechsler Adult Intelligence Scale-Revised (In percentile)		
Digit Span	83.82 (28.03)	96.85 (7.41)
Arithmetic	47.50 (28.09)	50.55 (27.92)
Similarities	47.00 (28.08)	41.27 (26.05)
Picture Completion	43.68 (22.06)	50.55 (29.62)
Block Design	49.17 (27.89)	59.45 (27.70)
Digit Symbol	59.50 (29.44)	54.91 (33.50)
Hong Kong List Learning Test (In percentile)		
Total Learning	58.61 (16.48)	55.90 (23.64)
Delayed Recall	59.17 (26.20)	62.00 (24.20)
Wechsler Memory Scale-Revised (Visual Reproduction) (In percentile)		
Immediate Recall	83.08 (15.79)	90.91 (11.36)
Delayed Recall	80.75 (21.62)	87.73 (17.41)

Table 3. Emotional state profile of the two groups: patients with subjective memory complaint (SMC+) versus those without (SMC-)

	SMC+ Group (n=12) Mean (SD)	SMC- Group (n=11) Mean (SD)
Hospital Anxiety and Depression Scale (Raw scores)		
Anxiety	5.42 (3.00)	3.45 (2.73)
Depression	3.50 (3.85)	2.18 (2.40)
Item 1	0.92 (0.67)	0.45 (0.69)
Item 2	0.67 (0.89)	0.45 (0.52)
Item 3	1.08 (0.79)	0.36 (0.67)*
Item 4	0.08 (0.29)	0.18 (0.40)
Item 5	0.75 (0.75)	0.81 (0.60)
Item 6	0.58 (0.90)	0.45 (0.52)
Item 7	0.83 (0.72)	0.64 (0.50)
Item 8	1.08 (0.51)	0.82 (0.75)
Item 9	0.75 (0.45)	0.45 (0.52)
Item 10	0.25 (0.45)	0.18 (0.40)
Item 11	0.42 (0.51)	0.27(0.47)
Item 12	0.67 (0.98)	0.18 (0.40)
Item 13	0.75 (0.75)	0.64 (0.67)
Item 14	0.17 (0.39)	0.00 (0.00)

*$p < 0.05$

Conclusion

The study explored the relationships of subjective memory complaint with objective test performance and emotional state in 23 recovering SARS patients aged between 20 to 34. Comparing a group with subjective memory complaint and a group without the complaint, results did not reveal any significant differences in the objective test performance in terms of intellectual functioning and memory. The cognitive test scores and the mood scores for both groups are all in the normal range. However, the group with subjective memory complaint scored significantly higher on an anxiety item that described “a sort of frightened feeling as if something awful is about to happen.” This is a rather interesting finding as apprehensive expectation is the cardinal feature of anxiety according to the Diagnostic and Statistical Manual of Mental Disorders. These results would suggest the subjective memory complaint could be related to anxiety (APA, 1994).

Discrepancies between subjective memory complaint and cognitive test performance in neurological patients have been frequently reported (Piazzini et al., 2001). The present study is perhaps the first to document this discrepancy in recovering SARS patients. Findings suggest that subjective memory complaint in these patients may be related to anxiety. However, the present study has certain limitations. The subject number was relatively small and the age group was confined to younger patients. The choice of the age range was initially based on the availability of local test norms and the relative lack of other possible neurological complications in older adults.

To conclude, the present study highlighted the possibility of the relationship between emotional factors and the subjective sense of memory competence. A severe illness like SARS can cause major disruptions to activities in daily living. Furthermore SARS patients are also faced with social prejudice causing them difficulties in getting the support when they need them most. The subjective sense of frailty and fatigue can lower the sense of personal control to return to the previous functioning and lifestyle. Levels of anxiety and depression have been found to correlate with the subjective sense of mastery in local epilepsy patients (Au et al., 2002). Although future studies need to clarify the relationship between emotions and subjective memory, the findings of the present study reinforced the need to take into account the emotional state in the recovery in SARS patients. Results of the present study suggest that subjective memory complaints need to be assessed and treated in the context of the overall adjustment in individuals trying to recover from a sudden and severe illness. Specifically, psychological intervention may be needed to help patients to overcome their anxiety about their functional competence in psychosocial rehabilitation.

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Folie a Deux – a Social-Psychological Approach.

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Abstract

Since the introduction of folie a deux in 1877 by Lasegue and Falret (1964) few contributions were made to the understanding and treatment of this disorder. We suggest that folie a deux is a group-originated disorder. We use the theoretical elaboration of social psychology such as social influence, group leader role, and group identity to describe the processes within the folie a deux group. We propose a specific treatment approach that we call reconceptualization therapy, which is based on the group-relevant issues in folie a deux patients.

Keywords: social influence, group leader role, group identity

Folie a Deux – a Social-Psychological Approach.

> **"**Whether a statement is true is an entirely different question from whether you or anybody believes it. ... There can be truths that no one believes. Symmetrically, there can be beliefs that are not true. ... "
> [Elliot Sober, (1991) in Parsimony, Evolution, and Inference. Cambridge, MA, MIT Press, , pp. 15-16]

Introduction

In 1877 Lasegue and Falret introduced a totally new phenomenon in the realm of mental illness (Lasegue &, Falret , 1877). Until then, mental illness was associated with a single person who suffered from the disorder. For the first time the definition of an illness included the context of a specific social group. This was one of the few examples where a mental illness was initiated solely by communication. It is intriguing to understand the precise mechanisms that cause the previously “normal” person to loose his/her control of reality. The literature on the topic is scarce, and includes mostly case reports. Some classification attempts concentrated mainly on the individual features of the persons who participate in the shared psychosis (SP).

Scharfetter (Scharfetter, 1972) claimed that a hereditary schizophrenic predisposition was absolutely necessary for the development of SP. Gralnick (Gralnick, 1942) reported in his patient’s cohort that 91% of shared disorders had similar inheritance and he concluded that this formed the basis for the phenomenon.

Psychoanalytical theorists agreed on the assumption that the transfer of delusions and hallucinations in SP occurs to fulfill needs of both the source and recipient of the psychosis. Hart and McClure (Hart J, McClure , 1989) suggested that SP allows the mentally ill person to maintain a link to reality. For the submissive recipient, the underlying process is identification with the inducer that may fulfill dependency needs (Hart J, McClure , 1989) and avert threat of loss, which is greater than the threat of becoming psychotic (Salih, 1981). Few efforts have been made to understand the social framework of this phenomenon.

We suggest a group approach to shared psychosis, and postulate that the persons participating in folie a deux could be identified as belonging to a specific group. We hypothesize that some mechanisms that take place in the evolving and functioning of such a group are similar to that of any other social group. Thus this phenomenon can be investigated in terms of interactions within this group and intercommunication with other groups.

Social psychology addresses a number of characteristics that are inherent to a social group. Group is defined as two or more persons who interact and influence each other for longer than just a few moments and who conceptualize themselves as “we” (Shaw, 1981).

Social influence and reality testing

Social influence has been equated with conformity. Conformity is reliance on another’s judgment in the absence of or even in contradiction to one’s own judgment (Smith, 1982).

According to Muzafer Sherif (Sherif, 1936) norms emerge through social interaction and social interdependence is based on uncertainty reduction – people use the opinions of others as a guide to the reality in situation that is ambiguous and uncertain. Through interaction, groups converge on unique group norms. Group norms persist in later judgments of individuals. In the paradigm where electrical shocks were believed to be applied to an innocent victim, Milgram (Milgram, 1963) demonstrated that people are prone to act against their own beliefs and even to harm another when instructed by an authority to do so. Solomon Asch’s line length experiments (Asch, 1955) showed that in a constellation of 1 proband against more than 3 others, who deliberately provide wrong answers the overall error rate increased to 36.8% (compared to 0.7% in controls). Asch clearly demonstrated the influence of social pressure.

Two different explanations were provided to explain the phenomenon of social influence. Sherif et al (Sherif, 1936) regarded a rational process of information thought to be responsible, on the other hand Asch et al. (Asch, 1955) saw irrational acceptance of others’ judgments while within the group as a cause. One’s desire to be accepted and approved as a normative group member was considered a principle motivation. Deutsch and Gerard (Deutsch & Gerard, 1955) coined the terms informational and normative influence. In their understanding informational influence was influence to achieve accurate perceptions (stock market rates, weather forecast, etc.) and normative influence was based on approval and rejection avoidance and associated with peer group pressure.

Latan (Latan, 1981) in his Social Impact Theory argued that social influence depends on:
a) strength of the influence agent (powerful and important vs. weak and unimportant);
b) immediacy of the influencing agent (proximal vs. distant); c) number of the influencing agents (the larger the number the smaller the influence).

"Groupthink" was coined by psychologist Irving Janis in 1972 (Janis & Mann, 1977) to describe a process by which a group can make bad or irrational decisions.
In a groupthink situation, each member of the group attempts to conform his or her opinions to what they believe to be the consensus of the group. Thus, the group may ultimately agree on an action which each member might normally consider to be unwise. Janis' original definition of the term was "a mode of thinking that people engage in when they are deeply involved in a cohesive in-group, when the members' strivings for unanimity override their motivation to realistically appraise alternative courses of action." The word groupthink was intended to be reminiscent of George Orwell's coinages (such as doublethink) from the fictional language Newspeak, which he portrayed in his ideological novel Nineteen Eighty-Four.

Janis described 8 symptoms that characterize groupthink: invulnerability, rationale, morality, stereotypes, pressure, self-censorship, unanimity, and mindguards, where striving for conformity is one of the main motivating forces. Self-censorship is practiced in order to stick to the consensus, an illusion is formed that everything said and agreed within the group is true (unanimity), critical thinking is avoided. The closer the group the tighter the boundaries of conformity, and any disagreement within the group is perceived as a threat. The symptom of invulnerability is the shared illusion that the group is very powerful. This feeling prevents the group from critically evaluating reality. “Morality” in Janis’s sense is a conviction that what the group believes and does is always right. This symptom puts the group into position to justify its actions even if they are highly polemic – “rationale” in Janis’s definition. Stereotype “black-white” thinking facilitates the construction of enemy images. The “enemy” is always wrong and evil and any aggressive action against him is justified. Pressure is exerted against any disagreeing individual. Mindguards are used for that purpose. In Janis’s opinion groupthink may lead to a serious bias in the decision-making process of a cohesive group.

Moscovici and Zavallini (Moscovici & Zavallini, 1969) described a phenomenon of group polarization – enforcement of the average tendency of the group members. During group discussion a data bank of ideas is formed, most of which conform to the dominating point of view.

Turner introduced a new approach, which attempted to determine that group influence is not terminated after discontinuation of the physical contact of the individual with the group. In his Self-Categorization Theory (Turner, 1987, Turner, 1991) he conceptualized that a group is not necessarily an external influence and that the group values and standards (group norms) are internalized by an individual and become part of his/her social identity as ones’ self is defined in terms of social norms.

In (1954), Leon Festinger postulated in his Social Comparison Theory (Festinger, 1954) that there are two main sources of uniformity pressure within small groups: social validation and group locomotion. Accordingly, social reality testing only occurs when physical reality testing is unavailable and increases with the growing dependence of the members of the group. He noted that group members tend to check their opinions by comparison with the dominant opinion of the group. Group locomotion underlines the other source of social pressure. Presence of important group goals requires uniformity if they are to be attained. Several studies show that the more a deviant prevents attainment of a valued goal, the more rejected he becomes (Schachter, 1961, Earle, 1986). In the experimental elaboration of Theory of Social Influence, Deutsch and Gerard (Deutsch & Gerard, 1955) demonstrated that Festinger’s theory was incomplete as people sometimes conformed to social truth even if physical reality suggested otherwise only to avoid being stigmatized.
In 1950, Festinger summarized the basic principles of his cognitive dissonance theory: "If you change a person's behavior, his thoughts and feelings will change to minimize the dissonance." As Festinger described, "dissonance" is the psychological tension that arises when a person's behavior conflicts with his beliefs.

People prefer that their behavior, thoughts, and emotions be mutually consistent, and can tolerate only a certain amount of discrepancy between these three components. Psychological research has shown that if any of the three components changes, the other two will shift to reduce cognitive dissonance. Festinger's theory is based on three components: control of behavior, control of thoughts, and control of emotions, which were complemented by a fourth component - control of information introduced by Steven Alan Hassan (Hassan, 2000). Some of the means of information control mentioned by Hassan were use of deception, discouraging access to outside sources of information, etc. (Hassan, 2000).

The Role of a Group Leader

Leader is a person having authority over others in concert… (Webster's Dictionary).

Among the various leadership theories the Charismatic Leadership Theory (House, 1976) seems most appropriate for SP group dynamics.
According to this theory the charismatic leader possesses following features:

1. Determination and persistence 2. Exceptional self-confidence 3. Advocacy of change and challenge for the status quo 4. Ability to mobilize a critical mass of followers in the interest of the leader's vision. 5. Relative insensitivity to criticism 6. Low affiliative motivation or no conscious concern for establishing, maintaining and restoring close personal relationships with others. 7. Advocacy of a vision of a better future for the collective. 8. No interest in self-aggrandizement. 9. Sense of social responsibility and collective interests." (House, 1976) .

Destructive Cult. Thought Reform or Cohesive Influence.

A cult (totalist type) is a group or movement that exhibits excessive devotion or dedication to a person, idea, or thing and employs unethical manipulative techniques of persuasion and control (e.g., isolation from former friends and family, debilitation, use of special methods to heighten suggestibility and subservience, powerful group pressures, information management, suspension of individuality or critical judgment, promotion of total dependency on the group and fear of leaving it, etc.) designed to advance the goals of the group's leaders to the actual or possible detriment of members, their families, or the community (West & Langone , 1986).

The term "thought reform" was coined by Robert Lifton, one of the early psychologists to study brainwashing and mind control, and to describe mind manipulation in destructive cults (Lifton, 1989, Lifton, 1961). Margaret Singer (Singer, 1990). identified 6 conditions necessary to perform such thought reform in cult members. 1. The person is kept unaware of the processes occurring within the cult or its final agenda; 2. Person is led to think about a group and its content most of the time; 3. The belief in one's own perception and good judgment is discouraged, ordinary view of reality is destabilized, the member is led to a sense of inner confusion and powerlessness; 4. The person's former social identity is discredited through a system of rewards, punishments, and experiences especially designed for that purpose. 5. The creation of the new belief system is promoted though a system of rewards, punishments, and experiences especially designed for that purpose. 6. A closed system of logic is created within the authoritarian structure that permits no feedback and refuses to be modified except by leadership approval or executive order.
The destructive cult is usually led by a charismatic leader (Robbins, 1988).

"Folie a Deux" Group

In our opinion the "folie a deux group" is characterized by the following:
1) Group formation is spontaneous; 2) The group life expectancy is not self-limited;
3) The group includes 2 or more individuals; 4) Recruitment to the group is usually based on family bonds (ties); 5) Group members live in close proximity – usually within the same flat; 6) The group is based on pronounced hierarchical structure ; 7) One of the group members (inducer) possesses charismatic leader-like qualities; 8) The group has sharply defined borders; 9) The group is a "closed" group, there is no enrollment of new members; 10) Very high group cohesion; 11) The central element of group cohesion is a delusional

idea; 12) The group initially served completely different purposes – sexual bond, living together of closed relatives, and purposes were later modified due to the delusional idea; 13) The group norms are based on the delusional idea and are communicated by the group leader; 14) The input of external information is highly selective and is absorbed only after interpretation through the internal (delusional) group values; 15) Expressed intolerance to any "alternative" solution or interpretation or behavior; 16) The relation towards other groups is defensive and not cooperative ; 17) The defense mechanisms are psychotic – split, denial, grandiosity; black-white thinking; 18) At the beginning the group tends to propagate its central idea to the society and tries to gain its acceptance, later on it gives up and demonstrates a hostile attitude towards society.

Discussion

The conceptualization of folie a deux first published by Laseque and Faret (Laseque & Faret, 1877) at the end of 19th century has not essentially been challenged until the present. The therapist who confronts this disorder today uses mainly the same tools both in assessment and treatment of the disorder (apart from psychopharmacological therapy).

It seems to us that understanding of SP demands a multidisciplinary approach. The very fact that the disease is defined not through a single patient, but explicitly includes additional individuals invites other methods than we are used to in our traditional assessment of psychopathology. In a "pure" folie a deux case a psychiatrically morbid person "inflicts" a disorder on a previously mentally healthy individual. Though some authors claim that such an individual is a actually a myth, because in vast majority of cases there is a common genetic load, it can be argued that if this load alone would be of principal significance, a much higher incidence of the disorder might be expected. Interestingly, the definition of shared psychosis according to DSM-IV states explicitly that "The disturbance is not better accounted for by another Psychotic Disorder (i.e. schizophrenia) or a Mood Disorder With Psychotic Features and is not due to the direct physiological effects of a substance (e.g., drug of abuse, a medication) or a general medical condition". DSM-IV (American Psychiatric Association, 1994), in other words refers to a "pure" case of SP where a recipient is not mentally ill. Additionally, Musalek and Kutzer (Musalek & Kutzer, 1990) have indicated in their study of 107 patients affected with shared delusions of infestations that the ratio of blood relations to non-blood relations was 1:2.3, so that genetic factors seemed to be less important than the direct impact of deluded patients on their environment. Thus, one may conclude, other factors may be of greater importance in the creation of the phenomenon. The attempt to explain the evolvement of a disorder merely through the analysis of involved a person that has been undertaken by a number of psychoanalytically oriented authors may have contributed to the understanding of the interpersonal unconscious motives. It does not take into consideration, however, the universal mechanisms that occur in every group of humans and that have a profound impact on their behavior.

The analysis of SP patients as a specific group enables the observer to apply the powerful arsenal of tools that is commonly used in social psychology. The reality testing as it is understood in group context is very different from the reality testing of an individual, as described by Freud, for example – "a concern of the definitive reality-ego, which develops out of the initial pleasure-ego" (Freud, 1955). Distinguishing between physical and social reality testing (Festinger, 1954) provides us with the new understanding that is relevant to SP. Festinger et al. (Festinger, 1954) demonstrated that in situations with high levels of uncertainty social reality testing overrules and physical reality testing is rendered considerably less important. He also proved that social reality testing becomes more dominant in situations with increased dependence. This is precisely what happens within the SP group - where the recipient usually possesses features of dependency. The mode of social influence within a SP group is mostly of a normative character[11]. Checking the opinion of the dependent group members with the "dominant" opinion (in the case of a SP group, the opinion of the inducer) is also a common phenomenon as is avoidance of stigmatization (by the inducer in SP) (Deutsch & Gerard, 1955). In the case of a SP group physical reality testing by group members is discouraged, thus social reality testing is the main evaluation of reality. However, social reality testing is almost the same as physical reality testing of the leader, and he is psychotic. Festinger's locomotion is reflected in SP as grouping around the delusional idea that exerts powerful social pressure on the recipient to conform with the group. As a cohesive

and closed group, the SP group undergoes extreme polarization (Moscovici & Zavallini, 1969). The way the recipient is "talked into" SP could be partially interpreted by the manipulation of his behavior, cognition, emotion, and information he receives from the outer world though the inducer (Hassan, 2000, Festinger, 1959).
The SP group is an extreme example of "groupthink" (Janis & Mann, 1977). All 8 components mentioned by Janis are highly functional and reach psychotic dimensions.

The inducer in the SP group may be characterized in terms of the Charismatic Leadership Theory. He is generally expected to possess all the cited qualities except the sense of social responsibility and collective interests (at least in the general sense) (House, 1976).

The strength of the influencing agent (Latan, 1981) is maximal in the SP group – the inducer is powerful and important, he is in close proximity to the inducer and he inflicts his influence alone without sharing it with anyone else.

The tendency of many recipients to insist on their delusional content though separated from the inducer may be interpreted through the Self-Categorization Theory of Turner, the recipient internalizes the "social norms" of folie a deux group that actually become a part of his identity (Asch, 1955).

Some notes may be made about the analogous features in the destructive cult group and the folie a deux group. In a destructive cult the central idea is an overvalued idea, whereas in folie a deux it is a delusion. The destructive group is built according to the plan of a leader, in folie a deux the group is formed out of a previous group formation such as family bond etc. in a spontaneous manner (group transformation). The motivation of the destructive cult's leader is a conscious one, in folie a deux motivation is usually unconscious. Recruitment is possible in a destructive cult, in folie a deux no specific arrangements for recruitment are provided. The techniques of thought reform in a destructive cult are applied in a purposeful manner, whereas in folie a deux such mind manipulations are built on unconscious motives. Both groups are similar in their authoritarian structure, consolidation around a charismatic-like leader figure, sharp group boundaries, high level of cohesiveness, extensive use of external enemy image, isolation from the society, intolerance to any critical thinking, extensive use of thought reform, demand of total spiritual commitment, and social reality testing clearly overrules physical reality testing which is discouraged.
Both destructive cults and folie a deux groups may produce psychotic behavior in their members (Singer, 1990).
The analysis of both destructive cults and folie a deux suggests the existence of certain spectrum of affected groups – starting with classical folie a deux, folie a trois, folie a famille, and "folie a societe" in the case of an extended group.

Suggestion for therapy

Laseque's recommendation to isolate the originally mentally healthy recipient seems not to be sufficient. The persistence of delusions in a recipient even after separation from the inducer is quite common – 60% of reported cases (Howard, 1994). Some authors advocate the "conjoined" therapy where both individual and family therapy are applied.

We sense a need for a specific psychotherapeutic approach aside from pure separation. We suggest here a therapeutic intervention, that aims to rebuild the misconceptions, that in our view, play a crucial role in the establishment of psychosis in a recipient. We call it "reconceptualization therapy". It is based on an assumption that a recipient has internalized pathological group norms (in case of shared psychosis formed by the inducer) that have a profound influence on his emotions, thinking, and behavior. The goal of the reconceptualization therapy is to challenge these norms and to provide grounds for a more reality-oriented attitude. This approach is based on a conjoined model - both individual and family therapy, each one having its specific objectives.

The description bellow addresses the treatment of the recipient(s) only. The treatment of the inducer depends on the context of his psychopathology and is not the focus of this paper.

The treatment should be performed on an inpatient basis. In many cases, the recipient will be involuntarily committed. It is preferable to conduct a treatment within a closed ward. It should be mentioned that the therapy implies the total separation between the inducer and recipient (s). The inducer and the recipients are informed at the initiation of the therapy that no visits, no telephone calls, or any other contacts are allowed during the main course of the therapy. In the case that psychopathology of a recipient demands pharmacological intervention it will be initiated at the beginning. In questionable cases the initiation of the psychotropic therapy will be postponed until the final diagnosis is established.

Individual therapy

Three stages may be identified. 1. Trust Building phase. At this stage, anamnesis and heteroanamnesis is collected, the patient's immediate needs are addressed in an empathic manner. Empathy with the patient's suffering, his sense of defenselessness and his fears is shown. No critical evaluation of delusional content, no clarification, no interpretive interventions or confrontations are expected. Therapeutic alliance starts to form.

1. 2. Concept Reconstruction Phase. At the beginning of this phase, the general issues regarding the social influence are discussed with a patient in popular terms, illustrated by well known social-psychological experiments (Asch , 1951; Milgram, 1964; Festinger, 1957). Three main issues are addressed: a) social reality vs. physical reality; b) the only interpretation of an event or fact vs. possibility of alternative interpretations; c) "unmistakable" leader concept vs. "we all make mistakes" and critical approach to leader figure.

- Patient's delusional conceptions are analyzed in terms of socially formed conceptions. A patient is encouraged to suggest the ways of their verification. The process of verification must be as transparent to a patient as possible.
- Delusional interpretations of events and facts in the patient's life are discussed. The patient is encouraged to look for alternative interpretations. If it seems difficult for a patient to talk about himself, other more general subjects should be discussed (newspaper articles, TV programs, etc.).
- Different leaders (e.g. historical figures) are analyzed. A patient is encouraged to critically evaluate their actions and to build an integrative approach. At a later stage, the inducer himself becomes the subject for such an analysis; it is encouraged to switch from one-sided viewing to a more critical and comprehensive understanding of inducer's way of thinking and behavior.

Towards the end of this phase family therapy is initiated.

3. Concept Consolidation Phase. At this phase, for the first time, the patient is exposed to the inducer in an individual session (a meeting should be arranged) parallel, to family therapy. In the aftermath of the meeting a patient's evaluation of the inducer is discussed. The issues that need further elaboration have to be worked through.

Family Therapy

The therapy is performed with the extended family, including all the percipients and all members that have ambivalent attitudes towards the delusional ideas. Some non-family participants can be included if they may contribute significantly to the therapeutic process. The group actually has the character of a "transitional group", where the group members represent both worlds – from one side they are the members of the same family sharing family values, myths, etc., on another side they represent a door to society, where social and physical reality testing are combined.
The phases of the therapeutic process are similar to those of the individual therapy. The inducer will be excluded from the first two phases and introduced during the consolidation phase.

The present work is consistent with the main stream of psychiatric research that adapts a psycho-social-biological approach (Engel, 1977).
Folie a deux may serve as a model which underlines the importance of social influence on establishment and

course of a psychiatric disorder. The well established techniques of family and couple therapy that are in common use in everyday work with psychiatric patients may be enriched by instruments of social psychology both at the stage of assessment and treatment.

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July 2005 - June 2006

Brief Reports

Feature Articles

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IJPR
Brief Reports

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Creating a New Culture:

Establishing a Transitional Living Community at a State Hospital

(A Short Report)

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Abstract:

The Recovery and Empowerment model has been successful in many types of programs. Attempting to establish such a change of culture in a traditional medical model hospital has been well worth the efforts. This model, adopted in the Transitional Living Community (TLC) at Eastern State Hospital, narrows the gap that is intrinsic when moving from inpatient hospitalization to living in the community, provides a more appropriate level of care, is a much less restrictive environment and alleviates some staffing and budgetary difficulties.

Keywords: Recovery and Empowerment, Psychosocial Rehabilitation, Culture Chang

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Introduction

Eastern State Hospital, located in Williamsburg, Virginia, is the oldest public mental health facility in the United States. The hospital is a 412- bed inpatient facility serving adult, forensic and geriatric populations.

Non-geriatric and non-forensic patients are admitted through the Intensive Treatment Program. The average length of stay in the Intensive Treatment Program (ITP) is 42 days, with approximately 52% of the people admitted to Eastern State Hospital (ESH) being discharged from this program. Those who cannot be discharged from the ITP are transferred to the Psychosocial Rehabilitation (PSR) program. The Psychosocial Rehabilitation Program at ESH was developed in 1998 to provide centralized services to meet the active treatment needs of our seriously mentally ill adults.

Why the Transitional Living Community (TLC) was created

Eastern State Hospital is committed to providing excellent quality care. Ongoing program evaluation and development is essential in the process of enhancing efforts toward individualized care. Three main factors contributed to the development of the new program at ESH: programming deficits, budget concerns and staffing issues.

In evaluating the program's efforts, it was determined that there was a segment of the ESH patient population who might no longer be benefiting from the traditional inpatient model. It was determined that quality care could be improved by taking a closer look at how resources were being utilized with respect to individual patient needs.

Within the hospital there are individuals who are psychiatrically stable and ready for discharge, but who are unable to leave due to non-behavioral reasons. Problems with funding and placement issues in the communities are encountered and, although community efforts toward outpatient placement are strong, a large number of clients remain awaiting discharge. At any given time, there are approximately 50 clients on the Discharge Ready List.

Forensic clients with unescorted community privileges are another segment of Eastern State Hospital's population for whom programming was deemed insufficient. These individuals require minimal supervision and staff intervention, display an absence of significant psychiatric symptoms and possess levels of social competence compatible with increased expectations for self-sufficiency and independence. They participate in a full schedule of programming, maintain their privilege levels on a consistent basis and are actively involved in their recovery process. As such, these patients have needs reaching beyond that which could be offered in our traditional inpatient units. The acute care level of treatment traditionally offered and the restrictiveness of the environment is unnecessary and inhibits personal growth. These clients were developing the skills necessary for a high level of independent living while hospitalized but were unable to practice those skills due to the restrictions inherent in living in secured residential buildings.

Additionally, the national nursing shortage crisis has impacted health care everywhere. ESH has experienced an increase in mandatory overtime with subsequent staff burnout, recruitment and retention difficulties, and a large increase in spending for overtime pay. The average monthly expenditure for overtime was contributing to budgetary constraints.

Movement toward an empowerment and recovery model to develop independent community living skills for the patients who have maximally benefited from inpatient programming but are unable to be discharged was therefore considered. This model, adopted in the Transitional Living Community (TLC) at ESH, narrows the gap that is intrinsic when moving from hospitalization to living in the community. This provides a more appropriate level of care, is a much less restrictive environment and alleviates some staffing and budgetary difficulties.

Recovery Empowerment Plan

"Our vision is of a community-based system of services that promotes self-determination, empowerment, recovery, and the highest possible level of consumer participation in work, relationships, and all aspects of community life" (Governor's Conference: Self-Determination, Empowerment and Recovery, December, 2004).

The basic principles of psychiatric rehabilitation remain consistent with all programming efforts:

a) equipping clients with skills;

b) emphasizing client self-determination;

c) using the resources of the environment;

d) emphasizing social change;

e) providing different assessment and care;

f) emphasizing employment;

g) emphasizing the here and now; and

h) providing early intervention. (Cnaan, Blankhertz, Messeger & Gardner, 1990).

The establishment of a Recovery/Empowerment Model in the TLC at Eastern State Hospital is a natural extension of our existing rehabilitation model. The TLC attempts to promote recovery by facilitating individual preferences in regard to personal goals and the skills and supports required to reach those goals.

ESH created an environment that encourages and supports the development of autonomy and skills necessary for successful community tenure. Self-management skills are emphasized, to include self-medication, scheduling and performing home management and self-care tasks (meal planning and preparation, laundry, cleaning, money management, budgeting, shopping, making and keeping appointments, etc.). Individuals pursue their goals for employment or volunteer experience within the hospital or in the community. They explore community resources and support services, participate in off-campus AA/NA meetings and consumer groups, and practice resource acquisition skills. Opportunities for role development, peer counseling, self-advocacy and the development and practice of personal and social boundaries exist. It creates a smoother transition from being an inpatient to an outpatient and moving from forensic status to civil status. It increases the clients' self-confidence and decreases public safety concerns as they gain successes in the community. Community Services Boards are able to assess clients' progress in a less restrictive setting and are able to provide more suitable housing as available. This program also enables direct admission to a step-down level of care after being stabilized in the community. Finally, with the increased autonomy of the clients, nursing staff and other resources are able to redeploy to other areas of the hospital, thereby decreasing overtime.

The individuals referred to this program by their treatment teams are encouraged to function as independently as possible in this more normalized setting while working through their barriers to discharge. Individual goal setting and opportunity for achievement are an integral focus of the Transitional Living Community. The consultative model proposed that the program be staffed with one psychologist, one consulting psychiatrist, one social worker, one rehabilitation services staff member and, per shift, one direct services associate. One LPN comes to the unit twice daily for medication management issues. There is no full time nursing staff assigned to this unit.

How it was created

What did it take to make such a large change in the treatment modality?

1. Readiness for Change
2. Culture Change toward Recovery and Empowerment
3. Commitment from the top of the organizational structure (DMHMRSAS, Hospital Director, and Medical Director)
4. Committed staff
5. Innovative thinking
6. Belief in the clients
7. Clients' belief in themselves
8. Appropriate staff support

9. The ability to adapt to change

ESH was ready for a change and the aforementioned budget crisis and nursing shortage was pronounced. The Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) began implementation of a Recovery, Empowerment, and Self-Determination model of care and based on this philosophy, ESH Hospital Director, John Favret, redeveloped the idea of creating a TLC that was originally proposed in 1997.

The first step was to create a place for this community. One of the wards housed patients whose medical needs outweighed their psychiatric needs. These patients were not benefiting from the centralized programming available in PSR. It was decided that they would maximally benefit from the proximity and services available in our Medical Services Unit (MSU) and they were therefore relocated. The MSU contains medical equipment, medical and physical rehabilitation clinics, x-ray, lab, and pharmacy resources, and is staffed by several internists. ESH received several notices from the families of these medically fragile patients who were pleased with this move.

This relocation of patients left one 19-bed ward open for the use of the TLC candidates and allowed 11 members of the nursing staff to be redeployed to assist other wards experiencing staffing shortages.

A Recovery Council comprised of consumers and individuals who possessed an enthusiasm for the project was formed. The goals were established with the following premise in mind: "…recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles" (Anthony, 2000).

Recovery Objectives to Support Individuals:

1. Making increasingly independent decisions by identifying risks and benefits of daily living choices.
2. Moving toward self-management of medication and healthcare.
3. Learning to co-exist with peers in supportive environment.
4. Learning to problem-solve with decreasing staff involvement.
5. Developing a personal recovery plan.
    a. Setting daily, short and long-term goals
    b. Identifying and seeking resources, assistance and support
    c. Accepting consequences of personal choices
    d. Re-evaluating/self-evaluating individual plan
    e. Other independent choices

Admission criteria were created for the unit.

1. Interested, willing and capable of living in a co-ed setting with appropriate staff assistance, according to the TLC guidelines.
2. Able to safely manage unescorted grounds privileges during free time. If NGRI status, must have unescorted community privileges and be adequately managing their risk factors.
3. Is an active participant in programming that may include but is not limited to: Vocational/Clubhouse/Living Skills Groups.
4. Is knowledgeable about prescribed medications (i.e., can name medications and state the reasons for taking them). Is able to identify the risks/benefits of taking the prescribed medications and can state the risks associated with discontinuation.

5. Can assist in the management of their physical illness, if applicable.
6. Is capable of maintaining personal hygiene and room management.
7. Any history of assaultive or self-harm behaviors is carefully evaluated and does not contraindicate TLC placement.
8. Any history of sexually aggressive behaviors or sexual trauma is carefully evaluated and does not contraindicate TLC placement.
9. Actively participates in the discharge planning process.

Due to a large number of forensic patients referred for the TLC, the Internal Forensic Review Panel approved candidates to the unit and revised Risk Management Plans.

Outcome

The TLC opened May 31, 2005. The individuals housed on the TLC are very happy. One of the biggest changes came when the people referred to the unit were referred to as “individuals” and no longer as “patients.” They established their own recovery goals and are the leaders of their treatment team (now called a Recovery Team). These were new concepts for the staff, as the hospital has historically been based on the medical model. They understand they are the “pioneers” of this new concept and have been very excited about their new autonomy. They are a self-governing body and are learning to work together in decision-making.

The three rules the individuals suggested were:
“1) Be honest, 2) Respect others and their stuff; and 3) Keep the peace.” They have more choices, more personal freedom and subsequently more sense of self-worth. The positive change in the affect of some of these individuals is so pronounced, it begets the question, ”Why didn’t we do this sooner?” One of the individuals on the unit eloquently expressed himself in a progress note.

With his permission, I have included it here:
“My name is ___ and these are the reflections relating to my stay, and thoughts thereof, in the TLC unit at Eastern State Hospital. Being one of the pioneers of transitional living here, and pretty much the country, has been an honor only my fellow peers can identify with. It is a step to the positive in the further humanization of people who are mentally ill. We have faced challenges together and I believe each one of us is inspired to the better. My mind is in the best shape it has ever been in and my horizons, as I see them, are expanding. I continue to religiously take my medicine and understand and check it. As I move closer to discharge, I can’t help but speak about the many positive attributes I have acquired while staying here in Eastern State. No it wasn’t a bucket of roses but yes it has been a learning experience.”

Conclusion

The community is the ideal location for consumers to actualize their potential. However, the reality of limited facilities in the community, reinvestment issues, discharge planning responsibilities placed on the communities, inadequate community resources for the seriously mentally ill individuals, and the growing forensic population increases the demand for specialized inpatient services at this time. Establishment of the Transitional Living Community supports the pursuit toward individualized care and allows for improved utilization of staff and space resources for the individuals who require greater levels of treatment and staff intervention.

Eastern State Hospital’s mission is to assist patients and their families to efficiently utilize resources that encourage living within a community at the highest level of personal independence. The Transitional Living Community is a move toward that mission.

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Psychosocial Rehabilitation in Slovenia

(A Brief Report)

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Abstract

Development of psychiatric rehabilitation in psychiatric hospitals and of psychosocial rehabilitation in non-governement associations in Slovenia are described regarding historical and societal experience. Main obstacles to further development of community rehabilitation are searched for. Basic recommendation is to strenghten anti-stigmatization movement and to improve education in the field of mental health.

Key words: Psychosocial rehabilitation - history - stigmatization

Introduction

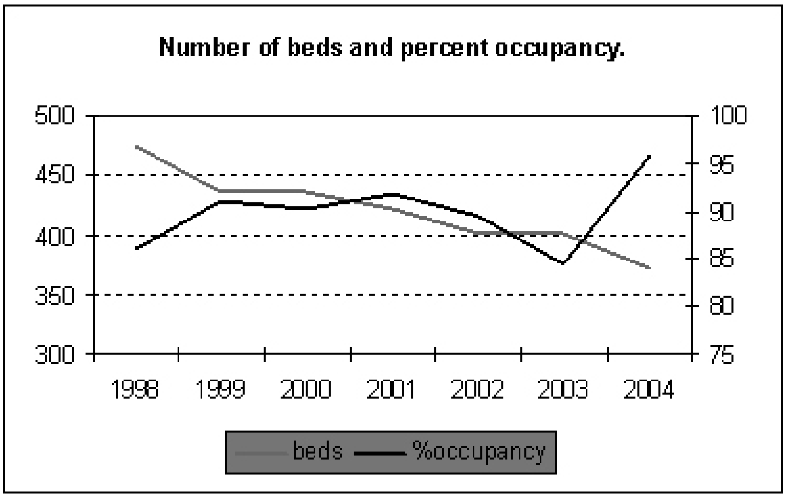
Slovenia is a Central European country with a population of two million. At the end of the 19th century it was part of the Austro-Hungarian monarchy, in the 20th century it joined with the Serbs and Croats to create a kingdom and also made up part of the communist bloc after World War II in the Federal Republic of Yugoslavia. As the northern and most developed part of former Yugoslavia Slovenia its gained independence in 1991 with a referendum, following a ten-day war with the Yugoslav army that had then started to disintegrate. The religion is predominantly Catholic (70%). Some 100,000 people from former Yugoslav republics still live in Slovenia. The country's GNP per capita was USD 10,400 in 2003, which is lower than most »old« European countries but better than most 'new' ones.

While Slovenia was previously engaged in a communistic regime all the time it still tried to achieve developed European social models. It had a relatively well-developed network of public health and social services. With democratic reforms and the removal of the planned economy myths about the firmness of the public network and citizens' social security started to collapse. The former social policy proved to be too expensive and counterproductive for the country due to the lack of support for private initiatives, non-profit voluntary organisations and civil society. People with mental illnesses were predominantly institutionalised, treatment and care were government regulated and separated from other illnesses. The mental health system used to work relatively well due to the fact that institutions and outpatient clinics were widely available to everybody in need. Deinstitutionalisation and community care only held academic and experimental significance and were chiefly influenced by the British model.

The social democratic government also tried to implement the Scandinavian model of social care involving strong public services and the influence of user organisations. The challenge of deinstitutionalisation was resisted by the firm stand of Slovenian psychiatrists also due to the experience of the Nazis' criminal euthanasia of psychiatric patients from a Slovenian psychiatric hospital during World War II. The work and education of psychiatrists was guided by the permanent warning that psychiatric patients require special safeguarding and protection which influenced the strengthening of institutional forms of care. There was no tradition of voluntarism and people then had to struggle for their own economic survival. The cultural perception of mental illness is still determined by a mixture of distancing, fear and pity. After criticism of psychiatric institutions (Gofman, 1968, Wing and Brown, 1970), European psychiatry was reformed in terms of the quality of hospital care and treatment (Curson et al., 1992) followed by community treatment and social care. Despite the rapid and – in comparison with the rest of Europe – early shrinkage of hospital capacities and hospitalisation days, attempts prevailed to maintain care and treatment within institutions such as social asylums and homes for the elderly. Simultaneously, a wide network of psychiatric outpatient clinics developed in the 1970s but without establishing any other complementary services. These should be linked with general practice and thus located as close as possible to patients' homes.

Hospitals have been renovated and provided with a greater number of staff, however it is still incomparable with that somatic hospitals. Chronic patients were de-hospitalised and moved to asylums, old peoples' homes and to their families. The majority of the hospital population of 20 years ago was quickly discharged, mainly with very little preparation and due to economic pressure. In Slovenia's main psychiatric hospital (University Psychiatric Hospital Ljubljana; hereafter: PH) there are only about 2% of long-term hospitalised patients. The number of admissions to the central Slovenian psychiatric hospital has been increasing rapidly while hospitalisations themselves have become shorter, chiefly as a result of the further rapid reduction of the number of psychiatric beds (by 22%) seen in recent years.

Figure 1. Hospital beds and admissions in the central Slovenian psychiatric hospital



The need for planning post-discharge care was increasing and therefore hospital staff were gradually undergoing training in the planning of treatment and care with patients, as well as in evaluations of their social functioning, work with family members and teaching daily and social skills. Special care has been dedicated to changing attitudes to patients and to implement the values of partnership and empowerment.

It was up until the middle of the last decade that our mental health care system managed relatively well the problems of homelessness, imprisonment of psychiatric patients, poor accessibility of care and suitable housing. Nevertheless, it was becoming increasingly apparent that institutionalised care was posing an obstacle to the recovery of people with a mental illness. Users' movements and protests supported by a few social care experts after 1982 sought to make this fact public. At this time the civil movement first organised a campaign for abolition of the biggest social institution in the country, in which patients had been living in unbearable conditions. Apart from calls for the total deinstitutionalisation of psychiatry and particularly the abandonment of psychiatric-social asylums, the campaign was the beginning of 'normal' socialising for the most severely disabled psychiatric patients. A group of dedicated social workers appealed for patients' employment, independent living and empowerment. Yet nothing much happened in this area in the following decade. The psychiatric profession persisted in protecting its patients and recent deinstitutionalisation after witnessing the deficient care of patients in Gorizia and Trieste, the two centres of Italian deinstitutionalisation, only one hundred kilometres from the centre of Slovenia.

The consequences of conflict between the psychiatric and social movements are still apparent and manifest themselves in extremely incompatible education programmes on mental health at the Medical and Social Work faculties and particularly in the negligible or even absent co-operation between the relevant professions. A change was brought about by the establishment of some non-governmental organisations in the mental health field which, aware of the evidently unsatisfied needs for rehabilitation of the mentally ill, tried to stimulate co-operation and contacts between social and health services, particularly those concerned with psychiatry. General practice joined the debate on the possibilities of mutual activities with some caution due to understaffing (1,800 patients per general physician). In 1992, the non-profit organisation ŠENT started to prepare multidisciplinary programmes for day-centres, vocational rehabilitation and group homes, which proved to satisfy certain needs of their users (Švab et al., 2003). Rehabilitation activity was also developed in parallel organisations operating across the territory of Slovenia. ŠENT developed educational programmes for work in the rehabilitation field, which were joined by social workers, occupational therapists, medical nurses and some general practice physicians and parallel tailored but essentially equal educational groups for patients and their families. In following years, these education programmes were launched in the central psychiatric hospital and transferred to some other regional psychiatric hospitals. The first textbook on psychosocial rehabilitation (Svab et al., 2004) was at least partly based on the Boston model of psychosocial rehabilitation (Anthony et al., 2002) and intended for all members of multidisciplinary work groups, including patients and their families. Parallel to that, users, family members and care-takers were joining in within the framework of different non-profit organisations, and have thus gained some political power in the last few years. While the family members are striving for the better quality and accessibility of care as well as timely intervention in critical situations, users' initiatives centre on the fight for a better social and economic status and a critique of psychiatric institutions.

The rights of psychiatric patients were regulated by the health law which provided the basis for involuntary hospitalisation. This law has been overruled by the Constitutional Court and at this point in time Slovenia has no legislation on mental health. The situation has been resolved by other legislative acts and by the decision of the Constitutional Court on obligatory co-decision of advocates about involuntary admission. In the last ten years the mental health law has remained an unfinished project. The fact that we have no law on protection of patients' rights in hospitals, upon admission and in the fields of treatment and rehabilitation enables at least the concealed abuse of psychiatric patients because of the lack of information about their rights. There is a report by the European Commission (Mental Disability Advocacy Centre, 2003:54) on the existence of a few cage beds in Slovenian hospitals and a few other complaints. Such concern is understandable due to the lack of professional monitoring and weak NGO influence on quality standards The abuse of psychiatric patients is more obvious when it comes to their low employment levels, lack of supported employment, housing opportunities, low incomes and regarding the paternalistic attitudes of psychiatric and social workers which, to our knowledge, is no different than in other countries.

Conclusion

The rehabilitation programmes outside the hospitals are solely financed by the social care system and through donations. Slovenian health care policy does not reveal any intention to support the implementation of rehabilitation programmes in the home setting, while in hospitals these are only carried out to a very limited extent due to the short hospitalisation periods. Attempts to connect hospital care, to facilitate the evaluation of patients' needs, health condition and functioning, with public and private organisations that perform rehabilitation in the community are still in a preliminary stage. The dissociation of health-care, social and private rehabilitation services represents the main obstacle to the implementation of co-ordinated and individually adjusted programmes. Attempted integration agreements such as those discussed at the Conference on Rehabilitation and Community Care (2002), and the Conference on Education in the Field of Mental Health (2004), although relatively well accepted, have remained overlooked in the planning of health care. The main reason for this indifference seems to be attributable to discrimination against patients with mental disorders. Therefore, our main efforts are directed towards destigmatisation. It is necessary to reduce the stigma associated with large institutions, encourage the decriminalisation of psychiatry, i.e. draw a dividing line between the forensic and other lines of psychiatry, and offer education for increasing the power and influence of the users of rehabilitation services. However, as pointed out by patients themselves, in order to achieve this it is necessary to improve their weak social status and poor living conditions, which are the biggest obstacles to their actual integration.

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IJPR
Feature Articles

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The Influence Of Psychosocial Rehabilitation On Patients With A First Episode Of Psychosis

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Abstract

Psychosocial interventions offer an important adjunct to pharmacotherapy in the treatment of psychosis. We examined the effects of a psychosocial rehabilitation programme by comparing first presentation and 4-year follow-up assessments among 96 first-episode psychosis patients. At first-presentation, those who completed the programme (N = 19) had a significantly poorer quality of life than those who received standard care (N = 77). At follow-up there were no statistically significant differences in quality of life between the two groups. We conclude that psychosocial rehabilitation should form an integral part of the treatment of psychosis and may offer distinctive benefits in improving the quality of life of such patients.

Key Words: Psychosis, rehabilitation, outcome

Introduction

Despite recent advances in the pharmacological management of the psychoses up to 80% of patients with schizophrenia experience more than one episode of psychosis. Additionally, the prognosis of affective disorder, traditionally thought to be more favourable, can be poor especially for those with psychotic symptoms (Wiersma, 1998; Robinson, 1999; Ohmori, 1999; Shepherd, 1989; Lee & Murray, 1989). Approximately 30% of patients with psychosis respond poorly to medication and continue to evidence persistent symptoms and functional impairment (Kane, 1988). Furthermore, pharmacological treatment on its own has only a moderate impact on the social function of patients with schizophrenia (Frangou & Murray, 2000).

Psychosocial rehabilitation offers an important adjunct to pharmacotherapy (Bachrach, 2000) and may offer unique benefits to patients with psychosis (Bacharach, 1992; Bachrach 1996). The goal of these interventions is to enable individuals to achieve the highest feasible quality of life by ensuring that they can perform the physical, emotional, social and intellectual skills required to live in the community (Anthony, 1988). Yet the potential benefits of psychosocial rehabilitation may not be fully understood as there is a relative shortage of published research in the area particularly among persons with a first-episode of psychosis (Huxley, 2000).

We sought to investigate the effectiveness of a psychosocial rehabilitation programme on the outcome of a group of patients recovering from a first-episode of psychosis. We compared the outcomes of those who attended the programme with those who received standard care to determine the effectiveness of the intervention.

Method

Subjects

Between 1995 and 1999 we conducted a first episode psychosis study at Cluain Mhuire Family Centre (a catchment area service which provides community based psychiatric care for an urban population in County Dublin of approximately 165 000) and St. John of God Hospital, County Dublin (Browne, 2000). The study received Ethics (Research) Committee approval. First episode psychosis was defined as a first ever presentation to any psychiatric service with a psychotic episode. Patients who commenced antipsychotic medication prior to referral were included in the study provided they were being treated for a first psychotic episode and that their treatment had not commenced more than 30 days before assessment. A further ethical submission was accepted and patients were followed-up 4 years after initial presentation. They were reassessed across the same clinical measures by an investigator blind to original clinical measures. As part of treatment for a first-episode of psychosis a subgroup of patients were referred to a psychosocial rehabilitation programme at one of our centres. Treating teams made referrals, the programme was open to all who presented with a first-episode of psychosis during the study period and all participants gave informed consent to study participants.

The REACH Programme (Recognition & Esteem through Accommodation, Catering and Horticulture) is a 32 week fulltime lifestyle management course. The aim of the programme is to enable participants to develop the necessary skills and confidence to achieve health and well-being with the goal of returning to work or progressing onto further training. Mental health education is an important aspect of the programme and aims to develop knowledge about illness, medication, relapse prevention and early warning signs. Other areas addressed in the programme include alcohol and substance misuse, communication skills, self-awareness and self-esteem, job seeking skills, generic work skills, teamwork, goal setting and use of community resources. The present study compared the outcome at 4-year follow-up of those who attended the psychosocial rehabilitation course with those who received standard care.

Clinical Measures

(a) ***Quality of life*****:** We measured quality of life using the Quality of Life Scale (QLS; Heinrichs, 1979) and the World Health Organisation Quality of Life Scale 'Bref' version (WHOQoL 'Bref'; World Health Organisation, 1996). The QLS is a semistructured interviewer-administered scale. It consists of 21 items divided into 4 subscales; Interpersonal relations, Instrumental role, Intrapsychic foundations and Common objects and activities. A total score is calculated by adding the subscale scores.

We used the World Health Organisation Quality of Life Scale - Brief version (WHOQoL-'Bref'; World Health Organisation, 1996) as a subjective measure quality of life. This 28 item self-report scale assesses quality of life across 4 domains (Physical health, Psychological health, Social relationships and Satisfaction with environment).

(b) ***Positive and Negative Syndrome Scale (PANSS)*****:** Psychopathology was assessed using the PANSS (Kay, 1987). This scale is divided into 3 subscales; 7 items assess positive symptoms, 7 items assess negative symptoms and 16 items assess general psychopathology.

(c) ***Insight*****:** We used the Insight Scale (Birchwood, 1994) to assess degree of insight. This self-report questionnaire is well validated and extensively used among patients with schizophrenia. It measures three dimensions of insight: 'awareness of illness', 'ability to relabel psychotic symptoms', and 'recognition of the need for treatment'. Each dimension is scored on a scale of 0-4, giving an overall insight score of 0-12 (higher score indicating greater insight).

All patients were diagnosed using the Structured Clinical Interview in accordance with DSM-IV criteria (APA, 1994) and we rated an individual's Global Assessment of Functioning (GAF) (Spitzer, 1995) and degree of substance misuse as part of this interview. We also assessed attitudes and concordance with medication using the Drug Attitude Inventory (DAI; Hogan, 1983) and the Medication Compliance Interview (Adams 1993). Number of admissions and days spent in hospital were calculated from hospital records.

Statistics

We divided the patients into two groups; those who completed the programme and those who received standard care. We compared assessments at first presentation between the groups using t-tests for continuous data and chi square tests for categorical data. Follow-up assessments were also analysed in this manner. We used paired t-tests to compare first presentation with follow-up assessments in each of these groups. All data was analysed using the Statistical Package for Social Sciences (SPSS, 2001).

Results

Ninety-six patients (63 male, 33 female) were assessed at first presentation and at 4-year follow-up. The demographic and clinical characteristics of these patients are outlined in Table I. Their diagnoses were as follows; Schizophrenia = 80, Bipolar affective disorder = 8, Major depression = 1, Delusional disorder = 3, Drug induced psychosis = 2, Schizoaffective disorder = 2. The mean length to follow-up for the total group was 43.5 months (s.d. 9.5 months). Thirty-one patients were referred to the lifestyle management course of whom 19 completed the course and consented to follow-up assessment (Schizophrenia = 18, Bipolar affective disorder = 4, substance induced psychosis = 1, schizoaffective disorder = 1).

Table I. Demographic and clinical characteristics of all 96 patients at first presentation.

	Mean	Standard deviation
Age of onset	25.81	9.26
Age at first presentation	27.62	9.85
DUP	21.68	39.05
Years in education	13.50	2.49
QLS total	63.23	25.58
GAF	22.48	7.69
PANSS total	76.43	18.03

DUP = Duration of untreated psychosis, QLS = Quality of life scale, GAF = Global assessment of functioning, PANSS = Positive and negative syndrome scale.

First presentation assessments

At first presentation the 19 patients who completed the REACH programme were indistinguishable from the 77 who did not in terms of age at first presentation (*t* = -1.48, P = 0.15), gender (c2 = 1.86, P = 0.17), duration of untreated initial psychosis (*t* = -0.69, P = 0.56), total PANSS score (*t* = 0.09, P = 0.93), insight (*t* = 1.67, P = 0.11), degree of alcohol / substance abuse (c2 = 0.33, P = 0.56) or GAF score (*t* = -0.77, P = 0.45). However, patients who completed the REACH programme had a poorer subscale and total QLS scores at first presentation compared to those who received standard care (Table II).

Table II. Comparison of quality of life scores (QLS) at first presentation between patients who completed the REACH programme and those who received standard care.

	REACH programme (N = 19)	**Standard care (N = 77)**	**df**	***t***	**P**	**95% CI**

QLS Social functioning	19.5	24.4	94	-2.0	0.057	(-9.91, 0.16)
QLS Occupational functioning	6.4	11.3	94	-2.9	0.006	(-8.36, -1.48)
QLS Intrapsychic foundations	18.3	23.6	94	-2.5	0.014	(-9.53, -1.12)
QLS Common objects and activities	5.9	7.3	94	-2.3	0.029	(-2.48, -0.15)
QLS total	50.1	66.5	94	-3.0	0.005	(-27.49, -5.38)

Follow-up assessments

Quality of Life

At follow-up there were statistically significant improvements in subscale and total QLS scores in both groups of patients (Table III). However, patients who completed the REACH programme were indistinguishable from those who did not in terms of their total QLS and subscale scores (Table IV). Furthermore, even though both groups evidenced improvement in quality of life at follow-up, this improvement was most marked among patients who attended the psychosocial rehabilitation course. These patients had a significantly poorer quality of life at outset and evidenced a 54% improvement at follow-up compared to a 33% improvement in those who received standard care.

Table III. Comparison of quality of life scores (QLS) at first presentation and follow-up among patients who completed the REACH programme and those who received standard care.

	REACH programme (N = 19) ***t***	**df**	**95% CI**	**Standard care (N = 77)** ***t***	**df**	**95% CI**
QLS Social functioning	5.4	18	(5.6, 10.3)**	6.9	76	(6.5, 14.9)**
QLS Occupational functioning	3.4	18	(3.5, 7.2)**	5.8	76	(2.6, 11.2)*
QLS Intrapsychic foundations	4.1	18	(6.2, 10.5)**	7.8	76	(4.5, 14.0)*
QLS Common objects and activities	3.8	18	(0.5, 1.4)**	4.0	76	(0.7, 2.4)*

QLS total	5.6	18	(17.2, 29.0)**	7.8	76	(18.5, 40.8)**

Table IV. Comparison of quality of life scores (QLS) at follow-up between patients who completed the REACH programme and those who received standard care.

	REACH programme (N = 19)	**Standard care** (N = 77)	**df**	***t***	**P**	**95% CI**
QLS Social functioning	30.2	32.3	94	-0.78	0.44	(-7.48, 3.28)
QLS Occupational functioning	13.3	16.7	94	-2.0	0.052	(-6.83, 0.03)
QLS Intrapsychic foundations	27.5	31.9	94	-1.9	0.07	(-9.17, 0.41)
QLS Common objects and activities	7.5	8.2	94	-1.5	0.148	(-1.74, 0.27)
QLS total	79.7	89.6	94	-1.5	0.14	(-22.96, 3.21)

We did not have a self-report assessment of quality of life at first presentation for either group of patients. However, at follow-up there was no significant difference between the two groups in terms of their subjective physical health (*t* = -1.86, P = 0.08), psychological health (*t* = -0.91, P = 37), social relationships (*t* = -1.12, P = 0.28) or satisfaction with their environment (*t* = 0.02, P = 0.99).

Psychoeducation

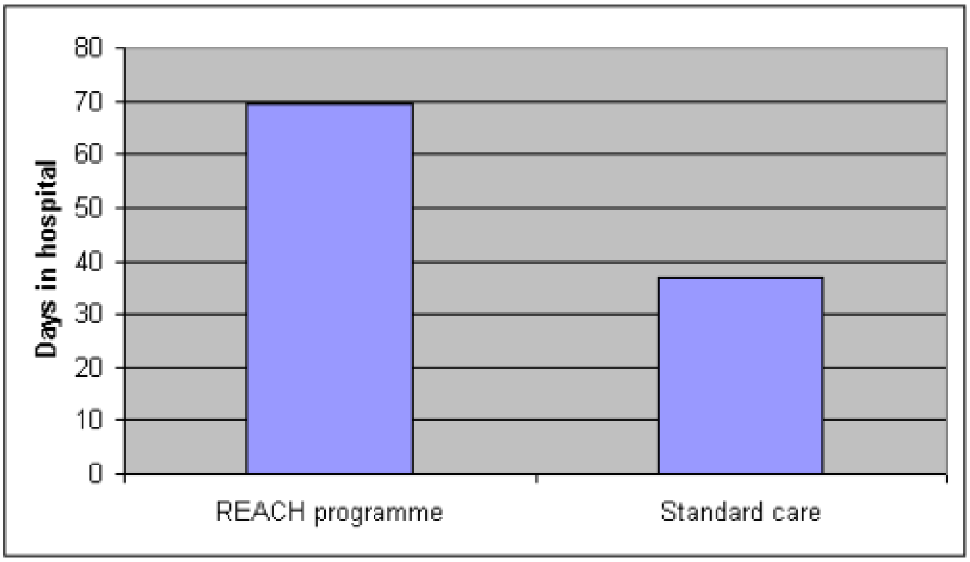
In terms of insight there was no significant difference in recognition of need for treatment (*t* = 0.76, P = 0.45), ability to relabel symptoms (*t* = -0.09, P = 0.92), recognition of illness (*t* = 0.81, P = 0.42) or total insight score (*t* = 0.57, P = 0.57) between the patients who attended the programme and those who received standard care. They were also indistinguishable in terms of in attitudes to medication (*t* = -1.19, P = 0.25) and concordance with medication (c2 = 1.38, P = 0.24). Similarly, there was no significant difference in psychopathology (PANSS Positive *t* = 1.39, P = 0.18; PANSS Negative *t* = 1.48, P = 0.15; PANSS Total *t* = 1.63, P = 0.11), GAF score (*t* = -1.17, P = 0.10) or the presence of comorbid substance misuse (c2 = 0.42, P = 0.52) between the two groups at follow-up.

Hospital admissions and bed days

When we compared the number of hospital admissions and in-patient days between groups we did not include initial hospitalisation data in our analysis as patients were only referred to the programme after assessment by their treating team. Consequently, patients admitted to hospital at the time of their first-episode of psychosis did not commence the REACH programme until they were discharged and including their initial admission data might have biased our results. The group of patients who received standard care evidenced statistically significant fewer hospital admissions (*t* = 2.98, P = 0.004) and a lower total number of in-patient days (*t* = 0.004, P = 0.005) compared to those who completed the REACH programme (Figures 1 and 2).

Figure I. Mean number of hospital admissions among patients who completed the REACH programme (N = 19) and those who received standard care (N = 77)

Figure II. Mean number of days in hospital among patients who completed the REACH programme and those who received standard care (N = 77)



Discussion

The main finding of this study was that patients who attended a psychosocial rehabilitation programme (REACH programme) evidenced a greater improvement in quality of life compared to those who received standard care. Those who undertook the programme had significantly poorer functioning in terms of their quality of life at first presentation especially in the areas of occoupational and social functioning than those who did not undergo the programme. However, after completing the programme their self-report and observer rated quality of life was indistinguishable from those who received standard care. Furthermore, the beneficial effect was maintained for over two years after completion of the programme. The improvement in quality of life among patients who completed the programme reflects the integrative nature of psychosocial rehabilitation programmes (Bachrach, 1992). The environmental focus of such programmes provides patients with the learning and skills necessary for societal integration, which is reflected in improved quality of life at follow-up.

The potential benefits of the psychosocial rehabilitation programme may not extend into reduced use of hospital beds as patients who completed the programme evidenced an increased number of readmissions and days spent in hospital at follow-up. A number of factors may explain this. Firstly, patients who completed the programme evidenced poorer functioning at first-presentation and may represent a poorer prognostic group compared to those who received standard care. The use of hospital readmission and bed days could also be criticised as admission rates are influenced by factors independent of clinical condition, such as adequacy of social and family / carer supports, structure of local services and local discharge policies (Ni Nuallain, 1987; Aberg-Wisteldt, 1995). Consequently, differences in admission rates across outcome studies may simply reflect the development of community-based services with different ‘thresholds’ for hospitalisation. Furthermore, psychoeducation was an important component of the REACH programme and patients were informed about signs of relapse and advised to avail of psychiatric services when unwell.

A further reason behind the shortage of research in this area may lie with the increased emphasis on pharmacotherapy in the treatment of schizophrenia. With the advent of newer atypical antipsychotics has come an increase in annual prescription drug expenditures (Kleinke, 2000). Although there is little doubt that these medications are cost-effective (Revicki, 1999; Kleinke, 2000) the recent escalation in medication expenses (Mehl & Santell, 2000) puts a significant strain on mental health care budgets. Consequently, resources for other services, particularly rehabilitation services, are invariably reduced as these resources are directed to pay for these medications (Baker, 2001). Clearly the reduction of these services is problematic for patients suffering from the psychosocial sequelae of chronic mental illness. Paradoxically, the reduction in services may also serve to further escalate medication expenses, as physicians may attempt to treat psychosocial problems with higher doses of medications (Baker, 2001).

There are a number of methodological limitations in this study. Firstly, this was an open study and the rater (P.W.) was not blind to whether a patient completed the programme or received standard care. Additionally, patients were not randomised to either arm of the study, as the REACH programme was open to all patients presenting with a first-episode of psychosis. Treating teams made referrals, which raises the possibility of a selection bias as patients who evidenced the greatest functional impairment in terms of their quality of life were more likely to be referred. This is not surprising as the programme was designed to help the more severely affected individuals who did not achieve adequate response from conventional treatments such as antipsychotic medication.

We did not have a formal ‘placebo’ treatment and it could be argued that the improvements noted are due to increased time spent in contact with the services and not the REACH programme per se. However, there are limitations inherent in psychotherapeutic control groups as psychosocial intervention research raises difficult ethical issues in terms of consent, confidentiality, boundary violations and risk-benefit issues (Saks, 2002). Our first-episode study was a best practice study and therefore we were bound by ethical considerations.

The modest sample size, especially in the intervention group, is a further limitation. This was the result of limiting our sample to cases presenting with a first-episode of psychosis. All patients were diagnosed by using the Structured Clinical Interview for DSM-IV (SCID 1 Interview) rather than case note review and included patients never admitted to an in-patient facility. Even though the sample size increases the risk of a type II error we were nevertheless able to control for potential confounding factors such as variable durations of illness and treatment.

Conclusion

Even though pharmacological treatment reduces psychopathology among patients with psychosis, it does not appear to have a positive impact on a client's living skills unless it is combined with rehabilitation interventions (Attkisson, 1992). The effectiveness of such intervention has often been questioned and research has been hampered by, amongst other things, patient selection with previous studies drawing on patients at different stages of illness with different durations of treatment. This study supports the use of psychosocial interventions for patients recovering from psychosis. However, the potential benefits of such interventions may not extend into reduced use of hospital beds. The field of psychosocial rehabilitation has been forced out on a limb and has tended to become an isolated and viewed as a separate treatment for patients with psychosis. Clinician biases and lack of adequate training are some of the reasons for this (Bachrach, 1996). If we are to offer the most effective treatments to our patients then we must address these issues and view psychosocial treatments as integral parts of treatment for the major psychoses.

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Peer Support: What Makes It Unique?

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Abstract

Peer support in mental health has recently gained significant attention. There is increasing talk about funding and credentialing, standards and outcomes. But what is peer support and how is it different than services, even services delivered by people who identify themselves as peers? In this paper we would like to present a perspective on peer support that defines its difference and also maintains its integrity to the movement from which it came. We will offer some thinking about practice and evaluation standards that may help different types of peer initiatives sustain real peer support values in action.

Introduction

Peer support for people with similar life experiences (e.g., people who've lost children, people with alcohol and substance abuse problems, etc.) has proven to be tremendously important towards helping many move through difficult situations (Reissman, 1989; Roberts & Rappaport, 1989). In general, peer support has been defined by the fact that people who have like experiences can better relate and can consequently offer more authentic empathy and validation. It is also not uncommon for people with similar lived experiences to offer each other practical advice and suggestions for strategies that professionals may not offer or even know about. Maintaining its non-professional vantage point is crucial in helping people rebuild their sense of community when they've had a disconnecting kind of experience.

Peer support in mental health however has a more political frame of reference. Whereas some support group's form around the shared experience of illness, peer support in mental health grew out of a civil/human rights movement in which people affiliated around the experience of negative mental health treatment. (e.g. coercion, over-medication, rights violations, as well as an over-medicalized version of their "story"). In other words, the shared experience has had more to do with responses to treatment than the shared experience of mental illness. The Independent Living Movement has been the quintessential guide to this way of thinking.

The Independent Living Movement grew out of a reaction to social, physical, and treatment barriers for people primarily with physical disabilities. It arose at a time when other movements were gaining headway in establishing rights for oppressed groups of all kinds. Through a strategic advocacy initiative, the Independent Living Movement focused on three general areas: The first, to enforce the civil and benefit rights for people with disabilities; second, to develop a way of thinking created by people with disabilities; and third, to create alternative services and advocacy centers (Deegan, 1992; DeJong, 1979).

Dejong (1979) writes:
According to the IL paradigm, the problem does not reside in the individual but often in the solution offered by the rehabilitation paradigm- the dependency-inducing features of the …professional-client relationship…The locus of the problem is not the individual but the environment that includes not only rehabilitation process but also the physical environment and the social control mechanism in society-at large (pg 443).

In identifying the critical elements of peer support Solomon (2004) reminds us, "Consumer provided services need to remain true to themselves and not take on the characteristics of traditional mental health services (pg 8)." Campbell (2004) also notes that "consumer operated programs should present an alternative worldview (pg 32)." So what does it mean to stay true to itself, to provide a different worldview? Identifying skills and ingredients that support this difference will help in determining what constitutes "good outcomes" for peer programs. It will help us to become more self-evaluative and therefore continuously build on emerging knowledge, and it will help us simply to challenge, "how we've come to know what we know."

Critical Ingredients literature

There have been many recent studies exploring the 'critical ingredients' of peer support. Findings are congruent with the IL framework and offer both structure and process standards (Holter et al., 2004; Solomon, 2004; Hardiman, 2004). Structural standards are elements of peer initiatives that define the basic rules and how the group is constructed. They include being free from coercion (e.g. voluntary), consumer run and directed (both governmentally and programmatically), an informal setting with flexibility, non-hierarchical, and non-medical approach (e.g. not diagnosing, etc) (Solomon, 2004; Salzer, 2002; Holter et al., 2004; Clay, 2004; Campbell, 2004; Hardiman, 2004). Process standards are more like beliefs, styles and values. They include:

- The peer principle (finding affiliation with someone with similar life experience and having an equal relationship)
- The helper principle (the notion that being helpful to someone else is also self healing)
- Empowerment (finding hope and believing that recovery is possible; taking personal responsibility for making it happen)
- Advocacy (self and system advocacy skills), choice and decision making opportunities, skill development, positive risk taking, reciprocity, support, sense of community, self help, and developing awareness (Campbell, 2004; Clay, 2004).

While these ingredients are clearly essential for maintaining a non-professional relationship, they also may fall short of describing how to provide a true alternative. This is where it becomes crucial that we begin to define those practice elements that really lead to different assumptions about our relationships and ourselves, different ways of thinking about our experience, and ultimately define our unique and valuable role in the larger 'help' arena. We must ask ourselves:

- What is it that we need to offer in order to help people begin to see things in a new way?
- What kinds of relationships really build community?
- How can we construct reciprocal help so that it is not attached to any particular role or interpretation of the

problem (e.g. a non-medical interpretation of the experience)?
Without thinking carefully about these questions it is likely that peer support will be defined and judged within the context of the dominant paradigm. Further, if we can establish some common parameters for all of peer support, it will support peers working in the service delivery system with a unique and fully distinguishable framework for thinking. If this framework becomes more widely known and considered, there should be less likelihood of cooptation. In order to create this identity and way of thinking it may be useful for us to consider some of the skills in peer support that build different kinds of help and ultimately a different recovery outcome.

Achieving difference

Recovery in mental health has most often been defined as a process by which people labeled with mental illness regain a sense of hope and move towards a life of their own choosing (President's New Freedom Commission Report, 2003). While this definition on the surface seems obvious, what remains hidden is the extent to which people have gotten stuck in a medical interpretation of their experiences. With this stuckness comes a worldview in which one is constantly trying to deal with their perception of what's wrong with them instead of what's wrong with the situation. In other words, even if I have hope of moving into a better life, I have been taught to pay a lot of attention to my symptoms. This interpretation of my experiences leaves me constantly on guard for what might happen to me should I start to get 'sick.' Even with recovery skills (learning to monitor my own symptoms), I find myself creating a life that is ultimately guided by something inherently wrong with me. With this understanding, I may continue to see myself as more fragile than most, and different than 'normal' people. I then continue to live in community as an outsider, no matter what goals I have achieved.

Critical learning

As we've noted before, peer support in mental health grew out of an affiliation based on the shared experience of negative treatment. Yet it is the medical model that has given us language, self-definition, an interpretive framework, and a notion of what it means to 'help.' In peer support we may pursue different kinds of conversations in which we start by thinking about "how we've come to know what we know." This means actively examining how we have learned to name our experience, what utility the naming has now and create the ability to step back and think about how that naming may be keeping us stuck.

Following is a typical example of interactions where peer roles often fall short in opening up this new conversation
Helpee: My depression is really acting up lately and my doctor says I need to increase my medication but I don't really want to.

Peer Helper 1: Boy, when my depression starts, I have to take a bit more medication or I get in trouble.

Peer Helper 2: Don't you remember the last time you didn't do what the Doctor said and you ended up in the hospital?

Peer Helper 3 What do you need to say to the Doctor so that he doesn't increase them?

Peer 1 is clearly operating on learned assumptions about help and borders on coercion. Although the second helper's role is more of an advocacy role, it is still presumed that the depression and the medication are the issue rather than what may have happened situationally. We don't learn what constitutes depression vs. sadness or grief, what the medication does and doesn't do, what depression means for that person, or about what is it that's being medicated.

In a different kind of conversation, new ways of thinking about the experience may emerge. For example:
Helpee; My depression is really acting up lately and my doctor says I need to increase my medication but I don't really want to.

Helper: What does it mean for you when you say that your depression is acting up?

Helpee: Well, I'm sleeping more and don't really feel like eating.

Helper: Boy I can remember a time when it seemed like every time I didn't feel too great I would interpret it as depression. I saw it as an illness that I had which meant, at best, that I could only learn to cope with it.. I had learned to think about many of my experiences and feelings through the lens of illness andI started getting kind of afraid of my own reactions. I've had to work at thinking differently so now when I have some of those reactions I simply wonder if it's just my body's way of saying I'm exhausted or frustrated.

Helpee: But the last time I felt like this I ended up in the hospital.

Helper: Was that helpful?

Helpee: Well they changed my medications around and gave me shock treatments…at least I wasn't so depressed anymore.
Helper: I wonder if there are other ways you could think about what you might need when you're feeling tired a lot and not wanting to eat…

Helpee: Like what?

Helper: Well sometimes when I'm doing something new or uncomfortable I don't feel very confident. In the past being uncomfortable led to going to bed and not wanting to eat. Then I'd just call the Doctor and they'd adjust my medication. Now I try to simply let it be ok to be uncomfortable. Instead of going to bed I go to the gym, or I ask myself how others might react if they were feeling uncomfortable about doing something new.

Critical learning doesn't assume a medical definition of the problem and opens us to exploring other ways of thinking about the experience rather than trying to deal with the 'it.' Asking about the phenomena of eating and sleeping vs. calling it depression, we change the direction and consequently the outcome of the conversation. By sharing our own process with this shift we aren't telling the other person what to do but offering our own critical learning experience. In this sharing we are exposing the other person to a potentially larger story, which may help them consider other ways of thinking about what's happening and therefore options that were not previously available.

Mutuality: Redefining help

Everything we have learned about help in the mental health system pushes us to think of it as a one-way process. Even when we refer to the helper's principle we are only talking about role reversal and we simply mean that now that we are in the helper role, we feel better just by providing help. This kind of help continues to maintain static roles of helper and helpee. Further, as Friere (1995) points out it is not uncommon for someone who moves from helpee into helper role to build a sense of confidence and even to abuse power in much the same ways as was done to them. One starts to identify as the more 'recovered' person and begins to see the relationship with his or her peer as one of service. Unfortunately, this dynamic will never really lead to meaningful community integration. Mutual help in peer support (and obviously in community) implies both people taking on both roles with each other. It means sharing our vulnerabilities and our strengths and finding value in each other's help. If we continue with the example above, the conversation might have led to

Helper: I was just on my way to the gym, would you like to come with me? I've actually had some difficulty going alone, I always feel so overly conscious about my body. I feel like everyone's staring.

Helpee turned helper: Wow I used to feel that way and it kept me from even wanting to use the locker room. Finally I just asked myself if I worried about what anyone else looked like. I realized that we all kind of think *about ourselves and decided that probably no one really was paying attention. That thinking took practice, but now I feel pretty comfortable at the gym. I'd be happy to go with you if you think it might help.*

The reciprocal nature of this interaction helps both people see themselves in multiple roles throughout the conversation. It is this level of mutuality that most resembles community type relationships and allows us to move towards full citizenship rather than feeling simply integrated in the community. It is crucial that even with paid peers we must figure out how the relationship can be more mutual and reciprocal. Perhaps we can consider it our job to model peer support rather than to be a provider of service.

Language

Using language that helps explore each individual's subjective experience is important in beginning to redefine recovery. The new use of language, however, becomes especially difficult when we are doing peer support in a traditional setting. When we are working with a team of traditional providers it becomes a much more simple and quick communication to talk about symptoms, illness, coping etc. As peers we find that we are misunderstood if we use other language and in order to feel part of the team, we begin to talk about people in medical terms (sometimes even without the presence of the peer). For example: Dr. A runs into a peer specialist in the hall one day and asks him how Peer One is managing his symptoms. The Peer Specialist says: "gee Dr. A, Peer B seems really symptomatic today." Aside from the fact that this conversation should not be happening without the presence of Peer B the symptom language has generated a set of assumptions that have major implications, and secondly, what are both of their assumptions about symptoms and what constitutes them. Unfortunately, this simple conversation may result in the team deciding to increase peer B's medication.

Different language supports a different conversation as we saw previously. If we avoid the code language of mental health we find that we are having very different conversations, which then require a different type of response. One example of this shift in language might include talking about experiences instead of symptoms, The language of experiences allows not only for unique description of that particular event, it also presumes only one person's interpretation. With this starting point we can explore other ways of knowing as well as reflecting on how the use of medical language keeps us stuck.

As long as we continue to adopt the language of mental health, we are stuck in power structures that impose a narrow meaning on our words and conversations. We then assume a lot about our experiences as they've been interpreted by the traditional system. It becomes easy to talk about "my depression," rather than I'm feeling pretty down and out today. This leaves us with a "thingness" that is intrinsic to us, generalizable to others, and occurs because we have "it." The language and constructs of mental illness begin to limit our much more subjective experience. If we can struggle with the language of the phenomenal, play with metaphor, take the time to really explain to each other, we begin a conversation that is rich with possibility rather than limited by what we know about the illness.

Mutual responsibility

We have talked about the need for mutuality in the peer support relationship but what do we mean by mutuality?

- It is assumed that both people learn from each other
- Both people figure out the rules of the relationship
- Power structures are always on the table and negotiated

In traditional helping relationships, it is assumed that it is primarily up to the helper to take responsibility for making the relationship work. When things are not working so well this kind of dynamic has led helpers to feel like they're 'doing something wrong,' or to blame the other person for not trying. We stop saying what we see, what we need and we begin to disconnect, falling into an assessment and evaluation role rather than working on it together. On the other hand, as patients we have been implicitly taught that we cannot or don't have to take responsibility in a helping relationship. We fall into believing that we are victim to our own reactions and then wonder why people disconnect or take over when we say things like "I'm suicidal."

In peer support relationships it is important to remember that it is not our task to assess or evaluate each other but rather to say what we see (our perspective), what we feel, and what we need to build connection. For example,
Peer 1 : I can't go with you today, I'm really suicidal

Peer 2: When you talk in the language of suicide I feel kind of scared and a little bit frustrated. If you're feeling lousy and don't want to go out with me, I need for us to figure out a way to talk about it differently.

In this scenario rather than starting a suicide risk assessment, we are once again exploring the use of language without presuming it means imminent action. We bring the relationship back to negotiating what will work for both of us and we remember that both our needs are important.

Redefining safety: Sharing Risk

We cannot talk about doing something fundamentally different until we address the topic of safety and the fact that it's simply come to mean risk assessment in the field of mental health. We've been asked, "Are you safe, will you be safe, will you sign a safety contract? As recipients this has left many of us feeling quite fragile, out of control, and has left us thinking of safety as simply soothing someone else's discomfort. If we don't begin to address issues of risk and power, we cannot help but replicate many of these dynamics in peer support.

For most people a sense of safety happens in the context of mutually responsible, trusting relationships. It happens when we don't judge or make assumptions about each other. It happens when someone trusts/believes in us (even when they're uncomfortable), and it happens when we are honest with each other and own our own discomfort. It is with this interpretation of safety that we can begin to take risks and practice alternative ways of responding. We can choose who to be with, when we can be there, and we can begin to talk about shared risk. Sharing risk in peer support tackles the issue of power, what it's like to lose it, abuse it, or balance it. We talk about how we each are likely to react when we feel untrusting or disconnected. We begin to pave the way for negotiating the relationship during potentially difficult situations. This level of honesty works well in trusting relationships but is critical to the health of a peer support group or program.

Staying on track

When we think about how to stay on track, how to not drift back to old ways of doing and being, one helpful process can be to formulate standards specific to peer support. The standards would represent statements about the alternative worldview that peer support tries to create - the ideal, or 'what ought to be' in the helping relationships. While we have addressed some of the current efforts in exploring 'critical ingredients' earlier in this paper, here we would like to offer further thinking about developing standards specific to peer support.

First, the kind of knowledge peers bring into the support relationship can be best characterized as practical knowledge, or a lived knowledge from which learning and understanding are embedded in contextualized lived experiences (Schwandt, 2002). When persons operate from this kind of lived knowledge, sometimes what is known is not necessarily evident, but rather is expressed through common values and stories that have been formulated through participation in a shared historical community – in this case that of being persons who have received mental health services.

So when peer support communities explore how they are different and what they know, the sophistication of the knowledge they posses is often not easily brought to the surface. The challenge presented in developing standards for peer support is in finding ways to translate practical knowledge into clear accounts of "what is the ideal" and why this is so. This 'realizing process' goes beyond soliciting information from peers related to how they act - to digging deep to discover what each and all peer supporters know.

Second, peer support knowledge is passed on through an oral culture and storied ways of meaning. This means that being attuned to the practical knowledge of peer support will require adopting a narrative framework for articulating peer support standards (MacNeil & Mead, 2004). It is a good method of fit. This can get very tricky when peer support practices are under the umbrella of traditional service organizations or when peer organizations are providing traditional services. Sometimes it can be difficult to tease out whose narratives are really being represented.

As one example, an organization can be viewed as a collection of people who interact with one and other primarily through dialogue (Cambell, 2000). In this dialogue they have the opportunity to constrain or influence each other's way of thinking and acting – and it is inevitable that this collection of people creates the organizational belief system. And within the organizational belief system there are more influential or dominant narratives that steer the activities of the organizational culture. In this regard, narratives are both structures of power and meaning (Bruner, 1984).

In initiating the development of standards in peer services or support communities, it can be very helpful to discuss within an organization the kinds of discourse that guide their activities. With that, we can then reflect upon whether these organizational narratives more so represent the attributes of peer support or if (consciously or unconsciously) they reflect a drift towards more traditional service practices. This process of examination also can create and reinforce a platform for mutually responsible dialogue.

Our third thought about standards development takes a transformative stance (Mertens, 2005). We assume it is possible to transcend thinking and practices that have been shaped by the lens of dominant narratives or power structures through the process of developing standards for peer support. Elevating different or historically marginalized narratives can help us to redefine the problem, seek new solutions and step outside of the box in our thinking about program standards. Likewise, creating processes of deliberation among organizational participants who hold different viewpoints about 'what ought to be,' and whose viewpoints are situated from different positions of power, can have positive influences on shaping shared understandings about standards, and can serve to better represent traditionally disenfranchised narratives (House & Howe, 1999; MacNeil 2002).

The possibility also exists to broaden the scope of evidence-based practices. Evidence-based practices have mostly been described by their program structures (staffing, case load size, etc.) and have overlooked the ingredients of the helping processes that occur within each practice and which research has shown to be related to how people change and grow (Anthony, 2003). Thinking further about standards of peer support guided by the constructs offered in this paper (*Achieving Difference, Critical learning, Mutuality: Redefining help, Language Use, Redefining safety: Sharing risk)* will help us to push our thinking around the parameters of evidence-based practices and to frame how peer support is different from other services – whether professionals or peers provide them.

Last of all, we have given some forethought to next steps beyond developing standards, those involved in creating 'measurement' strategies that are coherent with the values and standards of peer support. We must remember that the history of peer support shows us a culture that emerged as a response to doing things differently. Peer support programs are not intended to be routine mental health practices. It seems to us then, that the measurement of peer support standards should also look and feel very different. The fidelity of peer support is embedded in its storied culture and consideration should be given to developing narrative measurement strategies that can be acculturated into peer practices – the method of fit will also help to sustain the evaluative practices overtime. This is a future challenge for the field of evaluation and peer support programs.

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Peers working in services: Can we do peer support?

There is currently a national trend towards integrating peer services within the traditional delivery system. Certified peer specialists are funded through various Medicaid and VR waivers and recipients are finding meaningful support with their paid peers. Clearly this role has been beneficial in acknowledging the expertise of lived experience. It has also offered recipients a forum to speak about their experience differently, be exposed to strong role models, and develop new skills and strategies to help them heal and recover.
Peer services, if done well, can provide hope, role modeling and simple safe strategies for recovery.

While the task of the peer provider may coincide with the task of peer support, (e.g. working on recovery strategies, or sharing like experiences), there may also be times where the peer provider simply is not allowed to challenge the medical description of the client's experience. While empowerment and self-advocacy are important tools one can learn from a peer provider, it is not likely that a conversation may entail the "deconstruction" of the client's experience. One can't both work for the medical system and refute its very foundation.

With the development of this practice of doing peer support we can begin to help peer providers create a platform from which to offer their unique perspective. Perhaps it is here, with this new influence, that other providers may also begin to question the over-medicalization of people's experience. Either way, it is important that we don't lose sight of true peer support in our efforts to 'legitimize it.'

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Prevalence and Correlates of Cognitive Impairment in Stroke Patients in a Rehabilitation Setting

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Abstract:

Background: Stroke is associated with considerable physical and psychological impairment. Cognitive impairment in stroke patients is associated with adverse outcomes during their rehabilitative process. Identifying the baseline factors associated with cognitive impairment in stroke patients would help the multidisciplinary team involved in the rehabilitative process to maximize the functional recovery of stroke patients.
Aim: The aim of the study was to ascertain the prevalence of cognitive impairment and its baseline determinants in the rehabilitation settings.
Methodology: A cross- sectional study of 200 stroke patients was conducted in two community (rehabilitation) hospitals. Assessments were made on admission to the hospitals which besides including information on sociodemographic, clinical and neurological variables also included assessment of functional and neurological impairment, depression and cognitive impairment. Validated tools of assessment were used in the study, viz. NIHS for neurological impairment, Barthel Index for functional assessment. AMT for cognitive impairment and GDS for depression.
Results: On admission 54.5 % of the patients were with cognitive impairment. In multivariate analyses, the independent significant predictors of cognitive impairment were age more than 81 years (OR=6.78, 95% C.I. 2.34, 19.64), lesser education (OR=4.73, 95% C.I. 1.41, 13.11), severe neurological impairment on admission (OR=5.00, 95% C.I. 1.70, 14.67) and depression on admission (OR=3.19, 95% C.I. 1.61, 6.30).
Conclusion: Considerable proportion of stroke patients present with cognitive impairment during their rehabilitation which in turn is significantly determined by modifiable baseline factors like depression. Judicious identification of this group of patients would maximize the recovery of stroke patients.

Introduction

Stroke is a disease with considerabe physical [1,2] and psychosocial impairments. [3-7]

Dementia and cognitive impairment are such psychological impairments in stroke patients which besides having as high a prevalence of and 17-38% [3-7] respectively are also associated with many short and long term poorer outcomes including poorer functional recovery in stroke patients. [8-10]

Adopting clinical diagnostic criteria like DSM-1V for dementia may miss out the cases among the stroke patients who are cognitively impaired but not demented known as “cognitive impairment, no dementia” (CIND), [11] which besides being an important challenge in dementia epidemiology also has consistently been reported as a correlate of poorer functional recovery in stroke patients.[8-10] Low et al [11] in their cross-sectional survey observed that 33.3% were cognitively impaired but not demented (CIND) 2.4% had possible dementia and 64.3% of the subjects were cognitively normal.

Though the prevalence of cognitive impairment in stroke patients is high and is associated with adverse effects on the rehabilitative outcomes still there is a lack of consensual agreement regarding determinants of cognitive impairment e.g. increasing age was found to be a significant correlate of post stroke cognitive impairment by Allan et al. [12] but T.K. Tatemichi [13] did not find increasing age to be significantly associated with post stroke cognitive impairment. Likewise R.M. Parekh et al [14] did not find significant relationship between depression and cognitive impairment but R.G. Robinson et al [15] found a significant relationship between cognitive deficits and depression in stroke patients.

Knowledge about such baseline modifiable and non-modifiable determinants of cognitive impairment in stroke patients would help the multidisciplinary team involved in the rehabilitative process of stroke patients to adopt an appropriate treatment modality to reduce the burden of cognitively impaired stroke patients which in turn will help maximize the functional recovery of stroke patients during their rehabilitation.
The aim of the study was to ascertain the prevalence and baseline determinants of cognitive impairment in stroke patients.

Methods and Materials

Methods

Patients

A cross-sectional study was conducted on 252 stroke patients who were consecutively admitted into two rehabilitation hospitals in Singapore during the period from April 2002 to September 2002. The patients satisfied the WHO criteria for defining stroke (defined as a condition characterised by rapidly developed clinical signs of focal disturbance of cerebral function lasting more than 24 hours with no apparent cause other than vascular origin). All the patients in the study gave informed consent for participation in the study. We excluded 48 patients with severe dysphasia because the measurement tools used in the study required participants to be able to communicate. Another four patients refused participation, hence 200 patients fulfilled the inclusion criteria for enrolment into the study.

Measurements

Information obtained on admission for 200 patients included *socio-demographic variables* (age, gender, ethnicity, marital status, education level, living arrangement , presence of caregiver). *Clinical variables* extracted from clinical case records included presence of cardiovascular risk factors, viz. smoking, hypertension, hyperlipidaemia, diabetes, ischemic heart disease and atrial fibrillation, visual impairment and hearing impairment. *Neurological variables* included stroke lesion type (ischemic vs haemorrhagic), location of stroke (cortical versus non-cortical), side (left or right sided) and distribution (unifocal or multi-focal) based on CT head reports, and whether the stroke was recurrent. Post-stroke urinary incontinence (defined as involuntary loss of urine in a post-stroke patient), dysphagia (as diagnosed by a swallowing therapist), aspiration pneumonia (as diagnosed by a clinician) and post-stroke seizures (excluding those with pre-existing epilepsy), on-admission Ryle's tube and urinary catheterization.

On admission the patients were assessed on neurological, depressive symtoms, cognitive status, and physical functioning using the National Institute of Health Stroke Scale (NIHSS), Geriatric Depression Scale (GDS-15), Abbreviated Mental Test (AMT) and Barthel Index (BI).
Neurological and functional assessment was performed by a physician (SKS) and questionnaire interviews were performed by a trained research nurse, with translations for non-English speaking patients.

NIHSS: Assesses level of consciousness, horizontal gaze, visual fields, facial palsy, motor strength, ataxia, sensory system, language, dysarthria and extinction or inattention. The scale scores range from 0 to 42, with 42 denoting the most severe neurological impairment. The NIHSS has been shown to have high intra and inter-rater reliability 16, and predict long-term stroke outcome17, and post-acute care disposition among stroke patients[18]. Three categories of neurological impairment, namely mild, moderate and severe, were defined with the following cut-off values: mild impairment = 1-6, moderate impairment = 7-12 and severe impairment = 13-42.

GDS: The 15-item short form version of the Geriatric Depression Scale (GDS-15) was used to assess depressive symptoms. The short-GDS has been found to be a suitable instrument to screen for depression in the general population 19 and validated for use in the elderly Chinese population locally[20]. It has scores ranging from 0 to15, with a score of 5 to 10 indicating mild depression and a score of 11 to 15 indicating severe depression.

Abbreviated Mental Test (AMT) : was used to assess cognitive impairment. In elderly patients, AMT has been shown to give good predictive validity of cognitive impairment and dementia[21] and has been validated in local settings by Sahadevan et al.[22] The 10-item scale gives scores ranging from 0 to10 with a score of 7 or less indicating cognitive impairment.

Barthel Index: Physical functioning and disability was assessed by the Barthel Index (BI) [23] for independence in activities of daily living (grooming, transfer, walking, bladder and bowel control, dressing, climbing stairs, feeding and bathing) which has been validated and is widely used in stroke patients[24]. The scores of the scale range from 0 to 100, with a score of 100 denoting complete independence. Three ordinal categories of functional disability were defined using the following cut-off values: (1) severe: 0-50; (2) moderate: 51-75; (3) mild to no impairment: 76-100. ADL dependence upon admission, upon planned discaharge and at six months after stroke onset was defined as Barthel Index score ≤ 50.

Statistical Analysis:
Besides ascertaining the prevalence, the baseline factors predicting post stroke cognitive impairment were ascertained and modeled using Logistic Regression analyses. Significant baseline variables identified from univariate analyses were included in the final regression model using forward selection procedures for entry at p=0.05 and removal at p=0.10. The strengths of association of the predictors were expressed as the odds ratios and their 95% confidence intervals.

Results:

Patient characterstics
The patients in the study were aged between 40 and 96, mean 71.5 (S.D. = 10.5); 54% were males; 88% were Chinese, 7% Malays, and 5% Indians; 50% were married, 7% were unmarried and 43% were either widowed or divorced. Among them, 10% were living alone, 12.5% did not have an identifiable care giver.

Visual and hearing impairment were present in 10% and 5% of the patients. The prevalence of cardiovascular risk factors and co-morbidities were: hypertension: 87%; diabetes: 47%; smokers: 45%; ischemic heart disease: 22%; atrial fibrillation: 7%; hyperlipidaemia: 72%. The stroke lesions were hemorrhagic in 12.5% of the patients, and cortical in 28%; 47% had left sided lesion; multifocal 49%; 42% had recurrent stroke. Among the patients, 25% had post-stroke dysphagia, 59% urinary incontinence, 5% aspiration pneumonia; 2% epilepsy. Neurological impairment was assessed according to the NIH scale as mild in 47% of the patients, moderate in 36% and severe in 16% of the patients. On admission, 60% of the patients were with depressive symptoms and 54% were cognitively impaired.

Prevalence of cognitive impairment:
On admission 109/200 (54.5%) of the patients were cognitively impaired.

Univariate analysis of factors associated with cognitive impairment on admission
On univariate logistic regression the factors significantly associated with cognitive impairment on admission were (**Ref. Table 1**): *Socio-Demographic variables:*
(a) Age: 66-80 years (O.R.-2.03, 95%C.I.-1.06, 3.81); < = 81 years (O.R.-6.09 95%C.I.-2.42, 15.42); (b) Gender: Females (O.R.-1.83, 95%C.I.-1.04, 3.23) (c) Marital Status: Widow/er, Divorced/ee: (O.R.-1.88, 95%C.I.-1.04, 3.32). (d) Educational Level: < = secondary level (O.R.-4.52, 95%C.I.-1.91, 10.66)

Clinical Variable: (a) Depression (O.R.-4.23, 95%C.I.-2.31, 7.73). (b) Severe functional impairment: Severe (O.R.15.72, 95%C.I.-1.89, 130.44)
Neurological variable: (a) Moderate Neurological impairment (O.R.-2.96, 95%C.I.-1.57, 5.58) *(b)* Severe Neurological impairment (O.R.-7.10, 95%C.I.-2.66, 18.91) (c) On admission Ryle`s tube: (O.R.-5.81, 95%C.I.-1.93, 17.51) (d) Urinary incontinence: (O.R.-3.51, 95%C.I.-1.94, 6.33) (e) Post stroke aspiration pneumonia: (O.R.-8.06, 95%C.I.-1.002, 64.66)

Table 1: Univariate Analysis of the factors associated with cognitive impairment on admission:

Socio Demographic Variables		Cognitively Impaired No: 109(54.5%)	Normal Cognition No: 91(45.5%)	p	O.R.	95%C.I.
Age:	> = 65 yrs.	24 (22.0)	39 (42.8)		*1.00*	
	66-80 yrs.	55 (50.4)	44 (48.3)	*<0.05*	2.03	1.06,3.81
	< = 81 yrs.	30 (27.5)	8 (8.7)	*<0.01*	6.09	2.42,15.42
Gender:	Male	52 (47.7)	57 (62.6)		*1.00*	
	Female	57 (52.2)	34 (37.3)	*<0.05*	1.83	1.04, 3.24
Ethnicity:	Chinese:	95 (87.1)	82 (90.1)		*1.00*	
	Malay	9 (8.2)	5 (5.4)	NS	1.55	0.50, 4.8
	Indian	5 (4.5)	4 (4.3)	NS	1.07	0.28, 4.1
Marital Status:	Married:	49 (44.9)	52 (57.1)		*1.00*	
	Unmarried	5 (4.5)	8 (8.7)	NS	0.66	0.20, 2.1
	Widow/Divorced	55 (50.4)	31 (34.0)	*<0.05*	1.88	1.04, 3.3
Educational Level:	> Secondary:	8 (7.3)	24 (26.3)		*1.00*	
	< = Secondary	101(92.6)	67 (73.6)	*<0.01*	4.52	1.91,10.66
Living Arrangement:	Living with someone:	101 (92.6)	79 (86.8)		*1.00*	
	Living Alone	8 (7.3)	12 (13.1)	NS	0.52	0.20, 1.33
Care Giver:	Present:	99 (90.8)	76 (83.5)		*1.00*	
	Absent:	10 (9.1)	15 (16.4)	NS	0.51	0.21, 1.20

Clinical Variables						
Visual Impairment:	Present:	12 (11.0)	8 (8.7)	NS	1.28	0.50,3.29
	Absent:	97 (88.9)	83 (91.2)		*1.00*	
Hearing Impairment:	Present:	4 (36.6)	6 (6.5)	NS	0.54	0.14, 1.97
	Absent:	105 (96.3)	85 (93.4)		*1.00*	
Hypertension:	Present	97 (88.9)	78 (85.7)	NS	1.34	0.58, 3.11
	Absent:	12 (11.0)	13 (14.2)		*1.00*	
Diabetes Mellitus:	Present	54 (49.5)	40 (43.9)	NS	1.25	0.71, 2.18
	Absent:	55 (50.4)	51 (56.0)		*1.00*	
Smoking:	Present	49 (44.9)	42 (46.1)	NS	0.95	0.54, 1.66
	Absent:	60 (55.0)	49 (53.8)		*1.00*	
*Ischemic Heart Dis*ease:	Present	30 (27.5)	15 (16.4)	NS	1.92	0.96, 3.85
	Absent:	79 (72.4)	76 (83.5)		*1.00*	
Atrial Fibrillation:	Present	10 (9.1)	4 (4.3)	NS	2.19	0.66 ,7.25
	Absent:	99 (90.8)	87 (95.6)		*1.00*	
Hyperlipidaemia:	Present	78 (71.5)	66 (72.5)	NS	0.95	0.51, 1.77
	Absent:	31 (28.4)	25 (27.4)		*1.00*	
Depression:	Present:	82 (75.2)	38 (41.7)	*<0.01*	4.23	2.31, 7.73
	Absent:	27 (24.7)	53 (58.2)		*1.00*	
Functional Impairment:	Mild:	1 (0.9)	8 (8.7)		*1.00*	
	Moderate	37 (33.9)	47 (51.6)	NS	6.28	0.75, 52.37
	Severe:	71 (65.1)	36 (39.5)	*<0.05*	15.7	1.89 ,130.44
Neurological Variables						
Lesion Type:	Hemorrhage	12 (9.1)	13 (14.2)		*1.00*	
	Infarction:	97 (88.9)	78 (85.7)	NS	1.34	0.58, 3.11
Lesion Location:	Cortical:	37 (33.9)	20 (21.9)		*1.00*	
	Non Cortical	66 (60.5)	61 (67.0)	NS	0.58	0.30, 1.11
Lesion Distribution:	Focal:	49 (44.9)	36 (39.5)		*1.00*	
	Multifocal:	53 (48.6)	46 (50.5)	NS	0.84	0.47, 1.51
Recurrent CVA:	Yes:	18 (16.5)	18 (19.7)	NS	0.79	0.38, 1.64
	No:	89 (81.6)	71 (78.0)		*1.00*	
Neurological Impairment:	Mild:	36 (33.1)	59 (64.8)		*1.00*	
	Mod.:	47 (43.1)	26 (28.5)	*<0.01*	2.96	1.57, 5.58
	Severe:	26 (23.8)	6 (6.5)	*<0.01*	7.10	2.66, 18.91
On Adm. Ryle`s Tube:	Present:	23 (21.1)	4 (4.3)	*<0.01*	5.81	1.93, 17.51
	Absent:	86 (78.8)	87 (95.6)		*1.00*	
Dysphagia:	Present	32 (29.3)	18 (19.7)	NS	1.68	0.87, 3.26
	Absent:	77 (70.6)	73 (80.2)		*1.00*	

Urinary Incontinence:	Present:	79 (72.4)	39 (42.8)	*<0.01*	3.51	1.94, 6.33
	Absent:	39 (35.7)	52 (57.1)		*1.00*	
Aspiration Pneumonia:	Present:	9 (8.2)	1 (1.0)	*<0.05*	8.06	1.00, 64.6
	Absent:	100 (91.7)	90 (98.9)		*1.00*	
Epilepsy:	Present:	1 (0.9)	3 (3.2)	NS	0.27	0.02, 2.66
	Absent:	108 (99.0)	88 (96.7)		*1.00*	

Multivariate analysis of the factors associated cognitive Impairment in stroke patients on admission: (Ref. Table 2)
The significant predictors were: (a) Age more than 81 years (O.R. - 6.78, C.I. - 2.34, 19.64) (b) Education less than equal to secondary level (O.R.-4.73, C.I. - 1.41, 13.11) (c)Severe neurological impairment (O.R.- 5.00, C.I. - 1.70, 14.67) (d) Depression (O.R.-3.19; C.I.-1.61, 6.30)

Table 2: Multiple forward logistic regression of cognitive impairment on admission in stroke patients*

Variables		**Beta**	**p**	**O.R.**	**95% C.I.**
Age:	> = 81 years	1.91	<0.01	6.78	2.34, 19.64
Education:	Less than equal to Sec. Level	1.55	<0.01	4.73	1.41 , 13.11
Neurological Impairment:	Severe	1.61	<0.01	5.00	1.70, 14.67
Depression:	Present:	1.16	<0.01	3.19	1.61, 6.30

* at probability of entry at 0 .05 and removal at 0.10

Discussion

In this study we have been able to identify the group of stroke patients who upon their admission to rehabilitation settings are cognitively impaired and their baseline correlates. This group of patients is likely to make lesser functional recovery.

One of the main aims of the study was to ascertain the significant determinants of cognitive impairment in stroke patients.

We observed that increasing age, lesser education, severe neurological impairment and depression were significant determinants of cognitive impairment in stroke patients. Severe stroke at onset has been consistently reported to be a significant correlate of post stroke cognitive impairment. [25, 26] This suggests that stroke induced brain injury affects cognition as well. However the domains of neurological impairment affecting the cognition in stroke patients should be identified so that more concerted efforts can be mounted for better recovery from neurological and cognitive impairment.

Likewise consistent with previous observations we found increasing age and lower educational level [13, 27] to be significant correlates of post stroke cognitive impairment. The probable reasons for this could be because with the increasing age there may be a concomitant degenerative process setting in and the lower educational level may be associated with lesser mental reserve.

In our study we found depression to be a significant correlate of cognitive impairment. Till to date the intricate relationship between cognitive impairment and depression remains largely unclear. Hence an

independent long-term longitudinal study to evaluate a temporal relationship between the two would help understand the topic better as more concerted efforts may then be applied to identify and treat the entity which is causative of the other outcome.
Lack of association between functional disability and post stroke cognitive impairment has also been reported previously[28] which suggests that post stroke cognitive impairment is mainly the result of stroke induced neurological injury.

Post stroke ryles tube insertion and urinary incontinence were a significant correlates of cognitive impairment in univariate analysis but given the presence of barthel index scale, were not independent correlates as each of these domains are measured separately on the barthel index scale. Likewise vascular risk factors were not a significant correlate of post stroke cognitive impairment in our study as has also been reported previously. [29]

In conclusion considerable proportion of stroke patients present with cognitive impairment in the rehabilitation settings and that cognitive impairment in stroke patients is determined by modifiable factors like depression. Hence by judiciously identifying this group of patient the functional recovery of stroke patients can be maximized.

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The Use of Volunteers to Promote Community Integration for Persons with Serious Mental Illness

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Abstract

Social isolation is one of the greatest problems that people with a severe mental illness encounter while trying to reintegrate into the community. The Quality of Life Program is a project whereby volunteers are matched with residents living in foster homes to help them improve their social interaction, identify and build upon their strengths, promote autonomy and personal responsibility for change, and assist them on their road to recovery. This study reports on the evaluation of the initial implementation of this project and identifies its strengths and weaknesses. The concept of using volunteers as partners in the provision of services to persons with an SMI should be considered when developing programs for this population.

Introduction

Social isolation is one of the greatest problems that people with a severe mental illness (SMI) encounter. Individuals with SMI have great difficulty building and sustaining social networks and are likely to have limited social networks (Brown, 1996). Isolation, poor social functioning and poor quality of life are among the consequences experienced by those with SMI (Oliver et al., 1996). This group of people frequently has no friends, spouse, nor family with whom they are in contact. Although mental health service providers are committed to providing quality services to consumers with SMI, most consumers are frustrated and struggle with problems related to inadequate resources and a service system that does not always facilitate their recovery.

Prompted by the recognition that natural social networks for individuals with SMI are limited (Jablensky et al., 2000) and that traditional service delivery is deficient in providing appropriate support and social services (Senate of Canada, 2004), interest in volunteer programs has increased considerably during the past decade. Volunteers from the community can play a significant role in working with individuals with SMI. Evidence suggests that they are particularly cost-effective as they can supplement and extend the work of mental health professionals through individualized support for consumers and/or resource development. (Canadian Centre for Philanthropy, 2004)

The purpose of this article is to present the findings of an evaluation of a newly implemented volunteer program for persons with a serious mental illness, The Quality of Life Program, which was developed at the Douglas Hospital; a university affiliated psychiatric hospital in southwest Montreal, Canada. The Quality of Life Program was designed to operate within a network of 150 supervised residential settings (foster homes) which served over 800 persons with serious mental illness. Seventy percent of the resident population had a diagnosis of schizophrenia and their ages ranged from twenty to eighty with the average age being in the mid-forties. Length of stay in the foster home network ranged from 2 months to over 20 years with the average being 5 to 7 years.

Context

Emerging evidence suggests that social support is associated with greater life satisfaction, recovery from chronic mental illness, and enhanced ability to cope with life difficulties (Rogers et al., 2004). Previous studies on social interaction among individuals with SMI reveal that consumers demonstrate poorer social adjustment, fewer social skills, less elaborated social networks, poorer overall social competence (Mueser et al., 1990; Mueser et al., 1991; and Bellack et al., 1990) and increased social withdrawal. These difficulties often force persons with SMI into small, traditional social groupings which fail to provide the feedback necessary to build self-esteem and self-confidence (Hjorten, 1982).

In order to improve social interactions and support for persons with serious mental illness, volunteer networks may be created and mobilized to provide intervention services. Increasingly volunteers are playing an important function alongside paid labour. Despite the recognition that most public institutions involve volunteer programs and that volunteers can significantly contribute by enhancing the quality of programs (Hall et al., 2001) little is known about the impact of these volunteer programs on individuals with SMI.

Through contact with consumers, volunteers can acquire first-hand knowledge about the challenges and barriers facing individuals with SMI. They are also in a position to identify and build upon the individual's strengths, while promoting independence. Ultimately volunteers can assist consumers in their process of recovery and provide hope for a better quality of life as consumers learn how to help themselves.

Program Description

Implemented in 2003, the goal of the Quality of Life Program was to facilitate the integration of foster home residents into the community by promoting the development of their social skills, interpersonal interactions and physical and mental health, through activities and outings with volunteers. The primary focus of the program was the development of a relationship between the resident and the volunteer with the expectation that residents would participate in decision making and improve their self-confidence. Fundamental to the program was the belief that by becoming involved in meaningful social, cultural and recreational activities, foster home residents would develop new skills and experience less isolation.

Priority was given to those residents who were not enrolled in any day or vocational programs. This targeted population included those residents who, after many years of SMI had lost most social skills and suffered the effects of diminished social interaction and had an impoverished quality of life. In many cases the residents did not venture from the home by themselves, were not able (or refused) to attend day programs, had no involved family or friends, and had little opportunity to meet others. A full time coordinator recruited, trained and supervised volunteers. At the time of the study there were 45 volunteers involved in the program.

Purpose of the Evaluation

The purpose of the evaluation was to determine to what extent the program met its stated goals and objectives, as well as to identify which aspects of the program should be maintained or discontinued. An Advisory Committee composed of mental health consumers, service providers, foster home caregivers, and family members oversaw the evaluation.

Sample

The sampling frame for this study involved two stakeholder groups: (1) individuals with serious mental illness residing in the foster home network and participating in the program and (2) program volunteers. Participants were randomly selected among 96 residents and 45 volunteers involved in the program

Research assistants contacted residents and volunteers by telephone to explain the evaluation objectives and the nature and extent of their participation. Participation was voluntary. In the case where a resident or volunteer refused or was unable to participate, another participant was randomly selected until the sample size of 30 residents, and seven volunteers was attained. In all, 12 residents refused to participate and 15 volunteers were unavailable to attend a focus group. Typical reasons for not participating included: previous commitments, and finding it difficult to get to the hospital site during the winter.

Seventeen (57%) women and thirteen (43%) men participated in the study. Language shows the exact same distribution with 17 residents coming from an English speaking background, and 13 from a French speaking background. Four male and three female volunteers participated.

Research Instruments

Two questionnaires were administered: 1) The Resident Interview Questionnaire adapted from Taylor & Botschner (1998) and (2) The Focus Group Interview Guide. The Resident Interview Questionnaire consists of 53 items (27 close-ended and 26 open-ended) reflecting satisfaction with program objectives, including the following dimensions: 1) Relationships developed between volunteers and peers (19 items); 2) Skills learned (3 items); 3) Knowledge of services and participation in community activities (2 items); 4) Program activities (8 items); 5) Loneliness, isolation, and autonomy (7 items); 6) Quality of life (6 items); 7) General perceptions and suggested improvements (8 items). The questionnaire was administered in person by a research assistant and was approximately 30 minutes in duration.

The volunteer's perspective was elicited through a focus-group lasting two hours. Seven volunteers, randomly selected, participated. The researcher and research assistant conducted the focus-group. The focus group interview guide consists of 16 open-ended items and was designed to address common topics and specific issues as they arose. Dimensions explored included: 1) Relationships developed between volunteers and peers (1 item); 2) Skills learned (1 item); 3) Knowledge of services and participation in community activities (1 item); 4) Program activities (1 item); 5) Loneliness, isolation, and autonomy (2 items); 6) Quality of life (1 item); 7) General perceptions and suggested improvements (9 items).

Data Analysis
Completed questionnaires were returned to the research assistant for coding, data entry and analysis, using the Statistical Package for Social Sciences (SPSS 11.5 for Windows). The focus group was audio recorded and transcribed verbatim. Content analysis methods (Krippendorf, 2004) were used to analyse the data emerging from the focus group. Major themes were identified and findings were presented formally to volunteers, consumers and foster caregivers for validation.

Results

The relationship between residents and volunteers
The relationship between residents and volunteers was an important evaluation dimension. Nearly all respondents indicated that the program enabled friendships to develop between residents and volunteers. The majority of residents (86.7%) indicated that they were very or extremely happy with the volunteer assigned to them, and 28 (93.33%) stated that they became friends with their volunteer. They also felt that volunteers were good listeners (96.7%), and trustworthy (86.7%) and most residents (more than 73 %) rated volunteers as being very or extremely friendly, supportive and respectful.

General comments elicited from residents about the relationship with their volunteer included: “She believes in me, I feel more comfortable with her”; “I feel good about having a volunteer, it makes me look forward to the outing”; “She is a friend”; “She is made for me, responds to my needs, my ideologies, has good values, is funny, a good listener, and straight forward”.

Volunteers also reported a positive relationship with residents. Two stated that although residents never contacted them at the beginning of the relationship they now have developed the confidence, trust and comfort to do so. One volunteer who works with a resident with a short-term memory deficit indicated that while the person with whom she is paired does not remember most people, she remembers her.

Skills learned
Over half (56.67%) the residents stated that they had learned new skills since becoming involved with their volunteer. Specific comments highlighted the uniqueness of the skills learned eg.: “I have learned to speak more, I communicate more”; “I learned to participate in a group”; “I learned to like sports”; “Cooking”.

Volunteers also identified a number of skills that the residents learned. These included: repairing a television, reading, doing puzzles, writing, crafts and painting, and a resident teaching the volunteer a foreign language.

Knowledge of services and participation in community activities
Only 3 residents (10%) were more knowledgeable about community services since meeting with their volunteer, and 11 (33%) viewed themselves as being more involved in their community. Volunteers offered a different perspective on this issue. They stated that the program encouraged participation in community activities. Activities cited included: driving the resident to various places, going to church, the shopping mall and restaurants, and playing pool. One volunteer specified that while her role allows her to act as a liaison between the community and the individual, the resident was not yet ready to participate.

Program activities
Close to half the residents indicated that they had a role in determining what they did with volunteers and a majority (83.3%) stated that they always enjoyed the activities. One resident stated “My volunteer never forced me to do things, she presents a situation and if I don’t want to we choose something else”. Another resident stated “My volunteer is a fun person, tries to please us, and she makes us choose what we want to do and where we want to go.”

Almost three quarters of the residents (73.3%) stated that they did activities that they had never done before.

The most common type of activities described included in-house leisure activities, such as socializing, listening to music, exercising, playing cards and board games, and learning how to cook. Many residents referred to various outings such as visiting seniors, going to a restaurant, museums, shopping, and fishing.

Over half the volunteers described implementing a number of new “in-house” activities, which were the same as those mentioned by the residents. Twelve (40.0%) residents reported doing sports, such as a team sport, or walking, dancing, running, and cycling with their volunteers. Ten of these residents (83.3%) said that they felt healthier since doing sports and/or physical activities and seven (58.3%) stated that doing a sport with their volunteers had encouraged them to do it on their own. Typical benefits described included: “I have a better appetite, more energy” “I am more active, energetic and alert.”

Loneliness, isolation, and autonomy

Most residents confirmed that the program was successful in reducing their feelings of loneliness and isolation. Typical statements included: “I can talk more easily to people; communicate better what I mean to say”; “The presence of someone helps me and encourages me to do things outside”; “I was too isolated before, it wasn’t good”; “Because I know there is going to be someone who puts life into me, they make me forget about my illness.”

Most volunteers identified ways in which the program reduced the sense of isolation among residents. Emerging themes included: improved communication, residents talking more, increasing personal disclosure, and reaching out to the volunteers when needed. One volunteer indicated that the resident has begun to understand that she is not excluded from society and that there are numerous opportunities to socialize.

Fifty percent (50%) of the residents indicated that since having a volunteer they now go out on their own. Volunteers who observed autonomous behaviours noted changes such as residents going shopping and for walks on their own, residents taking more personal decisions, increased assertiveness, and being more capable of expressing personal needs.

Quality of life

Twenty-six (86.7%) residents indicated that they were happier since becoming involved with a volunteer. Their comments included : “The thought of being with a volunteer gives me positive thoughts about myself; I have a more positive attitude”; “Because when she is there I am happy, but when she is not I feel sad”; “I am not as lonely, more satisfied”, “I am happier, I know someone”.

Volunteers were also asked to identify successes they experienced with the residents and several comments relating to quality of life emerged. These included: residents being more hopeful, trustful, confident, assertive and caring. Others stated that residents went out more often on their own. One proudly stated that the resident had better self-esteem, was now more capable of making choices and taking control over certain aspects of her life.

General perceptions and suggested improvements

Ninety percent of the residents thought that the program was worthwhile. Although most (80.0%) would encourage other residents to have a volunteer five stated that it would depend on the individual. Typical comments about the program included: “It increases the strength to go on in life, to go ahead”; “Makes you come out of your shell, brings everybody together”; “It is truly worthwhile, it provides new training”, “It makes me active, I examine what my volunteer does; gives me a good example of what I have to do to be happy”, “It’s a good achievement it helps people, it makes them happier.”

Most residents (67.0%) noticed changes in themselves since their involvement with a volunteer. For the most part, additional comments related to increased sociability: “Helps me to socialize with the other residents”; “I am more outgoing”; “I understand people around me better”; “As a person, I can relate to people more effectively”; “I am friendlier around people I live with, my volunteer gives me good tips on how to react. I am open to do more outings, I have blossomed." Other comments related to having a friend, being happier, less anxious, more autonomous, and feeling less isolated and lonely.

Volunteers consistently observed changes in residents and described them as: being more open, being a better person, having more confidence, being in a better state of mind, being more comfortable socially, being more assertive and determined, and going out more often to visit friends on their own.

Volunteers also identified the need for more support for themselves. Suggestions included more supervision, input and feedback from program staff, mutual support among volunteers such as talking over the phone, and a regular support group where ideas could be exchanged. Some suggested that formal training and/or workshops would be very helpful in clarifying their role within the program and helping them to be more effective. Topics suggested included how to communicate with their residents and how to empower them.

Discussion

The majority of respondents confirmed that the program was successful in providing the opportunity for foster home residents to participate in social, cultural and recreational activities both in and outside the foster home. Volunteers have made a positive contribution to the residents' quality of life. Findings revealed that volunteers have enhanced the well-being of residents in a multi-faceted way; by helping to regain their self-confidence and emotional balance, by enhancing their existing skills, and increasing their optimism. Volunteers have successfully provided a high level of support to a vulnerable group thus helping them alleviate some of the loneliness, isolation and life difficulties experienced by the majority of residents.

Evaluation results indicated that residents had no difficulty socializing with their volunteers. In fact, the majority of respondents reported that residents and volunteers had developed a positive relationship. Results also indicated that the program was successful in reducing feelings of loneliness and isolation and both residents and volunteers identified greater self sufficiency and autonomy among the residents. Residents and caregivers were "very" or "extremely" satisfied with the volunteers, and most volunteers felt that they had a good relationship with their residents and respective caregivers.

The program was also successful in exposing residents to new activities. Those involved in physical activities reported feeling healthier and were encouraged to exercise on their own. Most residents reported being happier and experiencing positive changes in themselves since their involvement with the program. Ultimately, residents and volunteers all agreed that the program contributed to the improved quality of life of the residents.

The evaluation also indicated that there were some challenges to overcome. Results demonstrated that while most residents "always" enjoyed activities with their volunteer, only about half were involved in choosing their activities. This was consistent with the issue raised by volunteers where they questioned whether they should "stimulate" the residents regardless of their desire to remain " inactive" and stay at home.

Another issue which emerged from the evaluation was the socialization and involvement of residents in the community. The majority of respondents indicated that residents did not make new friends or meet new people besides their volunteer. In addition, respondents indicated that residents were not more knowledgeable or involved in their community. This was consistent with the statements of many volunteers who explained that despite considerable effort they had not yet succeeded in doing more outings with their residents.

Conclusion

The evaluation determined that the program met most of its stated goals and objectives. Although the program is still relatively new it was decided to maintain its original objectives but place more emphasis on community integration and socialization of this population. Developing a trusting relationship with a volunteer is an important first step in integrating foster home residents into the community.

Several limitations to this evaluation should be noted. First, residents were not asked their age nor their specific diagnosis. This missing information could partially explain the reasons for fewer reported outings and a limited exposure to the wider community. This may also explain why some residents were hesitant to socialize or be involved in the community. In order to measure the specific outcomes, such as getting out of the house, meeting new people and becoming involved in the community, a longer term evaluation is required.

The evaluation has demonstrated that volunteers can be extremely useful in helping persons with an SMI to broaden their social network, to develop new skills and become more involved in a variety of activities both at home and in the community. It also showed that based on their experiences with volunteers, residents can learn to become more independent. The concept of using volunteers as partners in the provision of services to persons with an SMI should be considered when developing programs for this population.

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Assisting Adolescents Experiencing Emotional and Behavioral Difficulties (EBD) Transition to Adulthood

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Abstract

In this pilot study, we tested the effectiveness of Instrumentalism in Occupational Therapy (IOT) (Ikiugu, 2004a, 2004b, 2004c) as a guide for intervention to help adolescents with Emotional and Behavioral Disorders (EBD) transition to adulthood. It was found that after therapeutic intervention using the model as a guide, the 15 study participants engaged more in occupations classified as "neutral", and less in peer related occupations. For many of them, the vision of Desired Adult Life (DAL) and plans to achieve that life became clearer, which was an indicator of likelihood of more successful transition to adulthood. It was concluded that the model may be useful as a guide for therapeutic interventions with adolescents with EBD, to help them transition successfully to adulthood. Further longitudinal research with larger samples will help establish clinical effectiveness, generalizability, and cost-effectiveness of the model.

Key words: Instrumentalism, Complexity/Chaos theory, Adolescents, Emotional and Behavioral Disorders.

Introduction

Adolescence is an age of transition. During this period, an individual leaves childhood and prepares to enter adulthood (Bruce & Borg, 1993). Many adolescents make this transition without serious difficulties (Haiman, Lambert, & Rodriques, 2005). However, in this stage, there is always uncertainty in that the individual is expected to act like an adult, while often being treated as a child (Haiman et al., 2005; Shannon, 1972). According to Bogin (1999) and Haiman et al. (2005), adolescents learn and practice behaviors including economic, social, and sexual activities of adults. At the same time, they are treated like children who are not expected to handle adult responsibilities (Haiman et al., 2005; Shannon, 1972). The mixed expectations from adults lead to uncertainty and turbulence which manifests as confusion, insecurity, indecision, disorganization, moodiness, and alienation. At this time, one also tends to question his/her identity.

For adolescents with signs of emotional or behavioral disturbances particularly, there is need to find ways of helping them overcome the turbulence so that their transition to adulthood is successful. This may be accomplished by helping them focus more on developing skills necessary for engagement in adult roles. One approach to maintain this focus would be by helping them formulate a philosophy to guide behavior toward a desired future (Shannon, 1972). Such a philosophy would facilitate planning for the future, with adult occupations as the goal around which the adolescent's daily activity is organized (Haiman et al., 2005).

It is clear from available research, that adolescents with EBD need assistance to help them focus on preparation for future roles as adults (Farnworth, 2003; Masi, Mucci, & Milliepiedi, 2001; Posthuma, 2002; Sisun & Eskedal, 2005). They lack a personal philosophy to guide their transition to an adult future. The lack of philosophy makes it difficult for them to bridge the "discontinuity in a person's life space" (Blair, 2000, p. 232) which is a natural consequence of normal adolescence as a stage of transition to adulthood. As Farnworth (2003) found, adolescent offenders (many of whom have EBD) had fragmented lives and experienced emotional and financial deprivation. This fragmentation may often be due to lack of attachment to parents and other adults, leading to a deficiency in acquisition of "social, economic and parenting skills" (Bogin, 1999, p. 393).

Occupational therapy may be an effective intervention to assist adolescents with EBD transition to adulthood and assume adult responsibilities by helping them bridge the discontinuity in their lives. According to Blair (2000) occupational therapy is best suited for this task because of its emphasis on occupation. Action through occupation integrates "feeling, thinking, and doing" (p. 231), which provides a sense of coherence in an individual's life at this time of uncertainty. Action through occupation also facilitates change, personal development, and well-being, which makes the transition easier. The need for occupational therapy as a means of assisting adolescents with EBD transition to adulthood is further given credence by research findings indicating that such adolescents tend to participate in occupations that are significantly different from those in which typical adolescents engage (Farnworth, 2003). They tend to participate in "passive" leisure occupations such as watching television or "doing nothing" in comparison to their typical counterparts who tend to engage in "active" leisure occupations such as sports, and productive occupations such as part-time employment and school related occupations.

A review of literature reveals few occupational therapy programs established specifically to address problems of adolescents with EBD. Those that we found in the literature tend to focus on development of work/vocational skills [see for example the program described by Nochajski, Scheitzer, & Chelluri (2003)]. Other skills necessary to assume adult roles such as choosing and keeping good friends, being a spouse or parent, and participation in community organizations are often not addressed.

The purpose of the present pilot study was to provide a preliminary test of the effectiveness of a newly developed conceptual model of practice in occupational therapy as a conceptual guide to intervention to help facilitate transition of adolescents with EBD to adulthood by preparing them to assume the adult roles of worker, family member, social, and community participant. The overall research question that guided this inquiry was: Is intervention based on Instrumentalism in Occupational Therapy (IOT) conceptual model of practice (Ikiugu, 2004a, 2004b, 2004c) effective as a guide for intervention to assist adolescents with Emotional and Behavioral Disorders (EBD) transition to adulthood? The specific research questions were:

a) Did participants' occupational performance change after intervention using IOT as a guide?

b) Were participants clearer about Desired Adult Life (DAL) and a plan of action to achieve that life after intervention?

c) Is there predictive validity of IOT as indicated by correlation between change in participants' occupational performance after intervention and the Allen Cognitive Level Screen (Allen, 2000) scores?

d) Is there concurrent validity as indicated by correlation between participants' performance scores as measured on IOT instruments and the Canadian Occupational Performance Measure (Law, Baptiste, Carswell, et al., 2000) scores?

Instrumentalism in Occupational Therapy (IOT)

Reviewed literature suggests that useful interventions for adolescents should aim at helping reduce their maladjustment and enhance their healthy personality development within social contexts (Ge & Conger, 1999). However, little is known about the cause of maladjustment among adolescents or how to prevent them (Ellickson, Saner, & McGuigan, 1997). It has been suggested that: "An especially vital role for occupational therapy may be in the provision and formulation of transitional services and facilitation of meeting students' goals as they move from school to work or from adolescence to young adulthood" (Haiman et al., 2005, p. 314, emphasis original). One way that occupational therapy may fulfill this role is by helping adolescents: "Establish a personal philosophy and unique values and attitudes" that positively influence their life "in all areas of occupational performance in school, work, church, and peer group activities" (p. 301).

The researchers chose IOT to guide therapeutic interventions in this research study because this model was specifically developed to fulfill the occupational therapy role described above. It was developed as a philosophically grounded conceptual model, based on the argument that occupational therapy is based on the philosophy of pragmatism (Breines, 1986; Cutchin, 2004; Ikiugu, 2001; Ikiugu & Schultz, 2006). John Dewey's construct of instrumentalism was operationalized as a core construct to guide development of practice guidelines of the model (Ikiugu, 2004b, 2004c). Instrumentalism is the notion that the human mind is an extension of nature and as such, is a tool that the human being uses to assist in adaptation to the environment (Dewey, 1996; Ikiugu, 2001, 2004b; Ikiugu & Schultz, 2006; Sibley, n.d.). In this view, intelligence is viewed as a tool or instrument, just like any other tool, that can be used to help solve environmental or social problems, and in that way, to fashion out the environment and to make it home. In this perspective, behavior is viewed simply as instrumental action.

In developing the IOT model, Ikiugu (2004b) derived constructs from complexity theory to formulate his view of the human being as a complex, dynamical, adaptive system, interacting adaptively with its environment. Occupation was conceptualized to be the means of that interaction. Pathology was viewed as failure of the system to be adaptive due to either hyper rigidity or hyper mobility (Schultz & Schkade, 1992; Schkade & Schultz, 1992). The role of the therapist was conceptualized as assisting individuals to become optimally adaptive systems. Based on Dewey's construct of instrumentalism, Ikiugu (2004a) argued that in practice grounded on pragmatism, clients should be taught to use the mind in the most efficient way to help them adapt to their environment. In this sense, the therapist's interventions would be aimed at helping individuals who have become maladaptive systems for any reason, to use their minds effectively to help them become adaptive systems once more.

Based on the above rationale, guidelines were developed for use of IOT (Ikiugu, 2004c) including three phases: belief establishment, action, and appraisal of consequences. In the belief establishment phase, a client's beliefs that contribute to maladaptive life patterns are examined. A new set of beliefs that support desired function are established by helping the person create a mission statement specifying purpose in life. Activities are identified, whose regular performance would lead to achievement of the mission or perceived purpose in life. Self evaluation regarding performance of those activities and perceived satisfaction with performance is completed. In the action phase, goals based on identified activities and self assessment of performance of those activities are set. The client then commits to regular performance of those activities. In the consequence appraisal phase, the client and therapist collaboratively examine the consequences of performance of identified activities in terms of the extent to which established goals have been met. Depending on the consequences as experienced by the client, goals are adjusted accordingly. Therapy is guided by the Assessment and Intervention Instrument for Instrumentalism in Occupational Therapy (AIIIOT) which operationalizes the model's guidelines (Ikiugu, 2004c). In addition to the IOT conceptual model, because of the recognized advantage of group interventions for adolescents (Haiman et al., 2005), therapy during this study was completed in a group setting using the seven step format by Cole (1998) to establish group protocols for each session.

Materials and Methods

This was a mixed design research study consisting of naturalistic, phenomenological and pre-experimental pretest-posttest designs (Depoy & Gitlin, 1998). The pre-experimental part of the study was designed to provide an indication of post-intervention changes in participants' (clients will be referred to as participants throughout the rest of this paper to emphasize their role as research participants) clarity of DAL and participation in occupational activities that were likely to support achievement of the visualized DAL. The phenomenological portion of the design provided triangulation by generating qualitative data indicative of thematic changes of conceptualized DAL as a result of intervention. This part of the study was based on the phenomenological process of research described by Van Kaam (1959), Giorgi (1985), Paterson and Zderald (1976), Colaizzi (1978), Van Manen (1984), and Streubert (1991).

The phenomenon of interest was participants' perceptions of DAL, and what they thought they could do to ensure its realization. The study consisted of a variety of assessments before intervention (pretest), a 15 to 30 minute interview, a five week intervention based on IOT and Cole's (1998) group format, a repetition of the assessments after intervention (posttest), and another 15 to 30 minute interview.

Participants

Fifteen teenagers, ages 13 through 19, both male and female, participated in this research study. They were recruited from a local day treatment center. The center consists of two programs: a school program for adolescents remanded from public school and an after-school program for adolescents remanded by the court system (the drug court). The treatment program has as its foundation the concept of relational healing for high school teenagers with learning disabilities, attention deficit/hyperactivity disorders, or serious conduct disorders (Bethesda Day Treatment Center, n.d.; Napp, 2003). As such, counseling sessions are used to help individuals understand the link between emotions, such as feeling disappointed or angry with parents, and behaviors such as acting-out. After consultation with the program director, it was decided that intervention using IOT as a conceptual model to guide therapy would add a valuable component to the overall treatment experience of the adolescents.

Instruments

Daily Activity Inventory

An activity inventory derived from Ikiugu and Rosso (2005) was used to identify occupations each participant was engaged in from 6:00 A.M. through 12:00 midnight every day for four days. This instrument is similar to diaries that have been used in time-use research (Robinson, 2003).

Occupational Performance Measure

This instrument (Ikiugu & Rosso, 2005) was used to rank occupational activities engaged in by the client over the four days according to importance in helping him/her achieve the visualized DAL, with the most important activity being ranked number one. The top five most important occupations were used to compute a performance score for the client using the following algorithm developed by Ikiugu and Rosso: $Pt = \sum(Pi) = \sum(F \times PI)$, where Pt is the total performance score, Pi is the performance score for each of the five activities, F is the frequency of participation in the activity, and PI is the performance index of the activity according to rank (5 points for activity number 1, 4 for number 2, 3 for number 3, 2 for number 4, and 1 for activity number 5 respectively).

Occupational activity classification

Extensive review of literature revealed that occupations in which adolescents participate can generally be classified into three categories (Boisvert, 2004; Kuh, Hu, & Vesper, 1999; Kruppa, McLean, Eastabrook et al., 2003; Larson, 2001; Wills, Sandy, & Yaeger, 2001). These are: activities associated with health and well-being; activities not associated with health and well-being; and activities that are neutral (i.e., may enhance health and well-being or vise versa, depending on how they are used). The researchers labeled those activities active, passive, and neutral respectively. Active activities are constructive, engaging, challenging, and enhance community integration, personal development, and general quality of life, and therefore enhance health and well-being. Examples of these include academic activities, substantive peer interactions which include discussion of political, economic or social issues, finding and holding a job, etc.

Passive activities are destructive, non-challenging, and do not encourage community participation, personal development, or overall health and well-being. These include passive leisure activities such as partying, drinking, watching television (entertainment television), interacting with friends in unstructured contexts (hanging out), etc. Neutral activities are those that can go either way depending on the context. For instance, family related occupations may be active or passive depending on how the family as a unit spends time. We are aware that this classification could be misleading if the constructs "active", "passive", or "neutral" are understood to refer to the level of physical effort or energy expended. For the purpose of this paper the terms are defined merely to refer to the health and wellness enhancing qualities of activities. From analysis of activity inventories, 18 occupational activities in which all participants engaged over the specified times in the research period were identified.

Using the criteria described above, each of us independently classified the activities into the three categories. Another individual who is a teacher by profession but not an occupational therapist was also requested to classify the activities. To allow comparison of classification by the three raters using Pearson moment correlation coefficients, the categories were numerically coded as follows: Passive = 0; Neutral = 1; and Active = 2. Inter-rater reliability for this instrument was very good with correlation between rater 1 and rater 2 ($r=.827$, $p<.01$), rater 2 and rater 3 ($r=.869$, $p<.01$), and rater 1 and rater 3 ($r=.947$, $p<.01$).

Occupational therapy practice framework

The occupational therapy practice framework developed by the American Occupational Therapy Association (AOTA)(2002) was used to organize activities in which participants engaged over the four days into seven occupational areas; Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs), Education, Work, Play, Leisure, and Social participation (Community participation, Family related occupations, and Peer related occupations).

Assessment and Intervention Instrument for Instrumentalism in Occupational Therapy (AIIIOT) (Ikiugu, 2004c)

This instrument is designed to guide evaluation and intervention using IOT. It consists of three sections. In section I, instructions are provided to help therapist use guided imagery to assist the client formulate a mission statement. The mission statement consists of four areas constituting the vision towards which a client should strive in order to feel that he/she is leading a meaningful life. These four areas are family, socialization, work/profession, and affiliation to a church/community organization. Section II consists of instructions that the therapist uses to guide the client in choosing two occupational activities under each of the four areas in which he/she can regularly participate in order to achieve the visualized mission in life. In section III, there are four rating scales. The client rates his/her frequency, perceived adequacy, satisfaction, and belief in ability to participate in each of the eight activities. Each of the rating scales is on a 4-point likert type scale. In each of the four scales (frequency, adequacy, satisfaction, and belief), a composite score is calculated by adding the ratings for each of the 8 occupational activities. Each activity whose rating of satisfaction is less than 4 is discussed with the client and if it is perceived to be a priority for achievement of life mission, a performance goal for the activity is set.

Allen Cognitive Level Screen [ACLS] (Allen, 2000)
This is a standardized screening tool used in occupational therapy to determine the cognitive level of functioning of clients. Since IOT is a new conceptual model whose clinical usefulness has not been established, this instrument was used to test the predictive validity of the model. Since IOT requires clients to imagine and write down a mission statement, then identify occupational activities whose regular performance would lead to achievement of that mission, it was hypothesized that the model requires a high level of cognitive functioning. Therefore, the higher a client's level of cognitive functioning, the higher he/she would be expected to benefit from intervention based on this model. Change observed after intervention as determined by various types of measurement should therefore correlate positively with the ACLS scores.

Canadian Occupational Performance Measure (COPM)
This instrument, which is based on the Canadian Model of Occupational Performance (Law, Baptiste, Carswell et al., 2000) is used to guide a client-centered approach to therapy where the client and therapist collaboratively identify occupational performance issues and the client's perceived ability and satisfaction with performance. The COPM was used in part to guide development of the AIIIOT (see Ikiugu, 2004c). As such, the two instruments are conceptually close in terms of underlying constructs that they are designed to measure. Since the COPM is a standardized instrument whose reliability and validity has been well established through research, it was used to test concurrent validity of the IOT in general and the AIIIOT in particular. A high correlation between the COPM and performance scores as measured on the performance measure and the AIIIOT would mean that the IOT has concurrent or convergent validity as a conceptual model of practice.

Interview guide
An interview protocol consisting of five open ended questions was used to guide the 1-on-1 interviews. The questions were: What are some of the most important things in your life right now? Why are those things so important to you? How do you see your future (Say 10 years from now) unfolding? How do you see yourself realizing that kind of future? How do you think you can act right now in order to make sure that you realize the future of your dreams? Probes were used as indicated to elicit further information. The guide was designed to help gather information about the phenomenon of interest (participants' perceptions of DAL, and what they could do to attain it).

Interview rating scale
In a study investigating the relationship between meaning in life and indices of psychological well-being, Debats, Drost, and Hansen (1995) developed a method of quantifying qualitative experiences of meaningfulness so that they could contrast experiences of meaningfulness with meaninglessness by quantitative means. They asked participants to write down in detail an account describing an event in which they experienced a sense of meaningfulness. The text was examined using three questions to create subcategories: presence/absence of expressed meaningfulness and/or expressed meaninglessness, details of the account, and components of the experience. Using this process as a guide, we developed a quantitative method of measuring Clarity of Desired Adult Life (CDAL) as expressed in the pre and post intervention

interviews. We conceptualized CDAL to be indicated by clarity of detail provided in response to one of the questions in the interview guide, “How do you see your future (Say 10 years from now) unfolding?”

Details indicating whether or not the participant was clear about the DAL included whether or not he/she was clear about desired kind of job, how much money one expected to be earning, whether or not he/she was married, had children, the kind of friends one would have, the kind of house in which one would be living, etc. In addition, we conceptualized clarity about DAL to be dependent on awareness of activities that one needed to be engaged in right now such as studying, going to college, etc., in order to achieve that future. This included how clear one was about the subjects in which he/she needed to do well in high school, major in college, etc. Content analysis of the interviews was completed looking particularly for those details. Vagueness about the details was an indicator of Lack of Clarity about Desired Adult Life (LCDAL). The rating scale was therefore on a continuum as follows:

a) Clarity or lack of clarity about desired adult life;
    0 = Lack of clarity (No details of desired adult life)
    1 = Some clarity (Some details of desired adult life provided but not clear)
    2 = Complete clarity (Enough details provided to indicate that the participant has a vivid image of DAL)
b) Clarity of plan to achieve DAL
    0 = No clear plan (No details of a plan to achieve DAL)
    1 = Somewhat clear (Some details of a rudimentary plan provided but no clear, logical, realistic, step by step articulation of the plan)
    2 = Clear (There is a detailed, logical, realistic, step by step plan of how to achieve DAL).

Therefore, the scale ran on a continuum from LCDAL (0) to CDAL (4), and could be conceptualized in a linear model as follows:

> LCDAL (0) (4) CDAL, where LCDAL = Lack of Clarity about Desired Adult Life, and CDAL = Clear about Desired Adult Life.

Interviews were coded with letters of the alphabet before rating so that we did not know which ones were conducted pre or post intervention. Each of us rated the interviews independently. Inter rater reliability for post intervention ratings was good as indicated by the high Pearson moment correlation coefficient ($r = .606$, $p<.02$). Our ratings of pre intervention interviews were weakly correlated ($r = .258$, $p>.05$). The overall correlation between us for all the 30 interviews (both pre and post intervention was remarkably high ($r= .510$, $p<.01$).

Procedures

After the study proposal was approved by the University of Scranton IRB, invitations for volunteers to participate in the study were sent to the director of the day treatment center. The invitations (a letter to the parent/guardian and another one to the adolescent) were given to the case workers who distributed them to the prospective participants and their parents/guardians during their weekly home visits. Those who were interested signed consent forms, which were returned to us. It was required that all participants under 18 years of age have parental consent to participate in the study. During the first meeting, interested adolescents were informed that participation in the study was voluntary and confidential. Participants’ activities in the study were explained to them. Given that one focus of the study was to investigate use of time, they were advised that any admission of illegal activities would be reported to the program director who would deal with the issues as per the center’s policies and procedures. During this meeting, activity inventories were distributed to participants with instructions to fill out one of them every day.

In the beginning, participants were required to fill out activity inventories for seven days. However, this was found to be too demanding for some of them. Instead, they filled them out for four days, Tuesday through

Friday. While they were completing activity inventories, the first author met with each of them individually at the day treatment center and administered the ACLS and the first interview. Interviews were recorded using a cassette tape recorder and later transcribed verbatim. Each interview was 15 to 20 minutes long. The second author met with them individually and administered the COPM. On Friday, one week after the first meeting with participants, they came to the Community and Health Center run by the University. Using the AIIIOT, they were guided to write mission statements. The completed activity inventories were collected during that session. The following week, the first author met with each of them individually. In collaboration with participants, occupational activities under each of the four areas (family, relationships, work/school, and affiliation to church or some other community organization) were identified whose regular performance would help the participant achieve articulated mission in life. Participants rated themselves on the four scales of AIIIOT (frequency, adequacy, satisfaction, and belief) for each occupational activity. Based on the self ratings, therapy goals for each participant were formulated.

After gathering pretest data, we conducted therapeutic interventions with the assistance of two occupational therapy students who were in their senior year. Therapy sessions were held once a week for about one and half hours, for five weeks. All sessions were conducted in groups. Individual participants' therapy goals were used to set group goals and establish weekly group protocols (Cole, 1998). A goal that was common to most group members was used to make the group protocol for the first session, the second most popular goal the second session, and so on, until all participants' goals were addressed. Examples of group activities included collage making as a leisure occupational activity that also helped group members reflect on the importance of participating in family oriented occupations, a reading and listening activity to help participants develop academic skills, creation of a poster to be used to teach younger children the dangers of drug abuse, etc. After five weeks of group interventions, another set of occupational activity inventories was distributed to participants and collected after four days (Tuesday through Friday). Another interview was conducted. All assessments completed before intervention were repeated except the ACLS. Three groups of adolescents went through this process between February and December 2004. Five adolescents participated in the first group, three in the second, and seven in the third respectively.

Table 1
Example of a Group Protocol Used to Structure Intervention in one of the Sessions

Title of The Group

Family Oriented Activities

Purpose of the Group

To help group members explore activities in which they may participate in the family context in order to foster close relationships between family members and the benefits of such family relationships.

Description of the Group

Each participant will make a collage depicting the different types of activities in which h/she can participate with different family members. After completing the collages, group members will reflect on the importance of doing things with family members, as well as things preventing them from participating in family oriented occupations. Members' responsibility and role in facilitating ability of families to engage in activities together will be explored.

Supplies and Equipment

Large sheets of construction paper, old magazines with glossy photographs, scissors, glue, pens and pencils.

Goals of the Group

By the end of the group session, each group member will demonstrate:

Awareness of different types of activities in which he/she can participate with family members to facilitate family closeness.
Awareness of why it is important for family members to do things together.
His/her responsibility in facilitating family engagement in suitable activities.
Individual circumstances that prevent or facilitate engagement in activities as a family.

Questions to Guide Discussion Processing

What was your experience participating in this activity today? (What did you like about it? What did you not like about it?)
How do you feel about how this activity was introduced to you and how you were helped to engage in it?
What do you think is the importance of doing things together as a family?
What circumstances interfere or help you and your family to do things together?
How can you help your family get into the habit of doing things together as a family?

Generalizing

What have you learned today about the importance of and participation in family oriented activities? How were other group members' responses about their experiences in this activity similar to or different from your own experience?

Application

How will you use what you learned in this session to improve your relationship with your family members in the coming weeks?

Group protocols were based on the seven step group format by Cole (1998).

Data Analysis

Statistical Analysis

Activities in each of the participant's inventories were organized into seven occupational areas according to the occupational therapy practice framework (AOTA, 2002): ADLs, IADLs, education, work, play, leisure, and community participation. Frequency of participation in each activity as entered in the four day inventories was noted. Each participant was requested to rank occupational activities in the list generated from the activity inventories according to perceived importance in helping him/her achieve stated mission in life. The top most important activities were used to calculate the performance score for each participant using the algorithm by Ikiugu and Rosso (2005). In addition, the occupational activities in which participants participated in the eight days as entered in the pre and post intervention activity inventories were classified into three categories (passive, active, and neutral).

Using the Statistical Package for Social Sciences (SPSS), mean performance scores, frequency of performance, COPM, AIIIOT, and CDAL scores before and after intervention were compared using paired sample t statistics. The correlation between each variable and all the other variables (age, ACL scores, and changes in COPM, performance, AIIIOT, and CDAL scores) was calculated. Finally, correlation between changes in variables after intervention was calculated to determine their interaction.

Qualitative data analysis

The pre and post intervention interviews were analyzed using the phenomenological analysis methods suggested by Colaizzi (1978), Giorgi (1985), Paterson and Zderald (1976), Streubert (1991), Van Kaam (1959), and Van Manen (1984). The analysis process consisted of the following steps:

1. Each interview transcript was read multiple times to find out what participants had to say about the phenomenon of interest (perception of the DAL and how to achieve it). A summary of this sense of perception was written down.

2. Each of us then immersed him/herself into the data by reading each transcript again line by line and explicating essences indicative of the phenomenon of interest. Such essences were implied by statements indicative of participants' grasp of details of their visualized DAL and plan of action to achieve it.

3. The identified essences were grouped according to similarity into themes and thematic descriptions were generated.

4. Finally, a formal description of the phenomenon (participants' perception of, and clarity of how to act now in order to achieve visualized DAL) was synthesized from the thematic descriptions.

The formal description of the phenomenon and underlying themes before and after intervention were compared to determine changes in perception and clarity of actions required to achieve the DAL after intervention.

Establishing trustworthiness of qualitative findings

The trustworthiness of the qualitative findings was assured using the criteria provided by Lincoln and Guba (1985):

Credibility was assured by triangulation of data collection methods as well as multiple designs. Methods of data collection included use of a variety of instruments to collect the same quantitative data. Qualitative and quantitative methods were used to provide triangulation of research methods. Another measure taken to ensure credibility of findings was that each of us analyzed the qualitative data separately and compared resulting themes. We debated any themes that were not consistent until we arrived at a consensus regarding interpretation of the data in question, a process known as peer debriefing.

Transferability was achieved by detailed description of the research procedures so that this research study can be easily replicated.

Dependability was achieved through reflexivity. We wrote down any biases that could have influenced our interpretation of data as such biases occurred to us. This increased probability of objectivity in our data coding.

Conformability was achieved by each of us writing memos detailing the logic leading to conceptualization of themes. These memos provided an audit trail explicating how we arrived at our findings.

Results

As mentioned earlier, 15 participants, ages 13 through 19 (mean age = 15.9 years, 6 males and 9 females), completed enough study activities for their data to be included in the analysis. Following are the study findings discussed under each of the specific research questions that the inquiry sought to answer.

Occupational Performance Change Following Intervention

The first research question was: Did participants' occupational performance change after intervention using IOT as a conceptual guide? A paired sample t-test comparing composite frequencies of participation in activities classified in the three categories (Active, Passive, and Neutral) before and after intervention indicated that participation in occupations classified as neutral significantly decreased (t=-3.441, p<.01). There was no significant change in other categories, although participation in active occupations slightly decreased and participation in occupations classified as passive slightly increased. Results of a paired sample t-test comparing frequency of participation in specific occupations as categorized using the Occupational Therapy Practice Framework (AOTA, 2002) before and after intervention are shown in Table 2

Table 2
Comparison of Frequency of Participation in Occupations before and after Intervention (n=12).

Occupation	Mean Frequency Change	SD	t value	Significance (1-tailed)
Eating	-.25	3.3	-.260	.4
Peer related occupations	-2.17	4.1	-1.817	.048*
Bathing/Showering	-.92	2.6	-1.201	.13
Dressing	-1.25	2.8	-1.565	.073
Intimacy related occupations	-.58	2.0	-1.000	.17
Communication/Use of phone	-2.25	3.7	-2.123	.029*
Joy ride	-.17	.58	1.000	-.17
Community mobility	-1.5	2.02	-2.569	.013*
Education related occupations	1.67	9.86	.586	.285

As can be seen in table 2, there was an increase in education related occupations (t=.586, p>.05). Obviously, this change was not significant. Rather, there was a significant decrease in frequency of participation in peer related occupations (t=-1.817, p<.05) such as communication, particularly talking over the phone (t=-2.123, p<05). Community mobility also decreased (t=-2.569, p<.02). In addition, while there was no significant change in performance as measured on AIIIOT, there was a significant increase in COPM scores after intervention (t=2.075, p<.05) (not included in the table). Therefore, there was a significant change in occupational performance after intervention. Participants engaged more in education related (although this change was not statistically significant) and less in peer related occupations such as talking over the phone, and community mobility.

Clarity of Desired Adult Life (CDAL)

The second research question was: Were participants clearer about their vision of Desired Adult Life (DAL) and plan of action to achieve it after intervention? There was an increase in Clarity of visualized Desired Adult Life (CDAL) and current actions needed to achieve that future as indicated by rating scores for pre and post intervention interviews. This increase was not significant (t=1.242, p>.05). However, the change was collaborated by qualitative findings as discussed below.

Participants' perception of future before and after intervention: A phenomenological perspective

The phenomenon of interest was participants' perception of DAL and their ability to articulate a detailed plan to help them achieve that future. Phenomenological analysis of pre and post intervention interviews revealed that before intervention, many participants valued family and friends because they derived a sense of security and support from them. They had a vague idea of the DAL, and could only vaguely, if at all, articulate plans to achieve the desired future. After intervention, even more participants articulated their value of family and friends. A few of them expressed values that were not articulated before intervention such as getting off the drug court, staying free of drugs, studying and attaining good grades, and doing household chores. They continued to view family and friends as a source of security. Moreover, friends were perceived as valuable confidantes. A greater number of participants expressed concern about the future, and their visualization of the DAL was clearer, even though for some, this visualization was naïve and unrealistic. The expressed concern could be understood to imply that these adolescents were thinking more about their future after than before intervention. For some of them, the plan to achieve the DAL was clearer and more logical. These perceptual changes are demonstrated by changes in phenomenological essences derived from the interview data as shown in table 3

Table 3
Number of Participants for each Essence and Theme Pre and Post Intervention

Theme	Essences	Pre intervention (n=15)	Post intervention (n=13)
Values	Family	12 (80%)	13 (100%)
	Friends	11 (73%)	9 (69%)
	Getting off drug court	-	1 (8%)
	Staying free of drugs	-	1 (8%)
	School	2 (13%)	5 (38%)
	Studying and attaining good grades	-	2 (15%)
	Leisure activities	4 (27%)	4 (31%)
	Pets	-	2 (15%)
	Intimate relationships	-	1 (8%)
	Socialization	3 (20%)	1 (8%)
	Doing household chores	-	1 (8%)
Reasons for values	Family as source of security	4 (27%)	7 (54%)
	Friends as source of security	-	2 (15%)
	Friends as confidantes	-	2 (15%)
	Therapeutic value	-	1 (8%)
Theme	Essence	Pre intervention (n=15)	Post intervention (n=13)
	Diversionary value	1 (7%)	1 (8%)
Visualization of future	Vague	12 (80%)	8 (62%)
	Clear	4 (27%)	5 (38%)

	Concern	-	7 (54%)
	Unrealistic and naïve	1 (7%)	4 (31%)
	No interest	-	1 (8%)
Plan to achieve desired future	Vague	12 (80%)	6 (46%)
	Clear	3 (20%)	3 (23%)
	Logical	-	2 (15%)
	General awareness	-	1 (8%)
Change	Self Appraisal	-	1 (8%)
	Serious pondering of the future	-	1 (8%)
	Change of goals	-	1 (8%)
	Change of behavior	-	1 (8%)
	Awareness of need for self reliance	-	1 (8%)
Theme	Essence	Pre intervention (n=15)	Post intervention (n=13)
	New values	-	1 (8%)
	New sense of responsibility	-	1 (8%)
	Increased insight	-	1 (8%)
Perception of therapy	Therapeutic activities valued	-	7 (54%)
	Therapy seen as fun	-	2 (15%)

Data in table 3 shows that some participants experienced change in perception of DAL and what they needed to do to achieve that future as a result of intervention, as is evident in the six themes explicated from analysis of interviews. The six themes were: values, reasons for articulated values, visualization of future, plan to achieve DAL, change, and perception of therapy.

Values:

Participants identified family as one of their values. For example, when asked what was important in his life, participant number 2 instantaneously stated: “My family”, and continued to identify his mom as the most important person in his life. Similarly, participant number 6 identified his “grandparents, my sister, and my brother” as the most important people in his life. Similarly, participant number 202 responded, “Uh, my family and my girlfriend”. Participant number 5004 answered: “parents, my grandma, my grandfather, and that’s about it. I don’t associate with my dad much or my step dad, so just usually my mom, uncle, my grandfather, and my grandmother.” It is clear from table 3 that all participants identified a value of family after intervention compared to only 80% of participants before intervention.

Also, participants identified friends as a value. In answer to the inquiry as to what was important in her life, participant number 13 answered: “School, my family, my friends”. Similarly, participant number 201 identified his family “and my friends” as the most important. Participant number 3 responded: “My friend A and um… my other sister D”. Participant number 9 also responded; “Uh… my friends”. More participants (73%) indicated value of friends before intervention than after intervention (69%). This is consistent with the statistical finding that after intervention, participants engaged less in peer related occupations than before intervention.

Values such as getting off the drug court, staying free of drugs, studying and attaining good grades, pets, intimate relationships, and doing household chores were articulated as values after, but not before intervention. Following are quotes from participants’ responses to the inquiry about what was important in their lives demonstrating the above finding: “My family and getting off of court” (Participant number 2). “Just staying drug-free” (Participant number 2). “My family and my school” (Participant number 3). “Um… my grades and school" (Participant number 202). "Oh, and my cat" (Participant number 201) (This was interpreted as value of pets by this participant). "My family, and my friends, and my boyfriend" (Mentioning the boyfriend was interpreted to be an indication of value for intimacy by participant number 206). "Shopping" (This activity was interpreted as value of leisure by participant number 6). "and my friends are just there so I can hang out with" (Interpreted as a value of socialization by participant number 9). "Helping mom with activities, like chores" (Participant number 202). Thus, it seems that for some participants, the value of family, getting off the drug court, staying free of drugs, school, studying and attaining good grades, pets, intimacy, and doing household chores was perceived as a value more after intervention. Interestingly, only one participant expressed a value for socialization after compared to three before intervention. This is consistent with the statistical finding that peer related occupations (which symbolize socialization) decreased after intervention.

Reasons for articulated values: Participants indicated their perception that the family was valued because it provided them with a sense of security and support. In this regard, participant number 202 stated: "My family is important to me, because without them I wouldn't know what to do, wouldn't be here right now." He saw the family as the very source of his existence, which indicated that to him, the family was a source of security. Participant number 203 further stated that his family would do "basically anything I ask" indicating that to him, they were a source of support that could be relied upon. Participant number 2 valued his family because "they are always around and when I get into trouble, they are always there for me." Similarly, participant number 6 valued her family because "they love me." More participants (54%) articulated security as the reason for their value of the family after intervention than did before intervention (27%).

Some of the reasons given for values after intervention were not mentioned pre intervention. These included the perceived value of friends because they were seen as a source of support and security and as confidantes, and therapeutic value of activities. Participant number 12 for example stated that friends were valued because "they are always there for me and support me." Participant number 203 further explained that friends were valued because a friend was seen as "someone to talk to when I need to talk." This statement suggested that for this participant, a friend was a confidante to whom he could confide. Further, participant number 5004 articulated the idea of leisure activities being valued because they provided diversion by stating that basketball "keeps me out of trouble" because "if I don't do that stuff, I get into trouble. You do stupid things when you aren't busy." So, for him, basketball (leisure activity) diverted his attention by keeping him busy and thus out of trouble. Participant number 201 further stated that her pet was valued because "I don't know. It helps me to relax." Helping her to relax was interpreted to mean that she perceived her interaction with the cat as a therapeutic experience.

Visualization of the future:

Some participants were vague about their visualized DAL, and others were very clear regarding the kind of adult life they wanted for themselves. Vagueness about visualized future was indicated by statements such as the following in response to the inquiry about how they visualized themselves 10 years from the present: "Umm… I don't know. Married with two kids" (Participant number 201). The hesitation indicated that this participant was not very clear about how her life was likely to be as an adult. She probably had not thought about it very much. Similarly, participant number 204 answered the question: "I just wanna have a good life, get a good job. I don't really know what I wanna go for yet, cause I wanna go to college. I just do not know what I wanna go for yet. So, I really don't know anything yet."

CDAL was indicated by statements such as: "A good life I guess. Nah, I wanna be a doctor. So, I will probably still be in college" (Participant number 206). Thus, she knew what she wanted to do in future, and could see herself in circumstances (college) that would lead to the visualized DAL (being a doctor). Similarly, participant number 5004 had no hesitation in his statement that: "I want to try and be a mechanic. So, pretty much in the mechanic route." Fewer participants (62%) were vague about their visualized DAL after than there were before intervention (80%). Also, more participants (38%) had a clear vision of their DAL after intervention than before (27%).

Although more of the participants articulated a clear vision of the DAL, many of them tended to be unrealistic and naïve about that future (31% of the participants) after than before intervention (7%). Some of the statements indicative of this unrealistic, naïve view included a statement by participant number 6 who saw himself as having “a family of my own” at age 25, and also working as “a lawyer”. This view was rather unrealistic for a 15 year old adolescent who was still in high school and not doing very well either. Similarly, participant number 202, who was 13 years old, stated that at age 23, she would be “in college for medical school ‘cause I got my scholarship and I have a whole bunch of dogs ‘cause that’s what I wanted and I have a crocodile. Um… a tiger in my front yard ‘cause I love tigers and my mom admirers them and it would remind me of my mother if she ever passes away. And I will be getting my license for bone doctor.” As is evident from this statement, this participant seemed to be dwelling in fantasy. Although she was vivid in her description of the DAL as a 23 year old woman, this picture was not very realistic.

Some participants expressed concern about their future, which was not expressed before intervention. This concern was delineated from statements such as: “I want to do good. I want to graduate and get into college” (Participant number 206). This desire to do good so that she could go to college indicated that she was concerned about her future. Also, some participants expressed no idea or interest about the future, which was not the case before intervention. Participant number 6 for instance stated the following in response to inquiry about how she saw herself 10 years from the present: “I have no idea”, she said. “I don’t look at the future. Just one day at a time.” In other words, following intervention, more of the participants had a clear vision of their DAL and were concerned about their future. However, for many of them, visualization of that future was rather naïve and unrealistic. Some of them appeared to lose interest in the future all together.

Plan to achieve DAL: A smaller proportion of participants (46%) were vague about plans to achieve DAL after compared to before intervention (80%). On the other hand, a larger proportion of them (23%) articulated a clear plan to achieve DAL after than before intervention (20%). An example of a vague plan of how to achieve DAL can be seen in the following answer by participant number 11 to the question of how he was going to ensure that he graduated high school and went to college. He answered: “Graduating school; Going to college; Getting good grades, In the 90s, in all subjects.” There were no details of how he was going to ensure that he got those good grades, or subjects in which he needed to do well in order to achieve his dream. His plan was therefore vague. Similarly, participant number 6 wanted to be different from his father as an adult. When asked how he would achieve that, he said: “That’s kinda hard question. I don’t know how to answer it.”

Some participants were quite clear about how they would achieve the DAL. Participant number 12 for instance was sure that in order to achieve her goals, she had to: “Um… graduate school, get a job, and I have to stay off drugs.” She also stated that she had to: “Um… following up with my parole officer. Go to my meetings, my AA meetings, and my counseling sessions.” She further stated that she needed to: “stay away from my old friends”, and “Um… stay focused.” (This could explain the reason for decreased peer related occupations after intervention. May be participants started realizing the negative influence of some of their current friends). Thus, this participant was at least aware of specific actions that she needed to take in order to get her life back on course. Similarly, participant number 206 was clear that in order to realize her visualized DAL, she had to: “do really good in school; study; pay attention, do all my work” and stop hanging out too much with her friends when she “could be sitting here studying or something”.

After intervention, some participants articulated a clear, logical plan to achieve DAL. Participant number 9, for example, decided that he wanted to be both a mechanic and a security guard. His plan to achieve that dream consisted of not doing “anything bad in school, like do what you have to do in school, study hard”, and do well in “math, science, and history” because, “you have to work a lot with numbers, so, you need good math, history so I could know like when stuff was made, so you know how old stuff is, and science so you know all the scientific stuff about mechanics and um security guards”. This participant, as can be seen in the above statement, demonstrates clear thinking, and provides a logical rationale for his proposed plan of how to achieve his goals. After intervention, at least one participant (number 3) demonstrated increased general awareness of what she needed to do in order to achieve her visualized future, even though she did not have a detailed plan. She stated that she needed to: “Show that I am doing what I am supposed to be doing, behaving.” She elaborated: “Like not having any curse words, and come to school every day, get good grades.” It is therefore evident that following intervention, a larger proportion of participants was less vague, and therefore clearer, about plans to achieve the DAL. Their plans were more logical, and they developed increased awareness of what they needed to do to achieve their goals.

Change: Following intervention, a number of participants seemed to experience change in their attitudes and perspectives about life and about their future. Such change included serious pondering of the future, self appraisal, change of goals, change of behavior, increased insight and awareness of the need for self reliance, development of new values, and development of a sense of responsibility. Such changes were indicated by statements such as: “’cause when I was on drugs I was like really mean. I didn’t care what I was doing. I was really disrespectful to my parents.” This statement by participant number 2 indicated his increased awareness of the consequences of his behavior, which was a sign of increased insight. This interpretation was further supported by his statement that: “and I don’t want to go back that way”. Participant number 9 demonstrated change by adding being a security guard to his original goal to be a mechanic. Now, he wanted to be both a mechanic and a security guard. Participant number 202 indicated his change of behavior in the statement that: “Because I want to pass this year and know I am doing it and go on the trip, ‘cause I am behaving more this year than last year ‘cause I got suspended like every two days. So, now, I wasn’t suspended once this year, well, may be once ‘cause I, but not ‘cause I got free of it ‘cause it wasn’t on school property.”

Perception of therapy:

The majority of participants saw therapeutic activities used in this study as both useful and fun. Participant number 2 valued the pizza cooking activity because “I never cooked a pizza before.” For participant number 3, the valued activity was: “May be when we went to that lady’s computer class [referring to the session where the group visited career services department at the University] to help find out information about jobs and stuff.” The reason she valued this activity was: “Because I don’t have a computer or anything so I can look online, see what I have, what sites I have to go to and stuff, see what I wanna do.” Participant number 9 valued most the activity where the group worked on: “Study habits. By knowing how to study ‘cause before I didn’t know how to study and now I do got a little better idea.” Finally, for participant number 206, her perspective regarding all therapeutic activities was simple: “It was fun.”

The above analysis indicates that the finding of increased CDAL from the quantitative data, though not statistically significant, was supported by results of the qualitative data. Furthermore, use of IOT as a conceptual guide for therapeutic interventions led to therapeutic activities that were perceived by majority of participants to be valuable and fun.

Interaction between Variables

Correlation between change in beliefs, perceived adequacy, performance, and satisfaction

The relationships between belief in ability, perceived adequacy, frequency, and satisfaction with performance are shown in table 4.

Table 4
Correlation between Changes in Performance Variables as Indicated by Pearson r Correlation Coefficients (n=12).

	Neutral Occupations	Frequency (AIIIOT	Adequacy (AIIIOT)	Satisfaction (AIIIOT)
COPM Scores	.686**	-.364	-.169	.068
CDAL Scores	-.044	-.529*	-.423	-.337
Passive Occupations	.189	-.548*	-.405	-.153
Frequency (AIIIOT)	.047	__	.537**	.533**

Adequacy (AIIIOT)	.012	__	__	.562**

Notes: * Significant at p<.05, 1 tailed; ** Significant at p<.05, 2 tailed.

Pearson r coefficients indicate that increased COPM scores was correlated with increased frequency of participation in occupations categorized as neutral (r=.686, p<.02). This suggests that change in frequency of participation in neutral occupations accounted for observed significant change in COPM scores.

Another statistically significant interaction was that clarity of participants' visualized CDAL was correlated with decreased participation in occupations identified as important to achievement of life mission as identified during pretest using the AIIIOT (r=-.529, p<.05). This negative correlation could be because of change in participants' perception of what was important due to increased insight following intervention. This would support our hypothesis that the reason for lack of significant change in AIIIOT scores post-intervention is that we did not account for change in prioritization of occupations with increased insight. Since the same occupations identified as important for achievement of life mission during pretest were evaluated on the four scales of AIIIOT during post-test, if participants changed their perceptions of the importance of these occupations due to increased insight following intervention, their scores on AIIIOT would decrease. This explanation would be consistent with the finding from qualitative data that some participants changed their goals and therefore their perception of what was important in their lives after intervention.

Correlation between changes in participation in specific occupations

Table 5
Correlation between Changes in Participation in Specific Occupations Following Intervention (n=12).

	Grooming/Bathing Occupations	Intimacy	Joy Rides	Peer Related Occupations	Passive Occupations	ACL Scores
Peer Related Occupations	.592**	.673**	.673**	__	-.114	.564*
Intimacy	.248	__	1.00**	.673**	-.283	.456
Homemaking Occupations	-.488	-.519*	-.519*	-.633**	-.198	-.501*
Education Related Occupations	-.316	.373	.373	.284	-.639**	-.034
Active Play	.122	-.531*	-.531*	-.270	.036	-.545*

Notes: ** Significant at p<.05, 2 tailed; * Significant at p<.05, 1 tailed.

As can be seen in table 5, the more participation in peer related occupations increased, the more participants tended to attend to self care occupations such as bathing and grooming (r=.592, p<.05), and the more they tended to engage in activities related to intimacy such as spending time with boyfriend or girlfriend (r=.673, p<.02) and to be involved in joy rides (r=.673, p<.02).

The more engagement in homemaking occupations increased, the more participation in peer related, intimacy related, and joy ride activities decreased (r=-.633, p<.05, r=-.519, p<.05, and r=-.519, p<.05 respectively). Also, the more participation in education related occupations increased, the more the frequency of participation in occupations classified as passive decreased (r=-.639, p<.05).

Validity of IOT as a Conceptual Model of Practice

Research question number 3 was: Is there predictive validity as indicated by correlation between change in occupational performance post intervention and the ACLS scores? No significant relationship was found between these two variables. However, it was found that the older the participants, the more their frequency of participation in occupations classified as passive increased after intervention ($r=.510$, $p<.05$). Thus, a participant's age seemed to be related to the type of change likely to result from therapeutic intervention using the conceptual model. The final question was: Is there concurrent validity of IOT as indicated by correlation between participants' performance as measured on IOT instruments and the COPM scores? In answer to this question, a strong correlation was found between changes in COPM scores following intervention and changes in performance scores as calculated using the formula $Pt=\sum(Pi)$ ($r=.786$, $p<.02$).

Discussion

The main finding in this study is that there was significant change in participation in occupations perceived by self and others as important, as measured on the COPM. This change, did not correspond to changes in the frequency, efficacy, satisfaction, and belief in ability to engage in occupations perceived to be important for attainment of personal mission in life as measured on AIIIOT, as was predicted. This finding puts in question the criterion validity of IOT as a conceptual model of practice, since its development was partly based on the COPM (see Ikiugu, 2004c). However, a correlation was found between the COPM and performance scores, which were calculated based on the importance of identified occupations to attainment of life mission (see description in the procedures section).

We propose that this discrepancy may be explained by the fact that perception of occupations that were important for achievement of life mission and, therefore, personal future goals changed after intervention. This change in perspective would explain the lack of significance found in the change in AIIIOT scores. After intervention, we measured participants' perception of frequency, adequacy, satisfaction, and belief in ability to perform occupations based on activities that were identified as important for achievement of life mission during pretest. We failed to capture the change in priorities and, therefore, change of perception of what was important following intervention. This interpretation of the above results would be consistent with the other finding that as participants' visualized future as adults became clearer (as indicated by CDAL scores), their likelihood of participating in occupations identified as important to attainment of life mission (as indicated by AIIIOT scores) decreased. In other words, as participants' view of the DAL became clearer following intervention, their perspective of what was important to help them achieve that future changed. As a result, they engaged less in those activities that were originally ranked as important.

This explanation is further supported by the qualitative finding that after therapy, some participants expressed more clarity about their vision of DAL, and plans to achieve that life. This would suggest that participants thought more about their future and how to achieve it, which would be a first step in the journey of successful transition to that future. Therefore, use of IOT as a conceptual model of practice may have had some effect in facilitating change in participants so that they engaged more in occupations that were likely to help them achieve DAL. This conclusion would suggest that the IOT is consistent with cognitive models that emphasize a collaborative approach and guided discovery with adolescent clients to help them focus on concrete activities to assist them construct positive "mental packages' about themselves, relationships with other people, experiences, and the future" (Friedberg & McClure, 2002, p. 4).

It seems that using IOT as a conceptual guide to therapy may have been useful in helping participants in this study begin internalizing values consistent with a positive future as adults, by providing them with structure through focusing their imagination about ideal future goals. Internalization of values is significant because it has been found to be consistent with adolescents' ability to enjoy engagement in activities perceived to be consistent with attainment of future goals (Asakawa & Csikszntmihalyi, 1998). Furthermore, there was a significant decrease in frequency of participation in peer related occupations such as talking over the phone. Decrease in peer related occupations was consistent with another finding that participation in occupations classified as "neutral" (based on guidelines derived from Boisvert, 2004; Kuh & Hu, 1999; Krupa et al., 2003; Larson, 2001; Willis et al., 2001) also decreased significantly. Such occupations consisted of activities such as bathing, dressing, grooming, eating, intimacy, socialization, etc., whose frequency of performance is likely to be higher either in preparation for socialization with peers (such as bathing, grooming, and dressing), or in the company of peers (such as eating and community mobility, e.g. to visit the mall).

This change in peer related occupations is important considering that it has been found in previous studies that time spent in unstructured, unsupervised leisure activities with peers is associated with proclivity for delinquent activities by adolescents (Warr, 2005). It seems that our intervention may have led to increased concern about the future, and less peer related activities by some of the participants in our study. This finding may be seen as contentious by those who view socialization with peers as an important developmental task for adolescents (Letendre & Fukuzawa, 2001). Decreased participation in peer related occupations may be seen as leading to development of less holistic individuals. However, for adolescents with EBD who are prone to socialization with peers who are likely to support participation in delinquent activities (Warr, 2005), it may be a positive thing to help them divest their energy from socialization with such peers and focus more on their own goals, and then later, assist them to re-establish social networks with peers who can be instrumental in helping them resolve problems in a positive manner (Letendre & Fukuzawa, 2001).

Finally, our finding that participants in this study perceived therapeutic activities that we used to be both valuable and fun is significant since many therapeutic models emphasize the need for adolescent clients to understand the value of therapy, and to be motivated in order for intervention to be effective (Gil et al., 2001; Friedberg & McClure, 2002). Friedberg and McClure particularly emphasize that: “Children’s motivation will increase when they are having fun” (p. 8).

Strengths and Limitations

Limitations

One of the major limitations of this study is that because of the small sample, this research can only be viewed as a pilot study. Its findings can only be seen as an indication for further research to establish the validity and reliability of IOT as a conceptual model of practice. Also, because it was not possible to have a control group considering limitations in time and other resources, we cannot attribute observed changes to our therapeutic activities. We can only speculate that our interventions contributed somewhat to the changes.

Strengths

Although there was no control group, and we did not control for other variables that might have accounted for changes in our study participants, our use of a variety of methods to gather both qualitative and quantitative data allowed us to provide collaborative evidence, thus enhancing credibility of our findings. Credibility was further enhanced by our triangulation of research methods. Also, we used a variety of methods such as researcher flexibility, memoing, peer debriefing, and use of exemplars, to further enhance the trustworthiness of our findings.

Implications and Recommendations

Our findings indicate that IOT may be a valuable conceptual guide for therapeutic interventions with adolescents with EBD to help them transition to adulthood. There is also indication that there may be need to revise aspects of the IOT, such as the AIIIOT, in order to account for client changes in perspective during reassessment. Based on the above implications, it is recommended that further longitudinal research be conducted with larger samples, with a variety of clinical conditions, and from a variety of socio-economic and cultural backgrounds, in order to establish further the validity of IOT as a conceptual model of practice. It is also recommended that the AIIIOT be revised so that every time reassessment is done, activities that are important to the client’s goals at the time are identified and ranked afresh. This approach will make it possible to account for increased insight and changes in perspective as therapy progresses.

Conclusion

The purpose of this study was to test the effectiveness of Instrumentalism in Occupational Therapy (IOT) as a conceptual guide for therapeutic interventions designed to assist adolescents with Emotional and Behavioral Disorders (EBD) transition to adulthood. Analysis of the difference between pretest and post-test scores obtained with a variety of instruments indicated that following intervention, adolescents who were participants in this study significantly changed their pattern of engagement in occupations as measured on the COPM. They tended to engage more in occupations classified as "neutral" and less in peer related occupations. Qualitative data indicated that after intervention, visualized DAL was clear for more participants than before intervention. More of them were also clear about what they needed to do in order to achieve that future. Change in performance scores as measured using an inventory of daily occupations and an algorithm developed by Ikiugu and Rosso (2005) was significantly correlated with change in COPM scores indicating convergence validity of the model. It was concluded that although this was only a small pilot study, there is evidence that IOT has some usefulness as a conceptual guide for therapeutic intervention with adolescents with EBD to help them visualize more clearly their DAL, and engage in activities that would help them achieve that life. More inquiry, preferably longitudinal, and involving larger samples of adolescents with a variety of psychosocial conditions, is recommended to establish further the clinical effectiveness, generalizability, and cost-effectiveness of the model.

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Cultural competence and models in mental health: Working with Asian Service Users

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Abstract

The Asian population is one of the fastest growing ethnic groups in New Zealand and this raises questions regarding the ability of the mental health service workforce to respond appropriately to the needs of New Zealand Asian population. This paper provides an overview of key findings from the international and New Zealand literature on the concept of cultural competence and delivery within mental health settings. From this systematic review of literature, the authors present an outline of a ten week education programme seeking to improve the cultural competence of the mental health workforce providing services to the Asian population are summarised.

Keywords: Cultural competence, mental health, workforce development

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Introduction

As the New Zealand population becomes more diverse, the need for the delivery of culturally competent and appropriate health care services is becoming paramount (Ho et al, 2002; Nursing Council of New Zealand, 2002; Ministry of Health, 2004). Moreover, one of the key recommendations from the literature review on mental health issues for Asians in New Zealand suggests, “It is essential that the formal mental health care systems become more responsive to the needs of the Asian communities. Health care providers can deal with their clients more competently if they are knowledgeable of their clients’ cultural beliefs, their interpretation of mental illness and mental well-being, their help seeking patterns, and choice of traditional alternative health practices” (Ho et al, 2002, p. 51).

Cultural competence of the workforce is vital to ensure equity in access to appropriate and high quality care. Furthermore the literature indicates a growing need to develop resources on cultural competence to assist health service providers to address the needs of people from diverse backgrounds. For the purposes of this paper, cultural competence is defined as “the ability of individuals and systems to respond respectfully and effectively to members of all cultures, races, classes and ethnic backgrounds and religions in a manner that recognises, affirms, and values the cultural similarities and differences and their worth” (Tse et al, 2005, p. 23).

The aim of this article is to review the literature on cultural competence, leading to seven critical success factors in developing effective training programmes and present the beginnings of a ten week education programme.

Literature Review Findings

Literature reviewed for this paper included national and international sources with the purpose of establishing a comprehensive understanding of professional practice and organisational requirements for a culturally capable workforce. Documents dating between 1990 and 2004 were located using computer searches and entering key phrases, ‘cultural competence models’, ‘workforce development’ and ‘mental health’. Additional material was identified through professional networking and key expertise.

In the first instance, literature reviewed focused on investigating cultural competence, workforce cultural responsiveness and principles of culturally safe practice. Secondly, literature pertaining to models and programmes used when training in cultural competence was reviewed.

Cultural Competence

This section groups reviewed literature under three headings, Theoretical work; Policy document; and Mental health settings and training packages.

Theoretical Work

As a starting ground for cultural competence, international literature endorses the need for professionals working with culturally diverse populations to develop cultural awareness as a pre-requisite to developing collaborative relationships (Green, 1982; Papadopoulous et al, 2001; Harry, 2003). Cultural awareness is a beginning step towards understanding that there is a difference. Paralleling cultural awareness is cultural sensitivity which is the need to be aware of what one does not really know and the implications of this for clinical practice (Bhui and Bhugra, 1997). Both these concepts are considered critical in the build up to gaining cultural competence.

Bhui et al (2004) contend that cultural competence further demands the promotion of education and skill within the health workforce. One such skill is communication. Words that Harm, Words that Heal (Bedell et al, 2004) discusses the power of language by physicians in harming or healing their patients. Given the intertwined nature of language and culture, this article challenges the use of appropriate language as an important skill in learning to provide appropriate health care services that are culturally sensitive to patients from diverse cultures and languages, a stance supported by Huang (1997) and Lin and Cheung (1999). The need for this skill is also discussed by Hunt and Bhopal (2004) who conclude that one of the barriers on accumulation of reliable and valid information on ethnic minorities is the measurement error that results from inadequate translation procedures, inappropriate content, insensitivity of items and the failure of researchers to make themselves familiar with cultural norms and beliefs. Bhui et al (2003), also discuss issues of translation and validation as measures of mental health for use in a number of languages and cultural contexts.

Development of education and skill can be accessed through training and supervision which Bhui and Bhugra (1998) acknowledge as an integral component in the development of multicultural effective health services. However, development of cultural competence is not immediate nor a one off lesson, rather cultural competence is an ongoing process (Campinha-Bocte, 1994). As a way of assessing cultural competence within the workplace, Chin (2002) recommends ongoing training and staff development for working with culturally diverse groups.

Within New Zealand, the Mental Health Issues for Asians in New Zealand: A Literature Review (Ho et al, 2002) emerged in response to New Zealand's fastest growing ethnic group and reflects some of the findings of international literature. It highlights the difficulties, problems and barriers, faced by Asian immigrants and clearly supports the urgent need to cultivate responsiveness, such as use of interpreters for enhanced communication as a way of improving mental health services to Asian people.

Policy Document

In 2002, the World Health Organizationcalled attention to the need for improving the performance of health care workers worldwide, challenging workers to continuously change their practice behaviour to keep abreast of new developments in the health care field. A year later the National Institute for Mental Health (NIMH) in England (2003) published the first national approach aimed at reducing and eliminating ethnic inequalities in service experience and outcome. This document represented a landmark in health care in the United Kingdom, providing a cultural capability framework aimed at tackling institutional discrimination while educating the workforce to improve clinical practice with diverse cultural groups. This report was followed by the publication of a challenging government action plan to build a fairer and more inclusive society for people with mental health problems (NIMH, 2004). There is however, no mention of ethnicity of the groups in the report and while the Department of Health (2004) acknowledges ethnic monitoring their report Delivering Race Equality: A Framework for Action, the report fails to provide explicit guidance on how to improve clinical services.

In New Zealand, policy documents addressing cultural competence have primarily focussed on the development of the Maori Mental Health Workforce and the direction for Maori health (Ministry of Health, 2002a; 2002b; 2003) with minimal discussion of the Asian community. However in 2004, the Ministry of Health published the report Improving Mental Health: The Second National Mental Health and Addiction Plan. This is a promising document by the New Zealand Government to initiate action to develop resources and assist in making mental health services culturally competent.

Mental health settings and training packages

Research on cultural competence in mental health settings contain mixed results. Phelps and Johnson (2004) positively demonstrate how a health department rose to the challenge of assisting their health workforce to develop culturally sensitive and appropriate health services to a rapidly increasing population of Haitian immigrants. However, other literature questions the cultural competence of the health workforce. For instance, Kirmayer (2002) challenges clinicians to learn to decode the meaning of somatic and dissociative symptoms that are not simply indices of disease or disorder but part of a language of distress with inter-personal and wider social meanings. In addition, Tucker et al (2003) raise the need for mental health settings to provide culturally sensitive health care incorporating people skills, individualised treatment, effective communication and technical competence.

Literature included in this review suggests clearly cultural competence in individual health service practitioners requires resources, training, organisational support in order to be accessible, safe and effective. In 2001, the Mental Health Commission of New Zealand launched the Recovery Competencies Training Resource Kit. This is a helpful starter kit for training as well as a useful resource and tool. Because of its generic approach to all cultures it can be easily applicable and modified to suit any cultural group.

Training in Cultural Competence – Models and Programmes

Several models and workforce development programmes have emerged to meet the challenges of various multicultural health care systems. Some of these models include the “ethnic-sensitive practice” (Devore and Schlesinger, 1981), “ethnic-competence” (Green, 1982), “ethnic minority practice” (Lum, 1986) and “cultural specific care” (Leininger, 1967). Within this study, six training models or programmes used in the training of cultural competence by various organisations were examined.

The term ‘cultural safety’ was developed in the 1980s in New Zealand in response to the indigenous Maori people’s discontent with nursing care and in 1990, the Nursing Council of New Zealand amended its standards to incorporate cultural safety into its curriculum assessment processes and guidelines. The concept of cultural safety, which can be described as “a manner, which affirms, respects and fosters the cultural expression of the recipient” (New Zealand Nurses Organisation, 1995). is achieved in a gradual, progressive fashion, starting with cultural awareness, progressing to cultural sensitivity and finally cultural safety – an outcome that enables safe service to be defined by those who receive the service.

Similar to this model in that cultural competence is achieved in an ongoing manner is a programme designed by the Research Center for Transcultural Studies in Health at Middlesex University. Designed to deliver a team-based, practice-focused model of education and training to promote cultural competence in a small number of teams, cultural competence is taught through four key stages, starting with cultural awareness, moving through the second and third stages being cultural knowledge – understanding service users and their experiences of mental health; and cultural sensitivity respectively. The fourth stage, cultural competence is the synthesis and application of the previously gained awareness, knowledge and sensitivity (Papadopoulous et al, 2001).

The second of three objectives outlined in “Inside Outside: Improving mental health services for Black and minority ethnic communities in England” (NIMH, 2003) advocates the development of the workforce. It sets out two key approaches in ensuring a culturally competent and capable workforce. These include, mandatory training in cultural awareness and recruitment of multicultural workforce so that the workforce in mental health reflects the people it serves. It suggests that training needs to occur at three levels, organisational, community and individual.

Within Australia, the Queensland Transcultural Mental Health Centre (QTMHC) provides flexible educational programmes through lectures, seminars, workshops and Train-the-Trainer programmes for all professional disciplines working in the field of mental health. The training programmes employ adult learning principles, provide follow up support and encourage training participants to make contact with the service providers at any time. This is a relatively well established programme in Australia with a strong emphasis on active participation in learning and application to practice.

As with the QTMHC programmes, Purnell’s model of cultural competence (Purnell and Paulanka, 2003) was selected for its comprehensiveness and application to many disciplines, both within and outside of health care. The framework for data collection consists of areas such as communications, family roles and organisation, health care practices, and spirituality. Primarily, Purnell’s model is a guideline to understand service users from culturally diverse backgrounds. It is easily accessible and provides learning opportunities for professionals without affecting productivity in workplace.

Finally, Campinha-Bacote (1994) proposes the 'cultural competence model of care' which views cultural awareness, cultural knowledge, cultural skills and cultural encounter as components of cultural competence. A key feature of this model is that it represents a process in which health practitioners see themselves always in the process of becoming culturally competent rather than being culturally competent. In addition the model has clear awareness, knowledge and skills and provides the health practitioner with a sound framework for delivering culturally competent health care.

Learnings from the Literature

To gain the knowledge, attitudes and skills needed to effectively work with Asian people affected by mental illness, mental health workers must receive appropriate education and training. However, while it has been recognised that training staff to acquire the competencies to work effectively within a multicultural community is necessary, there is no consensus on the content, style or delivery of such training. Nevertheless, recent work in this area has begun to specify the core competencies, skills, values and knowledge base which would be fundamental in training.

Based on the literature review, critical success factors that make training on cultural competence effective and successful include:

1) Organisational support and commitment - When health practitioners are encouraged and challenged to develop skills and increase knowledge of cultural competence by their organisations, their motivation and learning ability tends to increase and is sustained over a longer period.

2) Guidelines and standards of cultural competence – Trainees need to know what they need to attain and develop in terms of providing culturally competent health care services.

3) Variety of mode of delivery – It is vital to use a combination of didactic methods as well as other styles of training such as a problem based learning method. Trainees learn both content and critical thinking skills better if the processes are based on actual problems (Barrows, 1985; Stepien and Gallagher, 1993).

4) Cultural awareness included in training programme – Cultivating awareness is vital because it provides a basis for accurate opinions, attitudes and assumptions.

5) Availability of resources, materials, information, follow up and assessment tools –given the understanding that acquiring cultural competence is an ongoing process, the availability of resources, materials and assessment tools is of utmost importance in assisting and supporting trainees outside of structured training sessions.

6) The importance of skills development – This is the ability to build on awareness and apply knowledge toward effective change in multicultural settings.

7) Communication skills and language support. Culture and language have considerable impact on how patients access and respond to health care services. Only through careful interaction and communication will it be possible to accurately identify problems, issues and work together to solve them in a cross cultural setting.

Still, no cultural competence workshop can make an individual culturally competent. Cultural competence is a journey, not a destination. It is a state of having a demonstrated ability to incorporate cultural concepts and data into care and is an ever-evolving process (Harris, 2004). Thus, health practitioners must anticipate variations and differences in the level of cultural competence that can be attained (Kirmayer, 2001; Ballenger, 2001).

Education Programme – An Overview

Table 1 provides an overview of proposed session topics utilising the ‘cultural competent model of care’ (Campinha-Bacote, 1994) to be covered in a ten week education programme aimed at providing New Zealand mental health workers with the necessary training in cultural competence.

Table 1. Overview of Education Programme Session Topics and key contents utilizing the Cultural Competent Model of Care (Campinha-Bacote, 94)

Cultural Awareness	Cultural Knowledge	Cultural Skill	Cultural Encounter
Be aware of one’s own cultural background · Define terms such as culture, ethnicity, race · Develop attitudes that will enhance empathetic and empowering relationships with Asian clients · Be aware of cultural transference and counter-transference or biases	**Immigration and mental health** · Understand history of Asian people’s migration in New Zealand · Identify different stages of post-immigration settlement · Biculturalism and multi-culturalism · Identify gains and losses, new opportunities and challenges · Concept of acculturation and the associated stress	**Work with Asian clients in assessment and diagnosis** · Understand the role of culture and language in assessment and diagnosis · Be aware of cultural impact on psychiatric manifestations, notion of normality and abnormality and culture-bound symptoms · Increase skills to identify cultural bias · Use cross cultural and cultural fair assessment tools · Appreciate code of rights and gain skills to advocate for Asian clients’ interest and welfare	**Effective cross-cultural communications** · Understand that there is a complex relationship between sense of self and language abilities · Identify the extent to which judgments of clients can be influenced by their second language proficiency · Use appropriate language around mental health problems and subtleties of that · Gain skills for improving the deciphering of strong accents · Practise on how to solicit and record culturally specific information relevant to mental health assessment and treatment planning
	Asian people’s culture and mental health · Discuss “who are Asians in Aotearoa New Zealand?” · Understand core nature of Asian culture · Realise intra-ethnic variations within the Asian population · Shame and stigma associated with mental illness in Asian communities	**Work with Asian clients in planning and implementing interventions – individual level** · Understand individual versus family, collective decision making · Understand challenges faced by family members/ care-givers · Identify issues and Asian people’s assumptions about therapeutic and psychosocial interventions · Understand ethnic variations in physiological responses to medications	**Work with interpreters in mental health settings** · Practise how to effectively work with interpreters · Consider how interpreters work as “cultural brokers” · Be aware of ethical issues that might arise for an interpreter who is also a member of his/her own community · Understand existing interpretation services

	Work with people from refugees background · Understand nature, course and impacts of torture · Physical and psychological sequelae of torture · Discuss the nature and early signs of complicated or pathological grief	**Work with Asian clients in planning and implementing interventions – individual and organizational level** · Develop skills or strategies for building trust and therapeutic alliance with individual clients and family members/ care-givers · Gain practical knowledge of potential services for Asian clients for example, employment, recreational services · Develop skills or strategies to minimise barriers in accessing mental health services	
	Asian culture as a source for resilience and strengths · Understand Asian people's concept of resilience, strengths, and various forms of coping mechanism of mental health problems · Understand individual, family and community as sources for resilience and strengths (and barriers in some cases) · Gain basic understanding of principles of folk and alternative approach to treatment		

It is suggested that the programme includes both practical and theoretical content. The latter providing an important framework and in-depth analysis of the practical material. Each session starts with outlining the aims, objectives and session content, followed by teaching and learning exercises to facilitate participants' development in the session topics. The next stage is to proceed to trial of the proposed education programme in the main cities in New Zealand. Authors welcome enquires from readers should they wish to find out more about this training programme and its trial outcomes.

Summary

The Asian population is one of the fastest growing ethnic groups in New Zealand and other western countries like the United States and United Kingdom. There is now acknowledgement from the New Zealand government of the need for mental health services to be able to cater for people from diverse cultural backgrounds.

A review of the literature was conducted to identify a range of cultural competence models and best practice in the mental health setting. Results of this indicated that cultural competency is a complex, multifaceted concept requiring practitioners to be on going learners, developing skills such as communication and self reflections while grappling with more abstract concepts of cultural awareness and cultural sensitivity.

From this review, a proposed education programme for implementation has been proposed. The authors suggest that the most pressing research from this study is to now test the effectiveness of different training methods in a variety of contexts and with different professional groups that reflect the diverse mental health workforce in New Zealand.

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Cultural and Demographic Factors of Schizophrenia

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Abstract

Schizophrenia has been described in all cultures and socioeconomic groups throughout the world. The perception of mental illness within the cultural dynamics may affect the diagnosis, treatment, and reintegration of an individual with schizophrenia. As culture influences the ways individuals communicate and manifest symptoms of mental illness, style of coping, support system, and willingness to seek treatment may be affected as well. The role of folk healing among minority cultures is explored. The purpose of this paper is to review the illness and to examine the cultural and demographic factors for schizophrenia.

Key words: culture, mental health, schizophrenia, treatment

Introduction

Schizophrenia has many effects on a person's ability to lead a meaningful life. The disease is found in all cultures throughout the world. Both genders are equally affected. The age of onset of schizophrenia appears to be a factor in the presentation of symptoms. Regardless of its occurrence, whether in Baltimore, Manila, or Rome, the rates remain the same, one percent of the population. According to Kaplan, Sadock, and Grebb (1994), about 0.025 to 0.05 percent of the total population is treated for schizophrenia in any one-year. While most of those treated require inpatient care, only about half of all individuals with schizophrenia obtain treatment, in spite of the severity of the disorder.

Although the manifestations of schizophrenia are varied, the majority of studies have demonstrated that the symptoms of schizophrenia typically form into three relatively independent complexes: (1) positive symptoms (i.e., hallucinations and delusions); (2) negative symptoms (i.e., blunted affect, anhedonia, poverty of speech, avolition, and diminished social drive); and (3) disorganized behavior, including bizarre behavior, and inappropriate affect (Buchanan et al. 1997). These symptoms are not concrete. Not all individuals will exhibit all or a majority of symptoms.

Perhaps living in a world that is distorted by hallucinations, delusions, and paranoia may cause people living with schizophrenia to appear frightened, anxious or even confused. The preoccupation with hearing voices that others do not may cause an individual to become distant and detached from others.

Differential diagnoses of schizophrenia

There are many disorders that may mimic schizophrenia, and the disease varies so greatly in its clinical presentation for different people and onset. The process of diagnosing schizophrenia is difficult, so several other disorders must be ruled out before the diagnosis can be made with a reasonable amount of confidence (Waldinger, 1990).

Mood disorders may be confused with schizophrenia as symptoms of mania and psychotic depression often present with hallucinations, delusions, and bizarre behavior. A variety of personality disorders may present with similar features of schizophrenia. Schizotypal, schizoid, and borderline personality disorders most closely resemble the disease. Personality disorders tend to have mild symptoms that are generally present throughout the person's life (Kaplan et al. 1994). Organic mental disorders may look exactly like schizophrenia but may be attributed to drugs, metabolic disease, neurological condition, or even infection. A thorough laboratory screening, history, and physical examination should be documented to rule out medical illness (Waldinger, 1990).

Disorders such as schizophreniform disorder or delusional disorder may present with the same symptoms as schizophrenia, with the exception of duration of symptoms. The symptoms of schizophreniform disorder have a duration that lasts at least one month but less than six months. Delusional disorder is an appropriate diagnosis if bizarre delusions have been present for at least one month in the absence of the other symptoms of schizophrenia or a mood disorder (Kaplan et al. 1994). Schizoaffective disorder is the appropriate diagnosis when manic symptoms or depressive symptoms develop concurrently with the major symptoms of schizophrenia (Kaplan et al. 1994).

Malingering or factitious disorders may be appropriate diagnoses for those individuals who may be imitating the symptoms of schizophrenia but do not actually have the disease. People who are completely in control of their symptom production maybe given the diagnosis of malingering. These individuals may be motivated by some secondary gain (e.g., financial or legal reasons to gain admission into a psychiatric treatment facility). People who are less in control of their symptoms may be given a factitious disorder (Kaplan et al. 1994).

Culture-bound syndromes

According to Niehas and others (2004), the term cultural bound syndrome, refers to any one of a number of recurrent, locality-specific patterns of aberrant behavior and experiences that appear to fall outside conventional Western psychiatric diagnostic categories. Cultural concepts, values, beliefs, influence health-seeking pathways, and traditional healers play an important role in the management of disease in many cultures where 'Western' medicine is unavailable, viewed with skepticism, or used in parallel with traditional treatment methods. Kaplan et al (1994) asserted that Western psychiatrists tend to view mental illness as culture-free, but certain disorders such as bulimia nervosa is as shaped by Western culture as koro is by Asian culture.

Niehas et al. (2004) conducted a study in West Africa and found that individuals with a family history of either schizophrenia or other psychiatric disorders were more likely to receive the diagnosis of ukuthwasa (symptoms include social withdrawal, irritability, restlessness, and appearing to respond to auditory hallucinations) than amafufunyana (described as a hysterical condition characterized by people who speak in a strange muffled voice, cannot be understood, and have unpredictable behavior. This state is believed to be induced by sorcery that led to possession by multiple spirits that may then speak through the individual ('speaking in tongues'). The authors assert that not all individuals with ukuthwasa and amafufunyana suffer from schizophrenia, but may be used as explanatory models in a subset of schizophrenia sufferers. It may be that families prefer the term amafufunyana, possibly due to fewer stigmas associated than a diagnosis of schizophrenia.

Similarly, among unacculturated Mexican-American families, the term nervios, is used to refer to a wide range of mental illness and psychological distress. With this condition, the patient is not considered blameworthy. However, among Anglo-Americans, schizophrenia is an illness for which the patient's personal character is implicated. (Lopez et al. 2004).

Asians who are less Westernized exhibit culture-bound syndromes more frequently. Early immigrants (40-60 years ago) are strongest believers in Chinese medicine, newer immigrants (past 20 years) combine both Chinese medicine and Western medicine; and first and second generation Chinese Americans are mostly oriented to Western medicine (Lippson, Dibble, & Minarik, 1996).

However, cultural-bound syndromes occur in European cultures as well. Kaplan and others (1994) note that in France, bouffée délirante, is marked by transient psychosis with elements of trance or dream states. In Spain and Germany, involutional paraphrenia, refers to a paranoid disorder that occurs in midlife and has features of, yet is distinct from schizophrenia, paranoid type. Cultural bound syndromes that share features of schizophrenia include: amok, marked by a sudden rampage, usually including homicide and suicide, ending with exhaustion and amnesia (documented in Southeast Asia and Malaysia); colera, marked by violent outbursts, hallucinations, delusions, and temper tantrums (documented in Guatemala); and latah, marked by automatic obedience reaction with echopraxia and echolalia (documented in Southeast Asia, Malaysia, Bantu of Africa, and Ainu of Japan) (Kaplan et al. 1994).

Explanatory Models of Illness

As culture influences the ways individuals communicate and manifest symptoms of mental illness, their style of coping, their support system, their willingness to seek treatment may be affected as well. Asian Americans and Pacific Islanders have the lowest rates of utilization of mental health services of any ethnic population. This may be attributed to cultural stigmas and financial shortcomings (Sherer, 2002). Patients may be reluctant to discuss emotional problems with strangers. Stoicism is a characteristic that is expected among many Asian Americans. Asian American patients may not express their emotional pain. Somatic complaints may be expressed instead. This somatization may be interpreted as a defense mechanism for the guilt and shame associated with seeking mental health treatment.

In studies examining Asians and Caucasians with schizophrenia, it was found that both groups had similar inception rates. Bhugra et al. (1999) found that it there are differences in symptoms manifestations between Asian and Caucasians and in the mode of onset. The London study found that Asians were more likely to commit suicide. Auditory hallucinations were more often reported than in Caucasians. Asians were more likely to show neglect of activities, lose appetite, and be irritable. Caucasians were twice as likely to have somatic complaints and perform violent acts compared to Asians. The study also found that Caucasians were more likely to suggest that others are responsible for the onset of the mental illness of the individual compared to Asians who were more likely to take responsibility for the onset and treatment of the disorder, suggesting higher pre-morbid functioning (Bhugra, et al.1999). These findings may reflect the Western cultural expectations for Asians to be more stoic and controlled than other cultural groups.

In a longitudinal study by Goater, King, Cole, et al.(1999), it was found that the incidence rates of schizophrenia and non-affective psychosis were higher in all ethnic groups compared with Caucasians in the United Kingdom. The researchers found that members of ethnic minorities tend to see general practitioners that are more likely overlook psychological symptoms. This may not only delay the diagnosis of schizophrenia, but the referral and subsequent treatment (Goater et al. 1999).

Overall, the inception rates of schizophrenia were similar between Asians and Caucasians. This may suggest that ethnicity by itself may not be as strong a factor associated with schizophrenia as previously hypothesized. Bhugra et al. (1999) concluded that other social factors might play a more significant role in the onset, diagnosis, and treatment of schizophrenia in different ethnic groups. The investigators for both studies concluded that further research is needed to study the impact of social support systems and family dynamics on individuals with schizophrenia. Socioeconomic status, perhaps reflected by level of education, may be a more accurate indicator of the recognition, diagnosis, and treatment of schizophrenia in ethnic minorities.

The researchers also noted that among the limitations of their respective studies was the ambiguity in the term "Asian". Defining who is "Asian" may cause a number of problems in the collection and interpretation of data. Neither study specified if "Asian" referred to immigrants, or if it included children of immigrants who were not born in their families' country of origin.

Some African Americans may view mental illness has a form of punishment or as "spells" being cast upon wrong doing. The onset and the subsequent treatment may be perceived as a disgrace and may suggest the inability to handle responsibilities and threaten an African American woman's position/role of mother (Amankwaa, 2003). McCabe and Priebe (2004) compared explanatory models of illness that may differ among people with schizophrenia from four cultural backgrounds (African-Caribbeans, West Africans, Bangladeshis, and Whites). They found that Whites cited biological causes more frequently than non-White groups, who cited supernatural causes more frequently. African-Caribbeans, West Africans, and Bangladeshis are more likely to have social or supernatural explanatory model. However, the type of explanatory model does not appear to be associated with treatment compliance (McCabe & Priebe, 2004).

Folk Healing

Krajewski-Jaime (1991) asserted that folk medicine and modern scientific practice have coexisted for many years. Folk-healing interventions that have validity and integrity within the client's cultural context may be interpreted as ignorance, superstition, or simply as abuse and/or neglect (Krajewski-Jaime, 1991). Practices and common elements of folk healers may be misinterpreted or even pathologized by members of the majority culture (Dana, 1993). New arrivals are more likely to use indigenous healers. For example, among Southeast Asians, the Vietnamese might seek out Taoist teachers and ethnic health practitioners such as Vietnamese physicians, the Khmer and Lao might use Buddhist monks, and the Hmong might use herbalists and shamans (Kitano, 1989). Curanderismo, or folk healing, is the treatment of a variety of ailments with a combination of psychosocial interventions, mild herbs, and religion (Salimbene, 2000). Some of the ailments that curanderos focus on are thought to be equivalent to those treated by mental health professionals. Bean et al. (2001) urges clinicians to be prepared to collaborate with folk healers when working with Hispanic Americans, as this cultural factor plays a prominent role in the delivery of health care services and treatment compliance.

One implication of folk medicine has to do with the strong ties with the extended family in many minority cultures. It is noted that when a person is ill, many of the family members are involved in deciding if indeed the patient or client is ill in the first place, and the extent of the illness, the treatment to be given, and by whom (Krajewski-Jaime, 1991). Rather than viewing folk healing as a barrier, it should be viewed upon as a strength and resource. Doing so may also help the worker to build rapport with the client. Folk healers may be consulted as a first opinion, because he or she has known the family intimately for many years, speaks their language, and does not dictate orders for care but makes suggestions, leaving the ultimate decision up to the patient and family (Krajewski-Jaime, 1991).

Use of herbs common may be a common practice among Asian American patients. However, this practice may interfere with the efficacy of psychotropic medications. Fundamental Asian health beliefs that may impact mental health treatment include imbalance of the yin and yang, and the corresponding conditions of "hot" and "cold". Illness may be attributed to an upset in this balance of forces (Salimbene, 2000). Braswell and Wong (1994) notes that Native American healing practices are those which may involve traditional medicine practitioners, such as medicine men and women, herbalists, and shamen, to restore an individual to a healthy state using traditional medicines, such as healing and purification ceremonies, teas, herbs, special foods, and special activities such as therapeutic sings, prayers, chants, dancing, and sand painting. Traditional healers may be combined with use of Western medicine. As many as two-thirds of this population continue to use traditional healers, sometimes in combination with mental health care providers (Galanti, 2004).

Native American beliefs hold that the individual is ultimately responsible for his own wellness (Dana, 1993). Wellness implies harmony in spirit, mind, and body, while unwellness, comes from natural causes of violations of taboos. This is supported by the Trimble and Hayes (1984) who stated that mental illness is the result of living beyond the rules of right living in which a shaman can be helpful. This is contrary to the mainstream White population in the United States, which views mental illness as the result of trauma and external stressors, a chemical imbalance, or a pathological process within the individual that can be relieved through medication and personal efforts toward behavior change (Trimble & Hayes, 1984).

Onset of schizophrenia

For many people, the symptoms of schizophrenia can be frightening and tragic. Confusing changes in behavior, complex delusional belief systems, and cold detachment from otherwise engaging members of families may tragically withdraw from society, unable to cope with the manifestations of a chronic and persistent debilitating illness. Individuals who are just entering adulthood are often struck down by the symptoms of schizophrenia. While it is generally regarded that this illness has an onset in late adolescence, a significant amount of people first manifest symptoms of schizophrenia in middle or even old age.

The type of onset is significant in the analysis of an individual with schizophrenia. Adolescent onset may be considered the age range from 10 to 17 years. Early-adult onset may be considered from 18 to 30 years of age. Middle-age onset may occur between the ages of 30 to 45 years. Late-onset may be considered after 45 years of age (Hollis, 2000). But the exact determination of the onset can be very difficult, as the illness does not suddenly “strike”. More obvious psychotic symptoms are preceded by more ambiguous behaviors. Misdiagnosis may often occur as the symptoms of other disorders overlap with schizophrenia.
According to a study by Howard et al. (2000), it was found that categorization by specific age at onset ranges is relatively arbitrary. The peak period of onset seems to be from 15 years up to 30 years. They found that early and late onset cases are more similar than different in terms of positive symptoms. Furthermore, no difference in type of cognitive deficits appears in early versus late onset cases. The researchers did note, however, that among cases involving later onset of schizophrenia, somewhat milder cognitive deficits might exist, especially in the areas of learning and abstraction.

Studies of the childhood histories of adult schizophrenic patients have suggested that some early patterns of developmental difference from children who did not become schizophrenic in their adulthood (Lewis, 1996). Children who subsequently develop the disorders have been noted to demonstrate premorbid patterns of behavior such as conduct problems, attentional deficits, or avoidant behaviors. Lewis (1996) reports that onset of disturbance appears to follow at least three general patterns: insidious onset, with a gradual deterioration in functioning; acute, without premorbid signs of disturbance; and insidious onset with acute exacerbation of disturbance. It is further reported that, as in adults, males appear to have an earlier onset of the disorder than females during childhood (Lewis, 1996). Generally, it appears that children who later developed schizophrenia demonstrate a significant delay in achieving developmental milestones by the first two years of life. By age two, they were less likely to reach such milestones such as sitting, standing, walking, and talking. Walker, Savoie, and Davis (1994) found that children who later developed schizophrenia demonstrated poor motor skills and had a higher rate of neuromotor abnormalities compared to their healthy siblings. They also reported that abnormalities were predominantly seen on the left side of the body.

In terms of symptomatology, late onset schizophrenia may have a higher proportion of women than early onset illness. Symptom variables such as emotional expressiveness and social activity, gender may play a factor in assessment. Research by Lindmer, Mohr, Caligiuri, and Jeste (2001) indicates that differences exist between patients who manifest schizophrenia for the first time after age 45 (late-onset schizophrenia, LOS) than those with early-onset schizophrenia (EOS). They found that patients with LOS are more likely to be female, with less negative symptoms, and have a significantly lower duration of illness than other patients. Avila, Thaker, and Adami (2001) hypothesized that according to evolutionary theory, in the case of schizophrenia, lower rates of reproduction constitute a negative selection factor reduce genes in the population associated with the expression of the illness. In effect, this hypothesis predicts the decrease in the prevalence of schizophrenia. Yet, the rates continue to appear a stable one percent across different geographic locations. Their findings are consistent with a model of reproductive fitness in that the more siblings there are of schizophrenic patients, more genetic material necessary for expression of the disease is maintained. This finding provides some insight to why the prevalence rates remain stable despite lower reproductive rates among individuals with schizophrenia (Avila, Thaker, & Adami, 2001). The risk for the general population is approximately one percent. This is a figure that is consistent in other countries as well.

Gender differences in schizophrenia

While it appears that schizophrenia is equally prevalent in men and women, the two genders show several differences in onset and course of illness. Kaplan et al. (1994) describe differences such as peak ages of onset. Men seem to have the onset of schizophrenia from ages 15 to 25 years. The peak ages of onset for women are from 25 to 35 years. The mean age of onset for men was 31.2 years for men and 41.1 years for women. It appears that studies overwhelmingly support an earlier age of onset in males by 3 to 5 years, regardless of culture. Females have several peaks of onset, first in their twenties, one in middle age, and another over age 65 years (Kaplan et al. 1994).

Differences in symptomatology exist between the genders. Studies have found that while men tend to display more negative symptoms, schizophrenic women tend to display more affective symptoms such as dysphoria, depression, irritability, hostility, inappropriate affect, impulsivity, sexually inappropriate or bizarre behaviors, and sexual delusions. Szymanski, Lieberman, Alvir, Mayerhoff, Loebel, and Geisler (1995) found that females displayed significantly less illogical thinking, but more anxiety, inappropriate affect and bizarre behavior. The study reports that women were diagnosed more frequently with paranoid and disorganized subtypes of schizophrenia than men. Females were found to be more likely than males to express persecutory delusions (Szymanski et al. 1995).

Pre-morbid functioning tends to be better in women than men. Perhaps this is based on more opportunities for women to be more socially adjusted and having greater chances of finding partners and starting families of their own before becoming ill. This may be reflected in the later onset of illness for women. In a study conducted by Rasanen, Nieminen, and Isohanni (1999), it was found that in Finland, men with serious psychiatric illness often stay home with their parents and fail to progress towards higher education, work, or marriage. This is consistent with other findings that may be attributed to the later onset of schizophrenia in women.

In general, the outcome for women who have schizophrenia is better than the outcome for men who have the illness. It appears that women are more likely to seek treatment. Diagnostic criteria have been found to be a factor in gender differences in schizophrenia. Seeman (1985) has observed that the more stringent the diagnostic criteria for schizophrenia are, the more females are excluded. Seeman (1985) further states that gender differences may be attributed to more severe roles stresses on males and social protective factors in females.

Estrogen hypothesis

The presence of estrogen has been hypothesized to protect women from the early onset of the severe symptoms of schizophrenia. As the start of puberty brings on hormonal changes, estrogen may serve to protect a woman against an earlier onset of the illness. Female hormones act on the developing brain to protect its integrity and delay the expression of psychosis.

Epidemiological studies have shown that women with schizophrenia present about five years later than men with the disorder (Kulkarnia, Riedel, deCastella, Fitzgerald, Rolfe, Taffe, & Burger, 2001). Life-cycle studies have suggested that women are more vulnerable for a first episode of psychosis or relapse of an existing illness during two major periods of hormonal change, the post-partum period, and the menopausal period (Kulkarnia et al. 2001). These findings are consistent with the hypothesis that estrogen may reduce dopamine concentration, which can then affect acute psychotic symptoms and general health status (Riecher-Rossler & Hafner,1993).

In a study by Howard et al. (2000), it was found that patients with late onset schizophrenia tend to have somewhat subnormal pre-morbid functioning and generally have a chronic course of illness without full remission. In a similar study by Cohen, Seeman, Gotowiec, and Kopala (1999), findings suggest that there may be an association between pubertal hormones and delayed age of onset of schizophrenia.

Upon an extensive review of the literature, Palmer, McClure, and Jeste (2001) conclude that although there may be a link between menopause and the onset of schizophrenia, as estrogen may act as an endogenous anti-psychotic, masking symptoms of schizophrenia in women who are otherwise predisposed to developing the disorder at some point in their lives. Psychosocial factors, the environment, and other influences may combine to serve as protectors or inhibitors of the disorder. Based on this estrogen hypothesis, investigators have begun exploring the possibility of estrogen replacement therapy as an effective supplement to antipsychotic medication in an effort to control the psychotic symptoms of postmenopausal women with schizophrenia (Palmer et al. 2001).

Hochman and Lewine (2004) investigated if this hormone, indeed, serves as a protective factor in the development of schizophrenia and posited that the earlier the age of menarche, the later the onset of schizophrenia. Although the results of their study suggest that an earlier age at menarche might predict improved clinical outcome after schizophrenia onset (in support of the estrogen hypothesis), the authors could not conclude that a causal relationship exists between age at menarche, and the timing of the onset of the disorder.

While it has been determined that schizophrenia affects men and women in equal frequency, there are some gender differences that occur, in terms of manifestations of symptoms. No cultures or ethnic groups are excluded from the illness, which is often misunderstood. Some cultural expectations may influence the interpretation of symptoms. But as symptoms of this disorder rarely present themselves in a sudden manner, onset of illness can be difficult to determine.

Socioeconomic factors

Socioeconomic reasons may become a barrier if treatment cannot be afforded. The cost of psychotropic medications and adverse side effects may result in treatment non-compliance or self-medication. However, there are community and state resources available for those uninsured who are in need of treatment. If symptoms progress and interfere with the individual's ability to function, involuntary commitment and/or forensic involvement become likely.

Tsuang, Stone, and Faraone (2001) modified the description of the term schizotaxia, which is the liability produced by schizophrenia genes, by incorporating biological and psychosocial factors. This concept may provide a basis for development of treatment strategies in non-psychotic individuals who may vulnerable to developing schizophrenia. The disorder appears to be more prevalent in groups that are considered lower socioeconomic class within urban areas. Perhaps this may be due to the relationship between downward mobility and the debilitating effects of the illness. At this time the relationship is unclear, but researchers continue to investigate the effects of stress and development of the illness. Poorer educational achievement is associated in individuals with schizophrenia. However, this may be attributed to attentional deficit, learning disabilities, major neurological conditions, or onset of schizophrenia before the age of 18 years (Tsuang et al. 2001).

Lefley (1990) researched insights from Third World cultures and suggested that patients may function better in developing countries because more kinship networks, buffering mechanisms, and apparently greater respect to tolerance of difficult behaviors may exist within social dynamics. For individuals with schizophrenia, there are also more opportunities for low-stress, non-competitive productive roles in communal societies and agrarian economics. It is possible that Lefley's (1990) comments may be applicable to the parallel conditions that exist in the rural setting.

Lefley (1990) further opined that the two-tiered system of care exists in the United States, private and public, in other words, for the “rich” and “not-rich” (including middle-class America). The author notes that astronomical costs of psychiatric care together with limits on private insurance can insure that ultimately, almost all chronic patients will end up in the public sector (Lefley, 1990). Almost all community support services are in the public sector, including psychosocial rehabilitation programs.

The presence of community support programs does not, however, insure their utility. Galanti (2004) reported that per capita income for Hispanic Americans is among the lowest of the minority groups in the US. This group is the least likely ethnic group to have health insurance, which impacts the delivery of health services. Limited access to mental health services among many Hispanic Americans is related to their lack of health insurance. Locke (1992) notes the cultural group with the lowest average income, least educated, and lowest standard of living, is the Native American population. This group represents the most economically disadvantaged and underserved group in the U.S. Geographical isolation has resulted in a lack of transportation, lack of employment, lack of skilled labor, and absence of capital. Therefore, the mental health problems of uninsured Hispanic Americans and Native Americans often go undetected and untreated because of the low rates of contact with, and access to, health care providers (Gonzalez, 1997).

In a study by Sullivan, Jackson and Spritzer (1996), clinical characteristics and service uses patterns were examined between individuals with schizophrenia who live in rural areas of one state and those who live in non-rural areas of the same state. The researchers found that rural subjects were more likely to live with family members. It was noted rural subjects were less likely to receive opportunities for psychosocial rehabilitation. A similar study by Sorgaard, Hansson, Heikkila, Vinding and Bjarnason (2001) found that while rural regions are said to be better arranged and have more well-functioning social networks, urban areas tend to offer better chances to establish voluntary relationships, resulting in greater satisfaction with emotional relations. The Sorgaard et al. (2001) concluded that women with schizophrenia generally function better socially than men, but this can be attributed to the later onset and development of family dynamics. Sullivan et al. (1996) report that their findings should not be generalized because rural populations across the U.S. differ in levels of poverty, percentage of minority clients, and quality of care provided by local mental health systems.

Seeking Treatment

An understanding of cultural themes is important as they may predominate and less self-disclosure may lead to disjointed information. The difference in health beliefs between the predominant culture provider and the minority client may result in an inappropriate assessment. If practitioners do not understand or respect a client’s traditional health beliefs and find ways to incorporate their beliefs into their treatment, their clients may not participate or become non-compliant with treatment.

Barnes (2004) suggests several factors that may be associated with an over-diagnosis of schizophrenia in African Americans. These include: diagnostic bias of clinicians, lack of cultural understanding between clinicians and minority clients, racial differences in the presentation of psychiatric symptoms. African-Americans may not immediately seek mental health service for a variety of reasons. Not recognizing the need for treatment certainly is a barrier. The onset of psychotic and/or affective symptoms may lead to consultation with spiritual and folk healers, members of clergy, or family members. Perhaps some turn to self-medication via drugs/alcohol. Pugh and Mudd (1971) found that African-American women ranked their mothers, female friends, family physician, and minister as primary sources of help, while African-American men ranked their mothers and their minister, followed by their wife and father. The strong religious and spiritual aspects of African-American culture can be an important part of mental health treatment.

Communication styles may become issues during treatment. A client who has cultural values, beliefs, and customs different from the provider might not only connote a different meaning to symptoms but also express it in a way that can be misunderstood. Out of respect for authority figures, eye contact may not be made when discussing personal issues. Again, out of respect, a patient may turn down an offer to receive services or for further assistance. Several attempts may be made before the patient accepts. Wait time during interaction may be perceived by the therapist as defensiveness or unwillingness to engage, when it may actually be out of respect for authority.

Delivery service style with Hispanic American clients should be sensitive to implications of respeto, personalismo, and platicando, in which informal, individualized attention and how they affect the therapeutic alliance (Santiago-Rivera, 1995).

Kim, Bean, and Harper (2004) present eleven specific guidelines when working with Asian Americans: Assess support systems; assess immigration history; establish professional credibility; provide role induction; facilitate "saving face"; accept somatic complaints; be present/problem focused; be directive; respect family structure; be non-confrontational; and provide positive reframes.

It is important to be aware of fundamental observations when considering the different approaches to the treatment of schizophrenia. Kaplan et al. (1994) propose three observations. First, schizophrenia occurs in a person who possesses unique strengths and limitations. Treatment should be tailored to capitalize on those strengths while corresponding to how the person is affected by the disorder. Second, the fact that numerous studies have suggested that the cause of schizophrenia is probably due to the genetic, environmental, and psychological factors leads clinicians to utilize pharmacological agents to address biological issues while using non-pharmacological strategies to address non-biological issues. Third, just as schizophrenia is a most complex disorder, the individual is also both complex and unique. Limiting the individual to one therapeutic approach rarely, if ever, seems appropriate in addressing this multi-faceted disorder (Kaplan et al. 1994).

Family Support

Culture shapes the way in which families construe schizophrenia. An understanding of a client's cultural heritage can improve the quality of the relationship between the mental health professional and client. Family education and ongoing support is beneficial in order to maximize the support the family network can provide the individual. This is especially critical when the individual with the disorder is under the direct care of the family. This is noteworthy in the treatment of males, whose onset occurs earlier than females, and are often still living in the family home. The extended family is important, and any illness concerns the entire family. Mental health professionals should be mindful that decision-making varies with kinship structure.

In Asian cultures, like many other cultures, family members generally do not institutionalize members. They care for them in the home. According to Bae and Brekke (2002), Asian families are more likely to accompany the schizophrenic patient on clinic visits and to actively participate in treatment decisions. The authors reviewed the literature regarding participation in treatment among Asians, They found that it is possible that variation such as geographical location, acculturation levels, and diagnostic criteria may account for different findings in the literature. Also, the combining of Asian-Americans into one group may have limited external validity (Bae & Brekke, 2002).

Therefore, the family may be involved in decision-making with the patient. Galanti (2004) recommends that family members be included to allow them to fulfill their familial duty by spending as much time with the patient as possible.

Sociocentric individuals with collectivistic cultural orientation tend to emphasize family integrity, harmonious relationships, and sociability. Bae and Brekke (2002) note the importance of incorporating cultural characteristics into the intervention process. Interventions that are designed to involve families in a collaborative effort may be more appropriate for minority members because of the interdependent nature of their family dynamics.

Conclusion

Schizophrenia is a severe and persistent mental illness that crosses all racial, ethnic, cultural, and demographic lines. The influence of class status, ethnic and cultural identity in relation to the presentation and the reporting of schizophrenia must be considered. Communication, coping styles, support system, and willingness to seek treatment are also affected. The factors discussed influence beliefs, attitudes, and behaviors regarding the identification of illness and health and in the process of treatment and recovery. The lack of educational and financial resources may create a barrier, in terms of utilization of services and compliance with treatment. Understanding how psychosocial factors within the cultural dynamics of this population would promote more culturally relevant care.

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Employment and Psychosocial Outcomes for Offenders with Mental Illness.

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Abstract

Mental illness, unemployment and continual involvement with the criminal justice system, results in a lower quality of life for offenders with mental illness. Prevalence rates of mental illness among individuals involved with the criminal justice system are 2-5 times higher than rates among the general population. Roughly 16% of offenders in the United States' prisons and jails have been diagnosed with mental illness or reported a prior admission to a psychiatric facility (Ditton, P., 1999). Mental health courts, similar to drug courts, are specifically designed to divert or decriminalize offenders with mental illness, by connecting them with appropriate community services. Recently these courts have expanded in number and scope, attempting to address diverse needs of offenders; however relatively little data exists regarding the employment outcomes of mental health court participants. The purpose of this paper is to provide employment related data from the evaluation of a mental health court in the Southwest United States.

Key Words: Offenders, Mental illness, Mental health court, Employment

Introduction

Rates of mental illness among offenders are markedly higher than those found among the general United States population (Lamb & Weinberger, 1998). Approximately 16% or 283,000 offenders in the nation's institutional correctional systems have a mental illness or reported a prior admission to a psychiatric facility (Ditton, 1999). Furthermore, jails have been referred to as hospitals of last resort for people with mental illness (Perez, Leifman, & Estrada, 2003). Similarly, Ditton (1999) found that more than 40% of jail inmates reported receiving some type of treatment for a mental illness. Employment rates of people with mental illnesses are lower than for other disability groups, and are disproportionate compared to the current United States population (Corbière, Mercier, & Lesage, 2004; Henry & Lucca, 2004; World Health Organization, 2000). Additionally, offenders with a mental illness face double jeopardy. That is, not only do offenders with mental illness have the stigma of a mental illness, there is the additional stigma associated with an offender status. Furthermore, poor treatment while incarcerated, and even less access to treatment and services post-release contribute to high recidivism rates for offenders with mental illness.

Employment and Mental Illness

Mental disorder or mental illness is defined in the DSM-IV, as "…a clinically significant behavioral or psychological syndrome or pattern …that is associated with present distress or disability or with a significantly increased risk of suffering death, pain, disability or an important loss of freedom," (American Psychiatric Association, 1994, p. xxi). In general, mental illnesses typically cause impairments in activities of daily living, with regards to familial, educational, social, and vocational responsibilities. Rates of mental illness in the United States are hard to pinpoint, for a variety of reasons. The definition of mental illness within the psychological, psychiatric, and research communities has changed over the years with various definitions used (Hong, 2002). Additionally, diagnostic criteria have been modified, updated, and revised to reflect current research and theories. One study, the Epidemiological Catchment Area Program in 1995, indicated that upwards of 28% of the current population in the United States has a diagnosable mental illness (Reiger & Burke, 1995).

Stigma and stereotypes about mental illness present barriers to gaining or maintaining employment for people with mental illness. Compared to people with physical disabilities, people with mental illness experience greater levels of discrimination, less access to services and treatment, and higher rates of unemployment (Brodwin, Tellez, & Brodwin, 2002; Henry & Lucca, 2004; Hong, 2002). People with mental illness are often characterized as irrational, illogical, prone to violent acts, and unreliable. All of these barriers combine to contribute to poor employment and psychosocial outcomes for individuals with mental illnesses.

There are a variety of other barriers to employment for people with mental illnesses. Specifically, Henry and Lucca (2004) identified a number of barriers to employment, through use of focus groups composed of consumers with mental illnesses and service providers across a variety of disciplines and human services. Disorder-specific symptoms for which there were few or no options for accommodations interfere with work. Also consumers' fear of a work-induced relapse creates a significant barrier. This barrier is so significant that individuals may be reluctant to even attempt to work. Consumers also identified limited skills, education, and work history as profound barriers. This barrier can only be overcome through some type of education or experiential training, which in turn may elevate a consumer's fear of returning to work. Also lowered work expectations, both on the part of the employee and employer contribute to lower employment rates. All of these barriers cause a Pygmalion effect, which serves to reinforce the stereotype that individuals with mental illness cannot maintain employment. Finally, financial disincentives and reliance upon entitlement programs was identified as a significant barrier. That is, a loss of healthcare benefits in return for engaging in employment. Consumers reported that disincentives are so prevalent, coupled with the complexity of entitlement systems, that even trying to gain or maintain employment almost did not seem worthwhile (Henry & Lucca, 2004).

Regarding mental health and rehabilitation service delivery systems a number of barriers to employment are also present for individuals with mental illness. Specifically, poor communication among service providers and conflicting expectations contribute to frustrating consumers. Moreover, lowered expectations among mental health and rehabilitation service providers were identified as factors related to fewer options for employment (Henry & Lucca, 2004). Consumers and service providers also reported that mental health and rehabilitation service systems seemed to value therapy and medications over work. This is an example of systems adhering more to the medical model of disability, than the psychosocial model, which emphasizes interactions with other people are considered important as are how the consumer perceives interactions with others (Henderson & Bryan, 2004). Also stigma, negative attitudes and stereotypes and their impact on the psychosocial status of the individual are considered as well. All of these factors contribute to the psychosocial model being more applicable to working with consumers who are diagnosed with a mental illness.

Employment rates of individuals with mental illness are lower than for other groups of people with disabilities. For people with mental illness, employment rates vary from 10-20% (Corbière, Mercier, & Lesage, 2004; Henry & Lucca, 2004; World Health Organization, 2000). Furthermore, high percentages of people with mental illness report a desire to work and stress the importance of work in establishing a good quality of life (Henry & Lucca, 2004; Jones, 2005; Scheid & Anderson, 1995). For offenders with mental illness, employment outcomes are even worse, often due to the added stigma of incarceration, lack of community resources to connect the individual with work, and increased likelihood of reentry into the criminal justice system.

Offenders with Mental Illness

Among offenders, several mental illnesses occur more frequently than others. Frequently present disorders among offenders include Axis I disorders such as substance-related disorders, mood disorders, anxiety disorders, and schizophrenia. Axis II diagnoses of mental retardation and personality disorders are also more prevalent in this population (Alexander, 2000). The high numbers of offenders with mental illness have been ascribed to a combination of factors: the deinstitutionalization movement, the homelessness epidemic of the 1980s, and the current War on Drugs (Lamberti, Weisman, Schwarzkopf, Price, Ashton, & Trompeter, 2001; Lamb, Weinberger, & Gross, 1999; Munetz, Grande, & Chambers, 2001; Perez et al., 2003). These factors have directly impacted people with mental illness and have substantially increased the likelihood of interaction with the criminal justice system.

Screening, assessment, diagnosis, and treatment for mental illness in the United States' correctional facilities have been documented as less than adequate (McLearen & Ryba, 2003; Applebaum, Hickey, & Packer, 2001). Also it is important to note that confinement can actually exacerbate psychiatric symptoms (Borum, 1999). Furthermore, the lack of adequate community services post-release has been identified as a predictor of exacerbation of the offender's illness and return to the criminal justice system (Harris & Koepsell, 1998; Lovell, Gagliardi, & Peterson, 2002; Osher, Steadman, & Barr, 2003). Lamberti and Weisman (2004) identified that access to mental health care was a primary concern for probation and parole officers who worked with offenders with mental illness.

The bulk of offenders with mental illness currently incarcerated have committed minor offenses (Ditton, 1999). This incarceration of minor offenders with mental illness has been characterized as the criminalization of the mentally ill (Lamb & Weinberger, 1998; Perez et al., 2003). Relatively few offenders with mental illness require confinement in a secure facility due to the severity of their disorder or offense, nor do they pose a clear danger to themselves or society. Complicating the issue of offenders with mental illness are the disproportionately high rates of co-occurring substance use disorders. Among offenders with mental illness, nearly 75% were also diagnosed with a substance use disorder (Substance Abuse and Mental Health Services Administration, 2002). In examining jail populations, offenders with mental illness were more likely to be under the influence of drugs or alcohol at the time of the current offense than offenders without mental illness (Ditton, 1999).

Due to a lack of community-based programs and services, the majority of offenders with mental illness have frequent contact with the criminal justice system. This group of offenders poses the greatest challenge to corrections and the criminal justice system. Offenders with mental illness have higher rates of recidivism compared to offenders without mental illness (Ditton, 1999; Lovell et al., 2002; Swartz, Swanson, Hiday, Borum, Wagner, & Burns, 1998). Without specialized supervision programs to link offenders with necessary services, offenders with mental illness are at a greater risk for recurring contact with the criminal justice system (Roskes & Feldman, 1999; Lurigio, 2001). In addition, most jurisdictions do not have specialized programs to supervise offenders with mental illness in the community (Lurigio, Cho, Swartz, Johnson, Graf, & Pickup, 2003).

Mental Health Courts

A variety of circumstances have contributed to large numbers of persons with mental illness in the criminal justice system. The impact of handling increased numbers of arrests of people with mental illness has fallen upon the court and jail systems. The impact on local jails and prisons is overwhelming. Specific problems that have been identified in providing services for offenders with mental illness include: few resources, high turnover rates of inmates and staff, and inadequate training of staff (Steadman & Veysey, 1997). Often if the offender does receive treatment while incarcerated, those services are likely to cease upon release from the institution (Lurigio, 2001). Mental health courts were created to address the previously discussed issues by establishing working relationships between the court and mental health agencies (Goldkamp & Irons-Guynn, 2000).

The Courts

Mental health courts were based on the drug court models with the first mental health court established in Broward County Florida in 1997 (Goldkamp & Irons-Guynn). The early courts emphasized the rehabilitation of offenders with mental illness by securing appropriate services in the community (Goldkamp & Irons-Guynn). There are over 100 mental health courts currently in operation in the United States (Steadman, Redlich, Griffin, Petrila, & Monahan, 2005).

The philosophy behind the mental health court is that the judge can take an active role in the case, have open communication with the offender and implement resources for therapeutic change (Goldkamp & Irons-Guynn, 2000). Interaction with the judge and court personnel as well as the judge taking on the new role by becoming a mechanism for change can be viewed as tenets of the psychosocial model (Henderson & Bryan, 2004). Furthermore, because of the interactive process, the offender becomes a stakeholder, having an active part in the process rather than being a passive recipient (Marinelli & Dell Orto, 1999; Smart, 2001). Poythress, Petrila, McGaha, & Boothroyd (2002) found that clients reported lower levels of coercion, perceived the system as more fair, and were more satisfied with the mental health court than a comparison group in a traditional court.

Method

Court Process

The court under evaluation has been in operation since October 2003, and was created to expedite the identification and treatment of individuals with mental illness within the local jurisdiction. Similar to other mental health courts, this court emphasizes early identification and screening of mental illness as well as the importance of connecting the offender to local community mental health and social service agencies.

Once referred to the court, offenders are explained the purpose and the process of the court, and voluntarily enroll in the pre-trial diversion program. Once enrolled, the offender aids in developing a treatment plan, which may include services such as counseling, therapy, medication access, referral to a variety of agencies and assistance in obtaining housing. Offenders in the mental health court program meet once a month with their assigned judge to review progress and performance. If the offender achieves his/her program goals at the end of an agreed upon period, the client graduates from the court and the charges may be dismissed. The goals of the court include reducing recidivism while maintaining community safety. Another goal is to establish community linkages with mental health and social service agencies to provide services for offenders with mental illness.

Data collection

Extant data. To date, 94 offenders have entered the court with close to 40 completions as of Feb. 26, 2006. The data for this analysis was gained by analyzing existing records of court participants, created and collected by the probation officer and case manager of the mental health court. Thus far these individuals have been collecting data on demographic and mental health variables such as age, race, gender, employment, criminal history, diagnosis, mental health services provided, referrals to services, prior hospitalizations, medication compliance, program violations and sanctions.

Descriptive results

Demographics. In total 94 offenders with mental illness have entered the court during this evaluation period. Over a third of offenders were between the ages of 17-25 and nearly equal percentages, between the ages of 26-35 (21.3%) and 36-45 (23.4%). Seventeen offenders were over the age of 46 (18.1%). More than half of the offenders served by the court were Caucasian (64.9%), 23.4% were African-American and just less than 10% were Hispanic (9.6%). The court enrolled an equal percentage of male and female offenders (50%).

Approximately half of the offenders lived with their parents (44.7%), 13.8% with other family members and 3.2% with a roommate. Less than one-fifth (18.1%) lived with a spouse, 11.7% reported living with a significant other and less than 5% lived alone (4.3%). Two offenders lived in a supported living home and only 1 offender was homeless at the time of intake. Nearly 63% of the offenders were single at the time of intake, equal percentages were married or divorced (17% each), with the remaining 3% reporting a status of widowed or separated.

Education. Surprisingly, 70% of the offenders in the mental health court reported having attained a high school education, high school equivalency or post-secondary degree. Of this group a third of the offenders received a high school diploma and nearly 15% received their GED. Ten offenders completed a post-secondary degree and 7.4% reported some college or ‘other’ degree or certification. Nearly 30% had less than a high school education.

Mental health characteristics. Thirty percent of the offenders had no history of hospitalizations for mental health problems. Nearly 47% reported being hospitalized 1-3 times and 13.8% reported 4-7 prior hospitalizations. A smaller percentage of offenders, 7.4% had more than seven mental health-related hospitalizations.

All of the offenders had a current psychiatric diagnosis. Less than half of the offenders (41.5%) were diagnosed with only one diagnosis, 36.2% reported two diagnoses and 11.7% had three psychiatric diagnoses. Eight offenders or 8.5% had four mental health diagnoses and two offenders had five diagnoses. Nearly a quarter of the offenders had a diagnosis of Schizophrenia (23.4%). Mood disorders, such as Bipolar Disorder and depressive disorders were the most prevalent among the mental health court clients (80.9%). Fifteen offenders (16%) reported an anxiety disorder, such as Generalized Anxiety Disorder and Post-Traumatic Stress Disorder. Just over a quarter of the offenders (25.5%) were diagnosed with learning or developmental disorders. Examples of disorders present included Mental Retardation, Pervasive Developmental Disorder and disorders typically diagnosed in childhood such as Oppositional Defiant Disorder and Attention Deficit Disorder. Nearly 20% (19.1%) of the offenders were diagnosed with a substance use disorder, and 9.6% reported diagnoses of personality disorders. While 19.1% had a reported substance use diagnosis, only 12.8% reported current daily use of alcohol and 8.5% daily drug use. Nearly a quarter of the offenders in the mental health court reported receiving treatment for substance abuse or dependency in the past (22.3%). The percentages do not total to 100%, because a majority of offenders were diagnosed with multiple disorders.

Nearly 12% of the offenders in the mental health court reported no current medication prescription. Roughly two-thirds of the group (62.8%) had between 1 and 3 prescriptions. Just over 20% of the offenders had between four and eight prescriptions, while four offenders reported having more than 8 current prescriptions. Participants in the mental health court had prescriptions for both physical and mental health conditions. Of particular interest to the court is the number of prescriptions for psychotropic medications. Nearly 12% of the offenders in the court program had no prescription for psychotropic medications, with 70.2% reporting between 1 and 3 psychotropic medications, and nearly 11% (10.6%) taking between four and six psychotropic medications. One offender reported taking more than 6 psychotropic medications.

At the twelve-month completion point, 27.5% of the court participants reported no current prescriptions. Another 40% reported taking between 1 and 2 prescriptions. The participants were rated as compliant or non-compliant with regards to their medication regimen, with 74.4% being rated as compliant. The majority

(86.8%) of court participants reported no hospitalizations prior to the close of the program.
Mental health services. More than half of the participants (56.4%) reported receiving no current mental health services when interviewed for the intake. Conversely, the court appears to have made the biggest impact in this area, as 61.5% of the offenders with mental illness reported receiving services from the court at the twelve-month assessment. Common types of services were mental health counseling, psychiatric monitoring, individual counseling, and group counseling. Of these services, 28% of participants received one service, and 25.6% reported receiving two types of services, and 28% of participants received more than 2 types of services.

Over four-fifths (81%) of the court participants receiving services received individual counseling during the program. Approximately a quarter received 11 or more hours of individual counseling and 19% received 1-5 hours. Only 9.8% of the offenders attended group-counseling sessions. More than half (54%) of the court participants had one or two psychiatric appointments (11.9% and 42.9% respectively).
Employment. At the time of intake, nearly 75% of the offenders were unemployed (74.5%). Twelve offenders (12.8%) reported they were employed full-time. Another 8.5% reported working part-time. One offender reported working less than 10 hours per week and 3 offenders described their employment status as retired.

At the end of the twelve-month program, the majority of mental health court participants reported no change in employment status (89.7%). One individual reported gaining full-time employment and one individual reported becoming unemployed. Regarding referrals to agencies for employment related needs, the court provided a variety of information packets and brochures to participants. Additionally the court used a psychoeducational approach working with court participants to emphasize the importance of accessing vocational rehabilitation, supported employment or other agencies that focuses on employment related needs. While 12 months is a relatively short period of time to expect vast changes in employment among the court participants, the absence of referrals for services that could potentially increase the probability of finding and maintaining employment is problematic. The failure to refer for vocational services may be due to the inability of the court to offer formal case management services. Furthermore, court personnel have noted the creation of informal collaborative practices among agencies; however, the need to refine and formalize these connections cannot be overemphasized.

Discussion

Employment can be viewed as a key factor in improving the quality of life of people with mental illness. Another factor that is important to consider in improving the quality of life for people with mental illness, is that a large number of individuals have a desire to work (Drake, Becker, & Bond, 2003; Jones, 2005; Scheid & Anderson, 1995; Strong, 1998). Additionally, employment provides individuals with a sense of purpose and accomplishment, helps delineate one’s identity, and provides a variety of social situations and opportunities for interaction with others (Henderson & Bryan, 2004). Furthermore, some individuals believe that if an individual is able to work, then they are obligated to do so, as part of being a good citizen (Marrone & Golowka, 1999).

A variety of research has demonstrated that employment services for people with mental illnesses must be specifically designed and delivered for the individual, to maximize employment outcomes. Of particular importance is the emergence of supported employment for people with mental illnesses. Supported employment, which grew out of vocational rehabilitation, is a program that has been modified over time to work well with people with mental illness (Clark & Samnaliev, 2005). This program is designed to increase a person’s chances of successfully acquiring and maintaining a job in competitive employment, rather than working in a sheltered workshop or remaining unemployed (Henderson & Bryan, 2004). The program entails on-site provision of services for the consumer. Thus far, a variety of studies have concluded that supportive employment is effective at improving competitive employment rates, hours worked per month, and average earnings per month (Clark & Samnaliev, 2005; Shankar & Collyer, 2002; Twamley, Jeste, & Lehman, 2003). Furthermore, the supported employment approach involves a case-manager, also known as a job coach. The job coach is the central person involved in this method, which identifies appropriate jobs and assists in providing training (Henderson & Bryan, 2004). In some instances the job coach or case manager may work with individuals on a daily basis.

As evidenced by the results previously discussed from the mental health court, 89.7% of the mental health court participants experienced no change in employment status. This means that the 74.5% unemployment rate of court participants stayed the same, as only 1 individual reported gaining a job and another individual reporting becoming unemployed. The court took efforts to provide the participants with informational and educational materials designed to refer and prompt court participants to seek out vocational services; however it appears these measures were ineffective with this population. The unique aspects of vocational rehabilitation services and more specifically supported employment programs, designed for consumers with mental illness, underscore the need for mental health courts to adopt a case-management style approach. Offenders with mental illness often encounter a variety of barriers to employment connected not only to their mental illness, but also to their status as an offender. In situations like this a case-manager can work with individuals to ensure they are accessing services, following up on scheduled appointments, and/or providing direct employment placements and training (Jones, 2005; Shankar & Collyer, 2002).

For offenders with mental illness, employment can be viewed as a therapeutic agent. Often unemployment, homelessness, and poverty lead to exacerbation of symptoms and an increased likelihood of reentry into the criminal justice system (Harris & Koepsell, 1998; Lovell, Osher, Steadman, & Barr, 2003). The mental health court was successful at linking court participants with a variety of types of services (counseling, individual and group therapy, psychiatric monitoring); however it appears employment related community services for offenders with mental illness requires a different approach. A more formalized case-management approach may be necessary to improve employment outcomes for offenders with mental illness.

Conclusion

Substantial research shows that people with mental illnesses are unemployed at a disproportionate rate compared to the general population. Additionally, the research shows that people diagnosed with a mental illness have a strong desire to work, but are faced with a variety of barriers. Offenders experience significant barriers to employment as well. For offenders diagnosed with a mental illness, the barriers to work are more problematic and rates of unemployment more staggering. Mental health courts have developed over the last decade, as a response to the disproportionate number of offenders with a mental illness in the criminal justice system. The objectives of these courts are to assist offenders by establishing linkages with community mental health agencies, increase motivation to seek and attend treatment and to provide an interactive process with the judge that can reduce recidivism and facilitate change. The mental health court examined in this study was able to increase participant access to a number of community-based services; however, the employment rates of the participating offenders did not change.

Employment is a key factor for improving psychosocial outcomes for offenders with mental illness, as it improves socioeconomic status, provides social interaction, helps provide a meaning or purpose for the individual, and may be viewed as a therapeutic agent. More formalized case-management techniques exist that may improve access to and performance in employment services for offenders with mental illness. Recent research indicates that supported employment may be the best-suited type of employment services for this population. Future research needs to address the unique challenges of evaluating mental health courts as well as the role of employment in improving psychosocial outcomes and reducing recidivism among offenders with mental illness.

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Integrated Psychosocial Intervention in Schizophrenia: Implications for Patients and Caregivers

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Abstract

A comparative pre and post intervention analysis to determine the extent of change in psychiatric symptomatology in schizophrenic patients attending a community based rehabilitation programme and the family burden and perceived quality of life of their caregivers was undertaken. An integrated intervention package comprising of pharmacotherapy, psychosocial therapies and spiritual therapy was provided to the patients and their caregivers. Instruments to assess the psychiatric status of the patients as well as family burden and quality of life of their caregivers were administered. Results indicate significant reduction in patient symptomatology as well as caregiver burden and enhanced QOL of the caregivers following intervention. Further, a significant negative correlation between the family burden and QOL scores of the caregivers was obtained. It is suggested on the basis of this study that spiritual therapy specific to the religious orientation of patients combined with pharmacotherapy and other psychosocial therapies may enhance the effectiveness of intervention in schizophrenia.

Keywords: Psychosocial rehabilitation, Family burden of caregivers, Quality of life of caregivers, Therapeutic intervention.

Introduction

Indian families have been typically described as often believing in causes like supernatural forces and therefore seek help from magico-religious healers observe Srinivasan & Thara (2001). Beliefs about the causation of schizophrenia could influence the attitudes patients' families adopt towards the patient and may also influence their help-seeking behaviour. This is particularly true of rural and semi-urban populations in India and those hailing from an orthodox and very religious background who throng religious centers of healing in search of a desperate cure for mental illness.

Schizophrenia is a severe mental illness, which is stressful not only for patients, but also for family members. Providing care to family members dealing with chronic illness may result in feelings of burden or strain for caregivers that can diminish their quality of life (Sales, 2003). Numerous studies have demonstrated that family caregivers of persons with a severe mental illness suffer from significant stresses, experience moderately high levels of burden, and often receive inadequate assistance from mental health professionals (Saunders, 2003). Martens & Addington (2001), observe that family members are significantly distressed as a result of having a family member with schizophrenia and Ivarsson et al. (2004) contend that family caregiver burden is complex and includes several areas such as activities in daily life, worry and social strain. Effective family functioning in families with schizophrenia may be influenced by a variety of psychosocial factors (Saunders, 2003). Family conflict and family intimacy have been found to reflect the degree of burden or reward experienced and it is suggested that the family system, as the context within which the patient exists, be seen as the mediating environment for caregiving burden and reward (Heru, 2000).

Identifying predictors of family burden in caregivers of patients with schizophrenia has been the focus of several investigations. Lanzara (1999), found that disability is the main predictor of family burden whereas manic and positive symptoms, time spent by the carer with the patient and carer's social support are less important. Satisfaction with mental health services is predicted by family burden. Disability related to work and sexual problems is frequent while social withdrawal, under activity, lack of participation in household duties and lack of self-care are less frequent. Family burden is severe in one third of relatives, mainly in social relationships. Solomon & Draine (1995), opine that the best set of predictors of burden, identified by stepwise linear regression, was young patient age, awareness of patient's suicidal ideation, and family resources. Mc Donell et al. (2003), found that 39% of the variance in subjective burden was explained by the severity of stressors related to the relative's illness and by mediators related to social support and coping capabilities.

Lauber et al. (2003), are of the view that the most important predictor of burden is burden in the relationship between caregiver and the affected representing the changes in the relationship occurring in acute illness. Threats, nuisances, time spent with the affected, and burden due to restricted social life and leisure activities were additional predictors. Winefield and Harvey (1994), observe that burden in the sense of interference in their daily lives was most marked for those caregivers who were in high contact with the patients. Stengard et al. (2000), found that caregivers were more likely to be dissatisfied with the situation if they lived with the patient and if the patient's functional state was poor or the patient's use of services, particularly medication and rehabilitation was low. Psychological well being of carers is affected by the dimensions of perceived burden (Madianos et al., 2004). Psychological impairment was related with high levels of burden and negative family atmosphere. Previous admissions and duration of illness were also found to predict burden. Winefield and Harvey (1993), found that caregiver psychological distress was high and the level of behavioral disturbance in the sufferer was found to contribute to caregiver distress after controlling for the caregiver's age, sex, and social supports. In general, changes in the parents' burden level are closely interconnected with the illness curve of the patients, and Jungbauer et al. (2003), observe that parents of continuously and severely affected patients are overloaded with their long-term caring tasks.

It is also seen that parents and spouses perceive the caregiver burden differently, although there are some apparent similarities (Lauber et al., 2003). Jungbauer et al. (2004), hold that the spouses not only face illness-specific burdens but also burdens resulting from their partnership and family roles. The chronic burden of everyday living can profoundly reduce the quality of life and the subject's satisfaction with the partnership.

Thornicroft et al. (2004), found that low quality of life in schizophrenic patients was associated with: anxiety, depression, psychotic symptoms, more previous psychiatric admissions, alcohol abuse, having no reliable friends nor daily contact with family, being unemployed, and having few leisure activities. The most frequently occurring unmet needs among the patients were: daytime activities, company and intimate relationships, psychotic symptoms, psychological distress, and lack of information. The most common worries of relatives were about the patient's health, and their own future, safety and financial position.

In a study from Germany, Angermeyer et al. (2000), report that more than half the participants expressed the need for more support and complained of not having enough opportunities to relieve their burden. Hence there is a distinct need to understand the extent and nature of burden experienced by the caregivers of schizophrenics and to initiate measures during intervention to enhance their quality of life.

Though there are several crossectional studies in the literature that have investigated family burden and quality of life in caregivers of patients with schizophrenia, it is seen that not many prospective studies have investigated change in these variables prior to and after intervention and such studies are woefully inadequate in the Indian context. This study attempts to address this lacuna and is a comparative pre and post intervention analysis that seeks to determine the extent of change in psychiatric symptomatology in schizophrenic patients attending a community based rehabilitation programme and the family burden and perceived quality of life of their caregivers.

Material and Method

Objectives

1. To portray the socio-demographic and clinical profile of patients with schizophrenia as well as their primary caregivers.
2. To assess the psychiatric status of the patients at admission and at first follow up.
3. To assess the caregivers of patients with schizophrenia before and after psychosocial intervention with regard to the following subject dimensions:
    a. Family burden (FB).
    b. Quality of life (QOL).
4. To bring out correlations if any between the subject dimensions.
5. To ascertain if the patients as well as their caregivers show any differences on these subject dimensions based on their gender.

Setting

The study was conducted at the community based care center, Gunaseelam, in TamilNadu, a southern state of India. The rehabilitation center is attached to a Hindu temple named after its presiding diety Prasanna Venkatachalapathy Perumal. The site is a known place for religious healing of the mentally ill for the past 200 years. Now a modified integrated treatment approach is offered in the temple premises for schizophrenic patients. It is a blend of traditional temple rituals and modern psychiatric intervention involving pharmacotherapy and psychosocial therapies. The center has 12 beds, and provides inpatient services exclusively for schizophrenia patients. The treatment follows an integrated approach which includes pharmacotherapy, psycho education and spiritual therapy. Professional services are provided by the Sowmanasya Hospital and Institute of Psychiatry, Trichy free of cost.

Components of Integrated Intervientiont

I. Intervention for the patients
    a. Pharmacotherapy
    b. Individual psychotherapy
        Supportive therapy, motivation, counselling, psychoeducation, relapse prevention, CBT, if required by patients.
    c. Group therapy
        Play therapy, movement therapy, Recreational therapy Art therapy.
    d. Occupational therapy
        Paper cover making, cleaning tulsi leaves.
        Attention and concentration exercises
    e. Spiritual therapy
        Pradhakshanam (circling around the deity in a clock wise manner twice a day).
        Attending four-kaala pooja (Performing ritualistic worship four times a day)
        Splashing holy water on their faces twice a day.
II. Interventions for the caregivers
    a. Individual psychotherapy
        Supportive therapy, psychoeducation, counselling.
        b. Group therapy
        Group family therapy, Group psychoeducation, and Raja yoga meditation.

Duration:

The stay period is for a minimum of 48 days to a maximum of 90 days for the patients and their caregivers. Professional team members: Psychiatrist, psychiatric social workers, occupational therapist, Nurses.

Research Design

This is a quasi-experimental study since no control group has been deployed nor have subjects been assigned randomly to an experimental and a control group as in a true experimental study (Judd & Kenny, 1981). It uses a single subject design comprising of a group of schizophrenia patients as well as their caregivers and compares pre-intervention baseline data with that following intervention in both groups. The attempt has been to bring out changes if any in the mental health status of the patients as well as the burden and QOL of their caregivers following intervention.

Selection of Respondents

Data was collected from thirty consecutive patients and their caregivers based on the following criteria:

Inclusion criteria for the patients
1. Patients should have been diagnosed schizophrenia (F20) (using ICD – 10 Diagnostic criteria, WHO 1992)
2. Patients should be above 20 years of age.
3. Patients should be co-operative for data collection.

Inclusion criteria for the caregivers
1. An adult aged 20 years or more
2. He / she should be of first or second – degree relationship to the patient.
3. Should be the attendant of the patient during the entire stay in the community care center and also should care for the patient after discharge.
4. Willing to co-operate and provide consent for the study.

The exclusion criteria for the caregivers and patients
1. Caregiver should be free from psychiatric or physical disorder which might interfere with the care of

patients and his / her co- operation during interviews.

2. Any other co- morbid psychiatric diagnosis in the patient like dementia, OCD, Substance abuse (excluding tobacco use).

Instruments

1. Family Burden Scale by Pai and Kapur (1983).
2. Perceived Quality of Life Scale by Patrick et al., (1998).
3. Positive and Negative Syndrome Scale (PANSS) by Kay (1986).
4. Self-prepared interview schedule to elicit socio-demographic data and clinical particulars.

The PANSS was administered to the patients for assessment of symptomatology and the remaining instruments to the caregivers. All instruments were administered twice; first at the time of admission and later after intervention during the first follow up contact 30 days after discharge from the center.

General Background of the Caregivers

The majority of the caregivers were female (53.3%) and their age ranged from 23 to 75 years with a mean age of 54.9 years. While the majority of them were parents (76.7%), 16.7 per cent of the caregivers were spouses and the remaining (6.6%) were siblings of the patient. The majority of the caregivers were married (70%) and had availed of basic school level education. Their mean income per month was Rupees.1408.80.(approx.32 $).

Profile of the Patients:

The age of the patients ranged from 21 to 50 yrs with a mean age of 32.7 years. The majority of them were female (53.3%) and were unmarried (66.7%) and had availed of school education. Seventy per cent of them were not employed while the remaining were earning and had a mean income of Rs. 533.30 per month. The majority of them hailed from nuclear families (76.7%) and had a mean family size of 3.8. Half of them belonged to the first two ordinal positions in their family. All of them had a F20 diagnosis and the majority were said to have the illness for 5 to 10 years (63.3 %). The majority of them manifested the disorder before the age of 22 and sixty per cent reported being treated for a duration up to 5 yrs. The majority (70%) reported irregular treatment and had a history of multiple hospitalizations prior to their admission at Gunaseelam. For 46.7% of them this was the first instance of hospitalization.

Results & Discussion

Data analysis was done by using SPSS (Ver. 10.0). The data was subjected to statistical procedures such as t-test, ANOVA, Scheffe procedure and Karl Pearson's correlation.

Psychiatric Symptomatology in the Patient

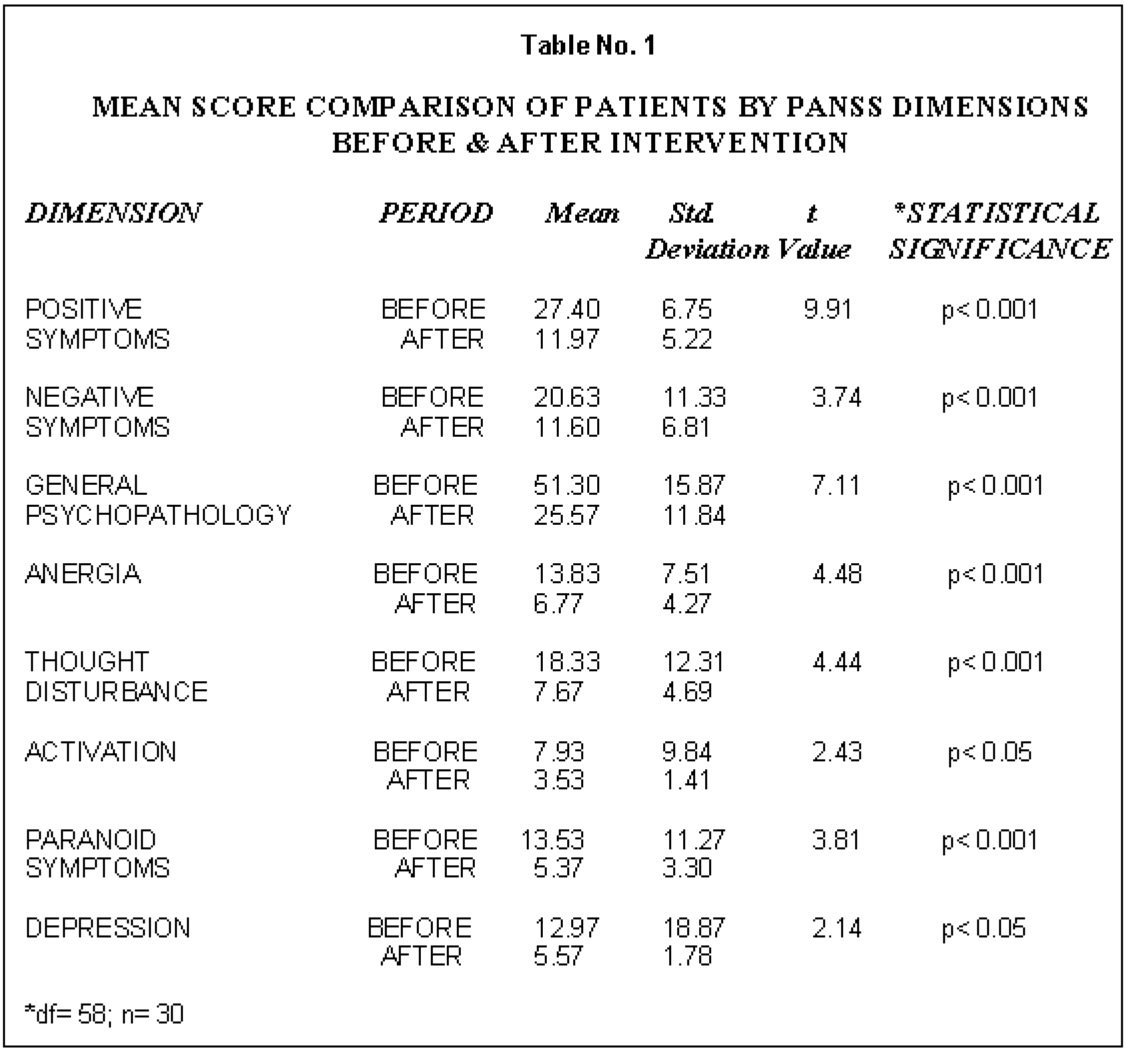

Table No. 1

MEAN SCORE COMPARISON OF PATIENTS BY PANSS DIMENSIONS BEFORE & AFTER INTERVENTION

DIMENSION	*PERIOD*	*Mean*	*Std. Deviation*	*t Value*	**STATISTICAL SIGNIFICANCE*
POSITIVE SYMPTOMS	BEFORE	27.40	6.75	9.91	p< 0.001
	AFTER	11.97	5.22		
NEGATIVE SYMPTOMS	BEFORE	20.63	11.33	3.74	p< 0.001
	AFTER	11.60	6.81		
GENERAL PSYCHOPATHOLOGY	BEFORE	51.30	15.87	7.11	p< 0.001
	AFTER	25.57	11.84		
ANERGIA	BEFORE	13.83	7.51	4.48	p< 0.001
	AFTER	6.77	4.27		
THOUGHT DISTURBANCE	BEFORE	18.33	12.31	4.44	p< 0.001
	AFTER	7.67	4.69		
ACTIVATION	BEFORE	7.93	9.84	2.43	p< 0.05
	AFTER	3.53	1.41		
PARANOID SYMPTOMS	BEFORE	13.53	11.27	3.81	p< 0.001
	AFTER	5.37	3.30		
DEPRESSION	BEFORE	12.97	18.87	2.14	p< 0.05
	AFTER	5.57	1.78		

*df= 58; n= 30

The data in Table No. 1 reveals a statistically significant improvement in terms of psychiatric symptomatology at first follow up. This is indicated by the considerable reduction in mean scores obtained on all the sub-dimensions of the PANSS as seen in the table. The efficacy of the intervention carried out is vindicated by the t-values, which show a significant difference prior to and after intervention. Magliano et al., (2005), have found that the provision of psycho educational intervention was associated with a statistically significant improvement in patients symptoms. Similarly a study from China has found that family education on schizophrenia was effective in improving knowledge and promoting improvement in patients' symptoms and functioning (Zheng Li & David Arthur, 2005).

Family Burden & Quality of Life of the Caregivers

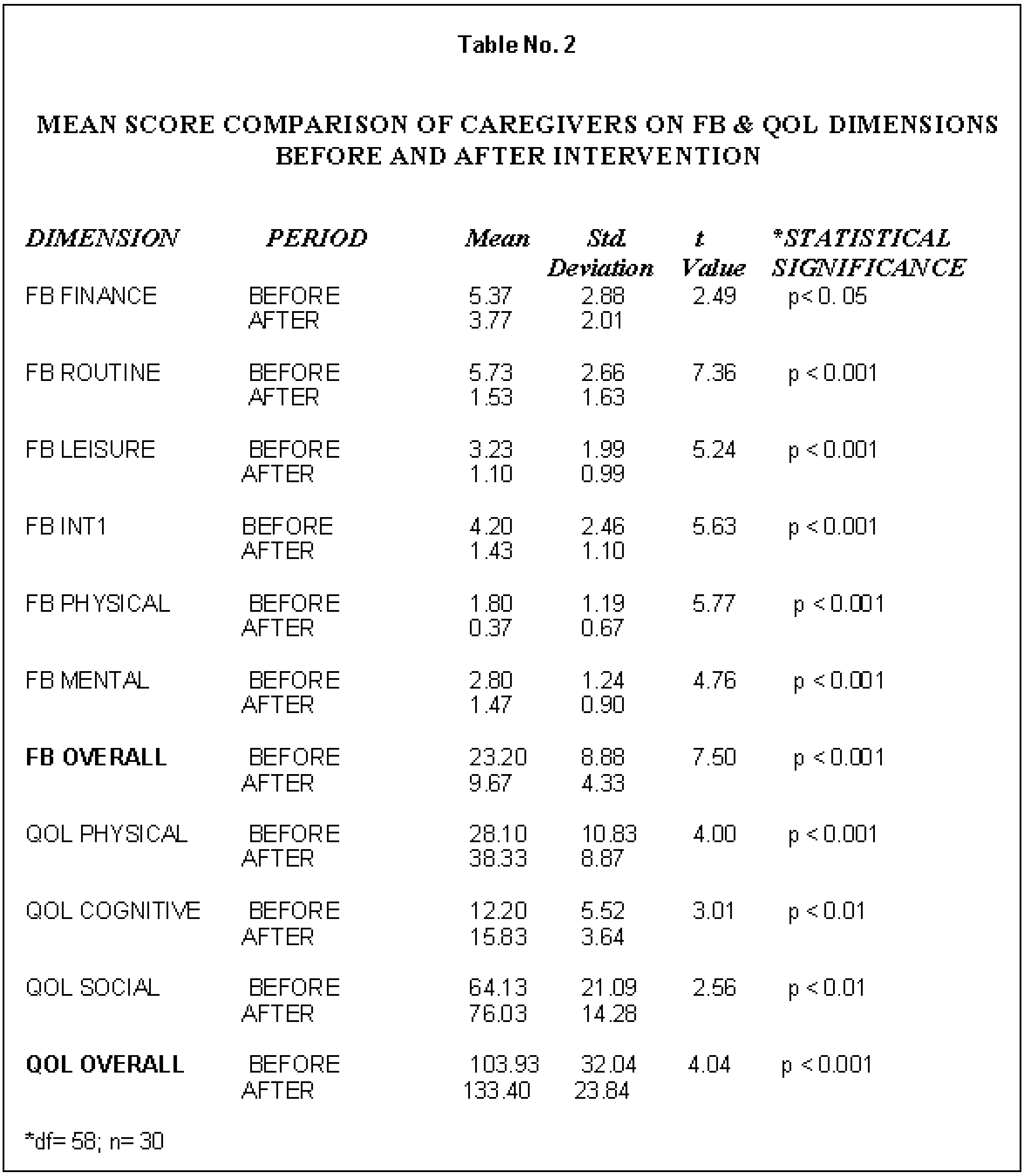

Table No. 2

MEAN SCORE COMPARISON OF CAREGIVERS ON FB & QOL DIMENSIONS BEFORE AND AFTER INTERVENTION

DIMENSION	*PERIOD*	*Mean*	*Std. Deviation*	*t Value*	**STATISTICAL SIGNIFICANCE*
FB FINANCE	BEFORE	5.37	2.88	2.49	p< 0. 05
	AFTER	3.77	2.01		
FB ROUTINE	BEFORE	5.73	2.66	7.36	p < 0.001
	AFTER	1.53	1.63		
FB LEISURE	BEFORE	3.23	1.99	5.24	p < 0.001
	AFTER	1.10	0.99		
FB INT1	BEFORE	4.20	2.46	5.63	p < 0.001
	AFTER	1.43	1.10		
FB PHYSICAL	BEFORE	1.80	1.19	5.77	p < 0.001
	AFTER	0.37	0.67		
FB MENTAL	BEFORE	2.80	1.24	4.76	p < 0.001
	AFTER	1.47	0.90		
FB OVERALL	BEFORE	23.20	8.88	7.50	p < 0.001
	AFTER	9.67	4.33		
QOL PHYSICAL	BEFORE	28.10	10.83	4.00	p < 0.001
	AFTER	38.33	8.87		
QOL COGNITIVE	BEFORE	12.20	5.52	3.01	p < 0.01
	AFTER	15.83	3.64		
QOL SOCIAL	BEFORE	64.13	21.09	2.56	p < 0.01
	AFTER	76.03	14.28		
QOL OVERALL	BEFORE	103.93	32.04	4.04	p < 0.001
	AFTER	133.40	23.84		

*df= 58; n= 30

The figures in Table No. 2 show that there is a statistically significant difference in the status of the caregivers before and after intervention vis-à-vis the burden experienced by them as well as their quality of life as revealed by the t-test. Further it is observed that there is a reduction in the mean score values on the overall burden score as well as all its sub-dimensions following intervention, at first follow up. In a similar study Moller-Leimkuhler (2005), found that though there was a considerable level of burden in most of the relatives at 1-year follow-up, a significant reduction in objective and subjective burden was seen while compared to their baseline status. The effectiveness of intervention in schizophrenic patients has been demonstrated in a study by Magliano et al., (2005), who found that the provision of psycho educational intervention was associated with a statistically significant improvement in family burden and coping strategies. It is also seen in Table No.2 that the mean scores have increased on the overall quality of life score and its three sub-dimensions, indicating an enhanced quality of life in the caregivers after intervention. This finding is in consonance with that of Moller-Leimkuhler (2005), who found significant improvements in well-being, self-rated symptoms and subjective quality of life in two-thirds of the relatives of patients with schizophrenia. Foldemo et al., (2005) have found that parents of schizophrenic patients were significantly less satisfied with their overall quality of life. Chadzynska (2003), who assessed quality of life in schizophrenic patients as well as their caregivers, found that both have a tendency to evaluate QOL similarly.

Analysis by Gender of the Patient

The next analysis was done by computing ANOVA values for the caregivers based on the gender of the patients before and after intervention.

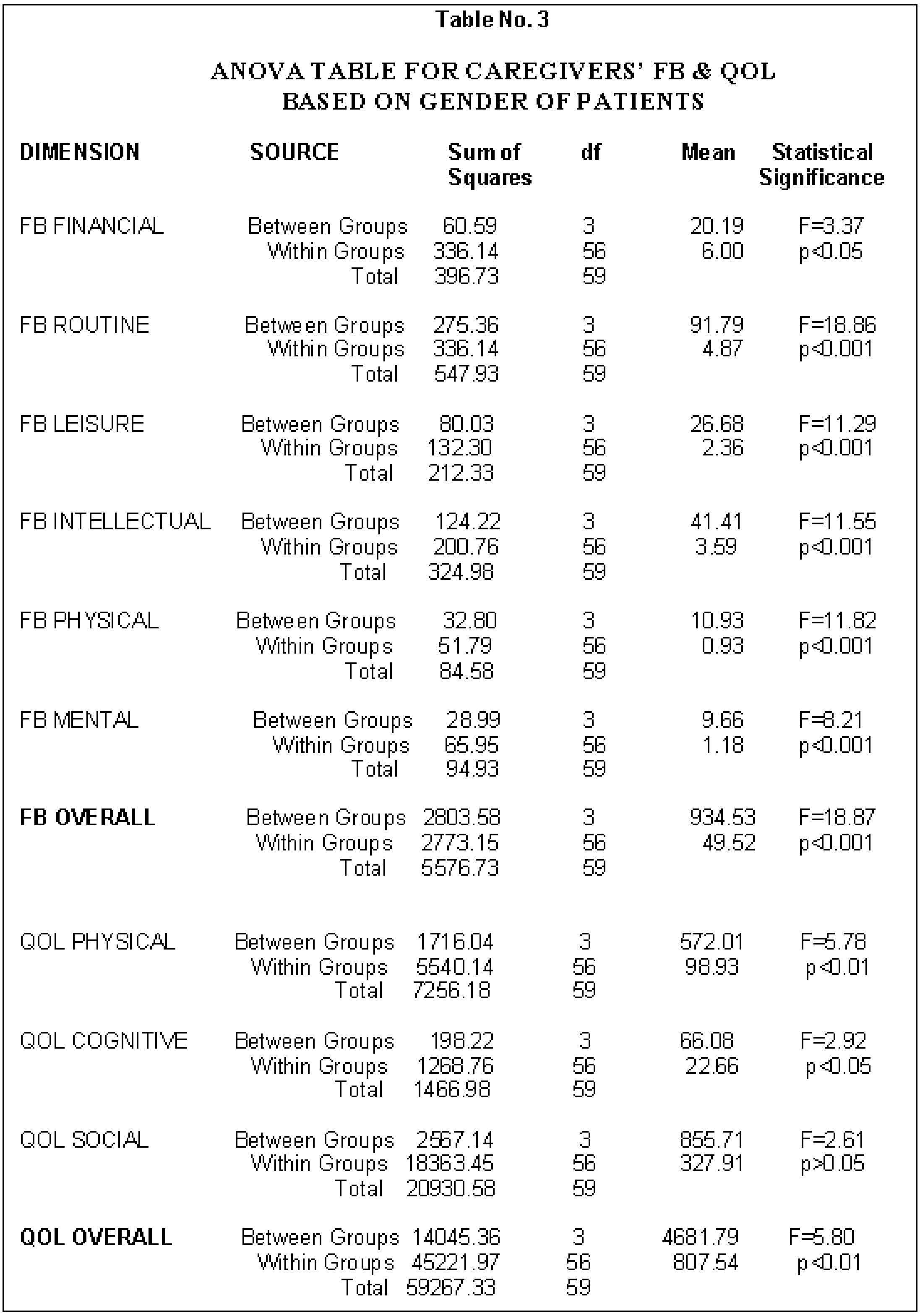

Table No. 3

ANOVA TABLE FOR CAREGIVERS' FB & QOL BASED ON GENDER OF PATIENTS

DIMENSION	SOURCE	Sum of Squares	df	Mean	Statistical Significance
FB FINANCIAL	Between Groups	60.59	3	20.19	F=3.37
	Within Groups	336.14	56	6.00	p<0.05
	Total	396.73	59		
FB ROUTINE	Between Groups	275.36	3	91.79	F=18.86
	Within Groups	336.14	56	4.87	p<0.001
	Total	547.93	59		
FB LEISURE	Between Groups	80.03	3	26.68	F=11.29
	Within Groups	132.30	56	2.36	p<0.001
	Total	212.33	59		
FB INTELLECTUAL	Between Groups	124.22	3	41.41	F=11.55
	Within Groups	200.76	56	3.59	p<0.001
	Total	324.98	59		
FB PHYSICAL	Between Groups	32.80	3	10.93	F=11.82
	Within Groups	51.79	56	0.93	p<0.001
	Total	84.58	59		
FB MENTAL	Between Groups	28.99	3	9.66	F=8.21
	Within Groups	65.95	56	1.18	p<0.001
	Total	94.93	59		
FB OVERALL	Between Groups	2803.58	3	934.53	F=18.87
	Within Groups	2773.15	56	49.52	p<0.001
	Total	5576.73	59		
QOL PHYSICAL	Between Groups	1716.04	3	572.01	F=5.78
	Within Groups	5540.14	56	98.93	p<0.01
	Total	7256.18	59		
QOL COGNITIVE	Between Groups	198.22	3	66.08	F=2.92
	Within Groups	1268.76	56	22.66	p<0.05
	Total	1466.98	59		
QOL SOCIAL	Between Groups	2567.14	3	855.71	F=2.61
	Within Groups	18363.45	56	327.91	p>0.05
	Total	20930.58	59		
QOL OVERALL	Between Groups	14045.36	3	4681.79	F=5.80
	Within Groups	45221.97	56	807.54	p<0.01
	Total	59267.33	59		

It is seen in Table No. 3 that the F values show a statistically significant difference on the overall family burden score of the caregivers as well as their overall quality of life. Statistically significant differences are also seen in terms of all the sub-dimensions of both these variables except for the social component of the QOL scale. However, Alptekin et al. (2004) did not obtain significantly different quality of life scores between relatives of patients and those of control subjects, but found that quality of life of patients was negatively correlated with the severity of their psychopathology and the extrapyramidal side effects induced by antipsychotic drugs .

Following the ANOVA, the data was further subjected to posthoc Scheffe analysis to ascertain if there were significant differences for caregiver scores based on the gender of the patients before and after intervention and these results are posted in Table No. 4.

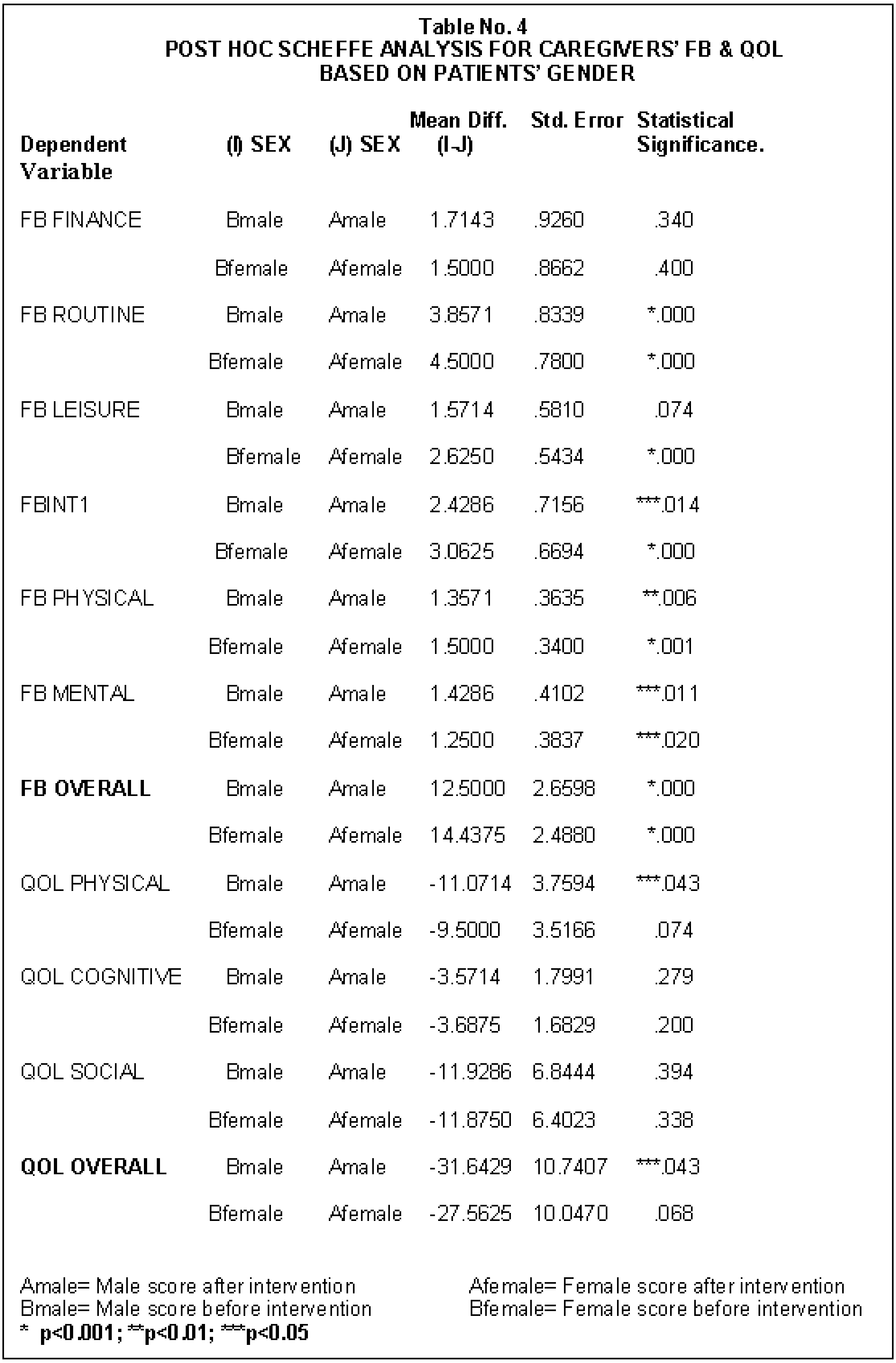

Table No. 4
POST HOC SCHEFFE ANALYSIS FOR CAREGIVERS' FB & QOL BASED ON PATIENTS' GENDER

Dependent Variable	(I) SEX	(J) SEX	Mean Diff. (I-J)	Std. Error	Statistical Significance.
FB FINANCE	Bmale	Amale	1.7143	.9260	.340
	Bfemale	Afemale	1.5000	.8662	.400
FB ROUTINE	Bmale	Amale	3.8571	.8339	*.000
	Bfemale	Afemale	4.5000	.7800	*.000
FB LEISURE	Bmale	Amale	1.5714	.5810	.074
	Bfemale	Afemale	2.6250	.5434	*.000
FBINT1	Bmale	Amale	2.4286	.7156	***.014
	Bfemale	Afemale	3.0625	.6694	*.000
FB PHYSICAL	Bmale	Amale	1.3571	.3635	**.006
	Bfemale	Afemale	1.5000	.3400	*.001
FB MENTAL	Bmale	Amale	1.4286	.4102	***.011
	Bfemale	Afemale	1.2500	.3837	***.020
FB OVERALL	Bmale	Amale	12.5000	2.6598	*.000
	Bfemale	Afemale	14.4375	2.4880	*.000
QOL PHYSICAL	Bmale	Amale	-11.0714	3.7594	***.043
	Bfemale	Afemale	-9.5000	3.5166	.074
QOL COGNITIVE	Bmale	Amale	-3.5714	1.7991	.279
	Bfemale	Afemale	-3.6875	1.6829	.200
QOL SOCIAL	Bmale	Amale	-11.9286	6.8444	.394
	Bfemale	Afemale	-11.8750	6.4023	.338
QOL OVERALL	Bmale	Amale	-31.6429	10.7407	***.043
	Bfemale	Afemale	-27.5625	10.0470	.068

Amale= Male score after intervention
Bmale= Male score before intervention
Afemale= Female score after intervention
Bfemale= Female score before intervention
*** $p<0.001$; **$p<0.01$; ***$p<0.05$**

The results in Table No. 4 reveal that there is a highly significant statistical difference for the overall family burden scores of the caregivers of both male and female patients before and after intervention. This significant difference is manifested for all the sub-dimensions of the family burden scale except with regard to financial burden where the before and after scores for both the sexes of the patients is not statistically significant. Similarly while a significant difference is seen for female patients before and after intervention in terms of family leisure, the same is not the case for the caregivers looking after male patients. It is important to note that the mean score difference (I – J) for the overall family burden score as well as all its sub-dimensions is positive for both male and female patients. This indicates that the scores prior to intervention (I) were higher than those following intervention (J). The reduced J values point to a diminishing family burden on all sub-dimensions in the caregivers following intervention regardless of the gender of the patient. Similarly the mean score difference (I – J) values for the overall QOL score and all its sub-dimensions is negative for both male and female patients, indicating that scores prior to intervention (I) were lower than those following intervention (J) thus showing enhanced QOL status in the caregivers following intervention regardless of the gender of the patient.

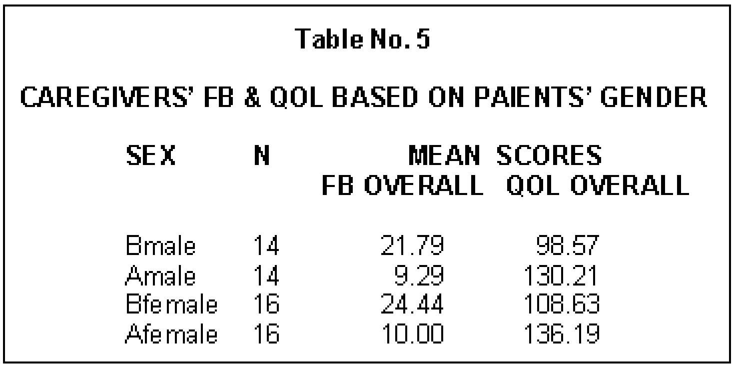

Table No. 5

CAREGIVERS' FB & QOL BASED ON PAIENTS' GENDER

SEX	N	MEAN SCORES FB OVERALL	 QOL OVERALL
Bmale	14	21.79	98.57
Amale	14	9.29	130.21
Bfemale	16	24.44	108.63
Afemale	16	10.00	136.19

When caregivers were compared with regard to their mean FB and QOL scores, it was seen that those caring for female patients scored higher on both these dimensions both before and after intervention (Table No. 5). Though this appears paradoxical, it indicates that though caregivers of female patients experience greater burden, they also manifest better quality of life than those caring for male patients. Consistent with this study, Winefield and Harvey (1993), also found that those caring for female sufferers reported greater distress than those caring for males. Similarly, Thornicroft et al. (2002) did not find support for their hypothesis that caregivers of male patients will show higher rates of psychological distress, and higher scores for 'supervision' and 'urging' than caregivers of female patients.

Analysis by Gender of the Caregiver

A similar analysis was done by computing ANOVA values and Scheffe analysis, this time based on the gender of the caregivers and the results are tabulated in Table No. 6.

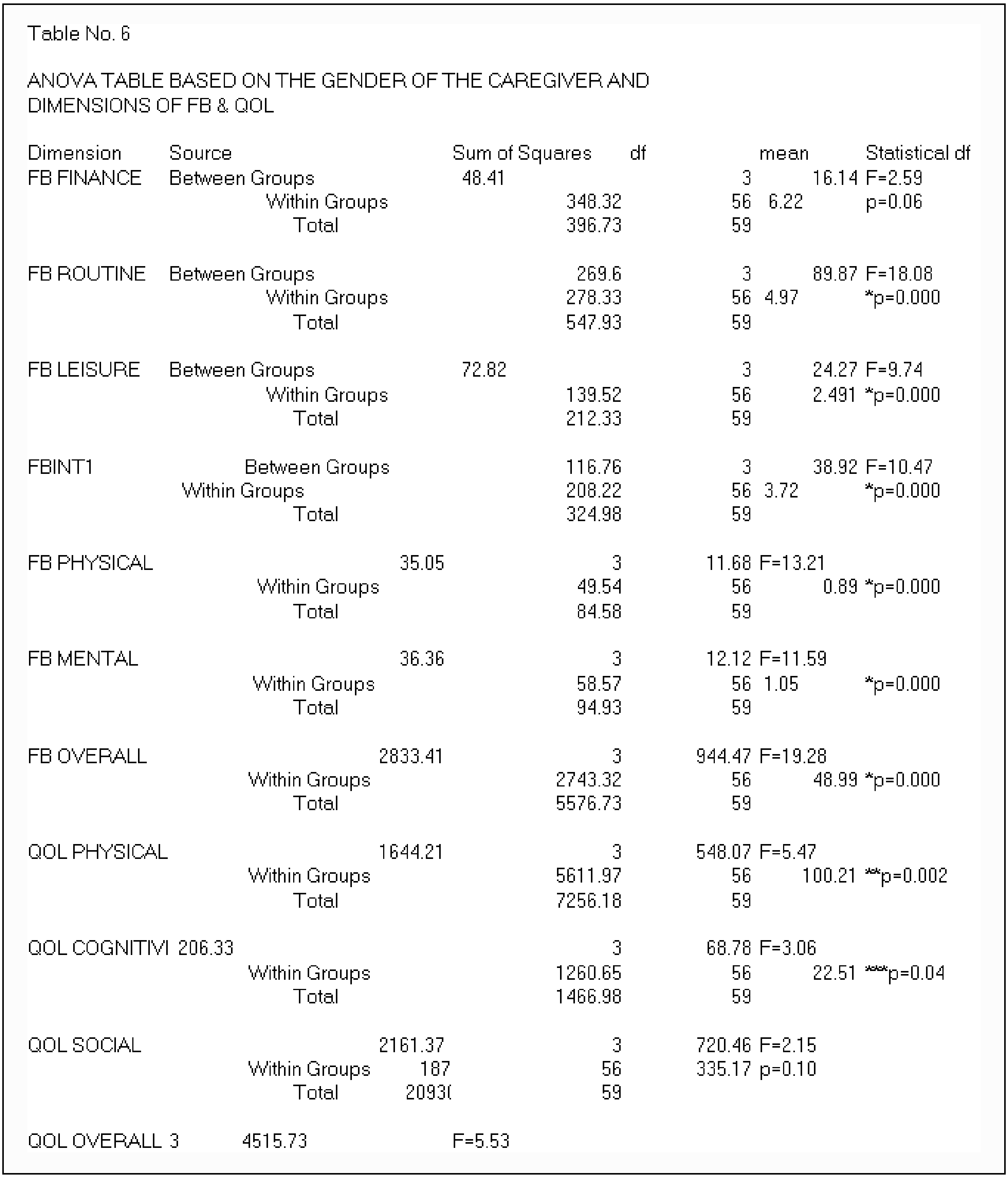

Table No. 6

ANOVA TABLE BASED ON THE GENDER OF THE CAREGIVER AND DIMENSIONS OF FB & QOL

Dimension	Source	Sum of Squares	df	mean	Statistical df
FB FINANCE	Between Groups	48.41	3	16.14	F=2.59
	Within Groups	348.32	56	6.22	p=0.06
	Total	396.73	59		
FB ROUTINE	Between Groups	269.6	3	89.87	F=18.08
	Within Groups	278.33	56	4.97	*p=0.000
	Total	547.93	59		
FB LEISURE	Between Groups	72.82	3	24.27	F=9.74
	Within Groups	139.52	56	2.491	*p=0.000
	Total	212.33	59		
FBINT1	Between Groups	116.76	3	38.92	F=10.47
	Within Groups	208.22	56	3.72	*p=0.000
	Total	324.98	59		
FB PHYSICAL		35.05	3	11.68	F=13.21
	Within Groups	49.54	56	0.89	*p=0.000
	Total	84.58	59		
FB MENTAL		36.36	3	12.12	F=11.59
	Within Groups	58.57	56	1.05	*p=0.000
	Total	94.93	59		
FB OVERALL		2833.41	3	944.47	F=19.28
	Within Groups	2743.32	56	48.99	*p=0.000
	Total	5576.73	59		
QOL PHYSICAL		1644.21	3	548.07	F=5.47
	Within Groups	5611.97	56	100.21	**p=0.002
	Total	7256.18	59		
QOL COGNITIVI		206.33	3	68.78	F=3.06
	Within Groups	1260.65	56	22.51	***p=0.04
	Total	1466.98	59		
QOL SOCIAL		2161.37	3	720.46	F=2.15
	Within Groups	187	56	335.17	p=0.10
	Total	2093(	59		
QOL OVERALL			3	4515.73	F=5.53

Comparison of data based on the gender of the caregivers before and after intervention reveals a highly significant statistical difference among all four groups in terms of their overall family burden as well as QOL scores. A similar difference is seen with regard to all the sub-dimensions of both scales except for financial burden and the social domain of QOL. While the ANOVA values are based on mean score comparison of the four groups studied, the Scheffe results helps to identify the precise status of the caregivers based on their gender before and after intervention.

Table No. 7

POSTHOC SCHEFFE ANALYSIS BASED ON CAREGIVERS' GENDER AND FB & QOL MEAN SCORES

Dependent Variable	*SEX (I)*	*SEX (J)*	*Mean Difference (I-J)*	*Std. Error*	*Significance*
FB FINANCE	Bmale	Amale	2.43	0.94	.097
	Bfemale	Afemale	0.88	0.88	.805
FB ROUTINE	Bmale	Amale	4.79	0.84	*.000
	Bfemale	Afemale	3.69	0.79	*.000
FB LEISURE	Bmale	Amale	2.71	0.59	*.000
	Bfemale	Afemale	1.63	0.56	***.047
FB INTERACTION	Bmale	Amale	3.14	0.73	*.001
	Bfemale	Afemale	2.44	0.68	**.009
FB PHYSICAL	Bmale	Amale	1.21	0.36	***.014
	Bfemale	Afemale	1.63	0.33	*.000
FB MENTAL	Bmale	Amale	1.14	0.39	***.042
	Bfemale	Afemale	1.50	0.36	**.002
FB OVERALL	Bmale	Amale	15.43	2.65	*.000
	Bfemale	Afemale	11.88	2.47	*.000
QOL PHYSICAL	Bmale	Amale	-10.86	3.78	***.051
	Bfemale	Afemale	-9.69	3.54	.069
QOL COGNITIVE	Bmale	Amale	-4.43	1.79	.120
	Bfemale	Afemale	-2.94	1.68	.390
QOL SOCIAL	Bmale	Amale	-12.93	6.92	.332
	Bfemale	Afemale	-11.00	6.47	.417
QOL OVERALL	Bmale	Amale	-29.64	10.79	.068
	Bfemale	Afemale	-29.31	10.10	***.048

Amale= Male score after intervention
Bmale= Male score before intervention
Afemale= Female score after intervention
Bfemale= Female score before intervention

*** p<0.001; **p<0.01; ***p<0.05**

It is seen that there is a highly significant statistical difference for both male and female caregivers before and after intervention (Table No. 7). This difference is also seen with regard to all the sub-dimensions of the family burden scale except for financial burden. In terms of the overall QOL score, while female caregivers show a significant difference before and after intervention, the same is not observed for male caregivers. Further while female caregivers show a significant difference before and after intervention on the physical domain of QOL, no such differences are seen on the remaining sub-dimensions of QOL for both male and female caregivers. It is also to be noted that the mean difference values (I – J) for the overall family burden score as well as its sub-dimensions is positive whereas it is negative for the overall QOL score and its sub-domains. This indicates reduced family burden and enhanced QOL following intervention for both male and female caregivers.

Table No. 8
INTERCORRELATIONS AMONG SUBJECT DIMENSIONS

	FB OV	QOL OV	PS	NS	GP	AN	TD	ACT	PAR	DEP
FB OVERALL	1.00	-.42*	.29	-.07	.03	-.05	-.02	.01	.05	.11
QOL OVERALL	-.42*	1.00	-.04	-.06	.07	-.05	-.11	-.21	-15	.24

*Correlation is significant at the 0.05 level (2-tailed).
LEGEND: FB OV- Family burden overall score, QOL OV-Quality of life overall score, PS-Positive symptoms, NS-Negative symptoms, GP-General psychopathology, AN-Anergia, TD-Thought disturbance, ACT-Activation, PAR-Paranoid symptoms, DEP-Depression.

The correlation values plotted in Table No. 8 show a significant negative correlation between the overall family burden and overall QOL scores. Though a cause-effect relationship cannot be interpreted on the basis of this, it indicates that increase in one domain adversely impacts the other and both seem to mutually influence one another. A recent study by Foldemo et al. (2005), have also found a correlation between lower overall quality of life and higher perceived burden in parents of schizophrenic patients. It is also important to note that the overall FB and QOL scores did not enter into a significant relationship with any of the dimensions of the PANSS. This is contrary to the finding of Hamada et al., (2003) who found that psychotic symptoms of schizophrenic patients were closely related to the mental state and QOL of their families. The lack of correlation seen in this study between psychiatric symptomatology of the patient and the FB and QOL scores of their caregivers perhaps indicates that both FB and QOL are complex variables not determined exclusively by the psychiatric status of the patient but by several other factors as suggested by previous authors (e.g. Saunders, 2003; Ivarsson et al., 2004). While no correlations were obtained in this study between the PANSS scores and the FB and QOL status of their caregivers, another study by (Karow , 2005), which also used the PANSS, found that anxiety and depression in schizophrenic patients correlated with their own QOL scores during and after hospitalization.

Implecations for Therapeutic Intervention

Caregiver burden and burnout are important, prevalent, and preventable. Physicians aware of the symptoms and signs can better assess, identify, prevent, and intervene in these situations. Such efforts result in improved quality of life for both patients and their loved ones (Kasuya et al., 2000). Early intervention could result in reduction in morbidity and better quality of life for the patients and their families. This study has revealed that an integrated therapeutic approach consisting of components such as pharmacotherapy, psychosocial therapies and spiritual therapy is successful in enhancing mental health status of patients with schizophrenia besides reduction of family burden and improved quality of life in their caregivers. A decade ago, Tarrier (1996), argued that a comprehensive and holistic approach to care in schizophrenia that combines, and continually refines, pharmacological and psychosocial interventions is required and that high-quality care and clinical management need to be provided by a partnership between pharmacological; and psychosocial interventions. He emphasized that psychosocial interventions can provide patients and their carers with skills that both increase the patient's resilience, and empower the patient and carer to forge a partnership with clinicians to define high-quality care. There is considerable evidence to emphasize the importance of combining drug therapy with outpatient psychotherapy, psychotherapeutic management, and psychosocial programs May (1976). Drug and psychosocial intervention is indicated as part of tertiary prevention to prevent further disability in the illness observe Lee et al. (2005).

Psychiatric rehabilitation for schizophrenia involves utilizing psychosocial interventions to assist persons with the illness to attain their highest level of independent functioning, strongest level of symptom control, and greatest level of subjective life satisfaction (Glynn, 2003). Psychotherapeutic intervention in schizophrenia should be goal-directed and aimed particularly at developing and promoting social and occupational skills and at eliciting cooperation with appropriate drug treatment and monitoring its progress May (1976). Pekkal & Merinder (2004), observe that psycho education approaches are useful as part of the treatment programme for people with schizophrenia and the fact that these interventions are brief and inexpensive should make them attractive. Further, psychosocial interventions decrease the frequency of relapse, encourage compliance with medication, improve general social impairment and the levels of expressed emotions within the family when compared to standard care (Pharoah et al., 2004). When relatives of patients with schizophrenia are able to improve their coping strategies, it is possible for burden to be reduced. This points to the necessity to provide families of chronic psychotic patients with psychoeducational interventions emphasizing the adoption of an effective coping style (Magliano et al., 2000).

Psychoeducation programs for caregivers need to focus on empathic engagement, education, ongoing support, better access to clinical resources, social network enhancement, and increased problem-solving, coping and communication skills. Thorup et al. (2005), in a recent study which adopted an integrated intervention modality conclude that the integrated approach is crucial, since, many aspects of the integrated treatment contributed to the reduction of both negative and psychotic symptoms in their sample. While a combination of pharmacotherapy and psychosocial procedures has been routinely used with schizophrenic patients and their caregivers, it is suggested on the basis of this study that they may stand to benefit by also including elements of spiritual therapy specific to their religious orientation during intervention.

Limitations of the Study

While this study establishes the efficacy of an integrated treatment modality, the data do not reveal the extent to which its components (pharmacotherapy, psychosocial intervention or spiritual aspects) individually have contributed to the changes seen in patients as well as their caregivers. The absence of a control group is yet another limitation against which the findings need to be viewed. Respondents of this study professed a faith in Hinduism and approached the Gunaseelam center owing to the ‘healing powers’ traditionally attributed to the diety there and as such those belonging to other religious faiths have gone un-represented.

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Perceived Freedom and Life Satisfaction for People with Long-Term Psychiatric Illness

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Abstract

This study aims at exploring the relationship between individual's perceived freedom and subjective life satisfaction for people with long-term psychiatric illness. Research sample included 146 subjects, coming from two large residential homes in Hong Kong. Results showed that individual's perceived freedom was found to be a good predictor of overall life satisfaction. Also perceived freedom was found to have stronger predictive power than other variables including demographic variables, medical variables, social functioning and current psychiatric symptoms. Program element in promoting perceived freedom was suggested to be included in residential home care.

Key words: Quality of Life, Perceived Freedom, Mental Illness

Introduction

People with long-term psychiatric illness are so disabled and impaired that they are difficult to be placed in the community [1]. In the past few decades, several models of community care program for these people have been developed in the Western countries [2-6]. However, these community care models are not widely developed in the community. In fact, the majority of people with long-term psychiatric illness live in residential settings such as hostels and nursing homes.

In the past few decades, there is an anti-residential care movement [7]. Some research studies found that large residential homes, such as nursing home and board and care home in U.S.A., were characterized by poverty of social environment [8-9]. These researchers criticized that these residential homes became other asylums in the community and took over the functions of the mental hospitals and that moving long-stay patients from mental hospitals means only a transfer from one institutionalizing situation to another [8-9].

This anti-residential care bias is based on the influence of the "literature of dysfunction" in relation to residential care, which is both conceptually limited in its analysis and scientifically flawed in terms of methodology [7]. Research evidences tend to show that residential care has its own value and has numerous advantages [10]. For example, Timko et al. [11] conducted a randomized control study of nursing home care in U.S.A. and found that, as compared with the hospital in-patients, nursing home residents had better choice, control in policies, more social and recreational activities while their subjective life satisfactions remained positive and unchanged. Similarly, Horan et al. [12] reported that residents of hostels and boarding houses in Australia were satisfied with their quality of life although they had negligible participation in daily activities, few family contacts and limited finances. Barry et al. [13], in a one year follow up study of a cohort of 65 long-stay patients who were discharged from mental hospital in U.K. and lived in supported housing schemes and group homes, found that residents had significant improvement in their social functioning and objective quality of life such as having more comfort, autonomy, social interaction, leisure activities and use of community facilities, while their overall life satisfaction remained positive and unchanged.

Although much have been done in exploring the quality of life of people with mental illness living in residential care, few research studies have been done in identifying those program elements leading to a better subjective life satisfaction for them. Indeed, mental health research is often confronted with the problem that the intervention or program under study takes place in a "black box", which makes it difficult to assess the relative importance of various components of the intervention [14]. Moreover, even with programme that have demonstrated successful outcomes, it is difficult to specify which components of the intervention are responsible for the observed outcomes [15]. Thus more research is needed in identifying those essential elements of residential home leading to life satisfaction or quality of life for its residents.

Among the few research studies in this area, Zissi et al. [16], in a cross sectional study of 54 people with long term mental illness living in a community based hostel in Greece, reported that individual's subjective life satisfaction were significantly and directly associated by autonomy and positive self-concept. However, the reliability and validity of the scale in measuring individual's autonomy has not been reported.

Rosenfield [17] has proposed a theoretical framework relating individual's autonomy to subjective life satisfaction, and stressed the importance of empowerment approach in psychiatric rehabilitation. Based on the research study of Rosenfield [17], program elements adopting empowerment approach could enhance individual's sense of mastery which in turn could lead to a better overall life satisfaction for people with long-term mental illness

The Sense of Mastery Scale, which has been developed by Pearlin et al. [18], was employed in the study of Rosenfield [17]. However, when the author interviewed several persons with long-term psychiatric illness with that scale as a pretest, the respondents had difficulties in understanding the relatively abstract concept of "mastery". Most respondents preferred to use the term "freedom" or "restrictions encountered" in their current living place. It may due to the fact that the characteristics of people with long-term psychiatric illness in Hong Kong were different from the studied group done by Rosenfield. People with long-term psychiatric illness were too impaired and disabled to have independent living, and in Hong Kong, most of them have to rely on residential or hospital care rather than independent living. Another reason may due to the cultural difference. People with long-term psychiatric illness in Hong Kong were mainly belonged to lower class and may not be familiar with the concept of "sense of mastery", which had been originated from the western culture. Result from the above pretest showed that respondents concerned whether they could enjoy certain kinds of freedom, including the freedom to go outside, freedom to enjoy community facilities, or whether the management of their current living place were restrictive in their daily routine. It indicated that respondents were familiar with the term freedom, rather than mastery, and concerned it very much. So, this study decides to measure individual's perceived freedom rather than sense of mastery.

Research Aims and Hypothesizes

The aim of this research study is to explore the relationship between individual's perceived freedom and subjective life satisfaction for people with long-term psychiatric illness.

The research hypothesis is that individual's perceived freedom predicts subjective life satisfaction well. In other words, individual's perceived freedom could lead to a better subjective life satisfaction for people with long-term psychiatric illness.

Research Design and Sample

In this study, the studied group of people with long-term psychiatric illness came from two large residential homes, named long stay care home (below referred as LSCH) which have been opened in 1990s in Hong Kong. In each LSCH, four to five residents lived in the same bedroom. It contained a large occupational unit. Various kinds of professional and non-professional staff had been employed to provide 24-hour personal care services for its residents. Staff to resident ratio is about 1:4.

Those residents, who were being assessed by registered psychiatric nurse as mentally stable, had suitable comprehensive and communicative skills, and discharged from mental hospitals and then lived at LSCH for more than one year, were eligible for being selected into the studied sample. Finally 146 residents had given their written consent and were interviewed by the author successfully. Data of the studied groups were collected and completed in 1998.

Measuring Scales and Data Collection

1) Quality of Life Interview scale

In this study, Lehman's Quality of Life Interview [19] is adopted to measure the subjective life satisfaction of respondents. The reliability and validity of the scale are well established [19-20] and the scale has been widely used [13, 21-22]. In this study, the reliabilities of sub-scales of overall life satisfaction as well as subjective QoL in various life domains have been tested to be satisfactory (Cronbach's α= .73 for overall life satisfaction sub-scale; and Cronbach's α ranked from .67 to .98 for other subjective QoL sub-scales.).

2) Perceived Freedom

When measuring perceived freedom of people with long-term psychiatric illness, it would be better to relate the measuring items to their daily lives as well as the management practice of their current living places. So the author has developed a measuring scale, named Perceived Freedom, for this study which is designed for the use in residential setting. It contains 18 items. It divides into two main sub-scales: perceived sense of freedom and perceived restriction. The perceived restriction sub-scale is a binary yes / no scale. The perceived sense of freedom sub-scale covers nine areas: money management, going out, bed time, bathing time, dressing, hair cutting, meal and vocational training as well as overall sense of freedom. Each of these items is rated at a four-point scale. The reliability of this scale has been tested to be satisfactory (Cronbach's α= .66 for whole scale).

3) Social Behaviour Schedule (SBS)

The Social Behaviour Schedule (SBS) is chosen for use in this study as this scale is especially designed for measuring the functioning in 21 areas such as hygiene, initiating conversations, depression, violence, etc. for people with long-term psychiatric illness [23]. The reliability and validity of the scale has been reported to be satisfactory.

4) Specific Level of Functioning Assessment (SLOF)

The Specific Level of Functioning Assessment (SLOF) is designed to measure more directly observable behavioural functioning and daily living skills of people with chronic mental illness [24]. The reliability and validity of the scale has been reported to be satisfactory.

Characteristics of the research sample

Table 1 Demographic characteristics of the samples.

	LSCH1 **(N =77)**	**LSCH2** **(N=69)**	**Test**	**significance**
Gender (%male)	54	51	Chi-square	.657
Age (mean year)	57	50	Student t-test	.000**
Education			Chi-square	.321
% none	21	12		
% primary school	43	55		
% secondary school	34	28		
% higher education	1	4		
Marital status (% single, divorced or widow)	82	84	Chi-square	.611
Financial Situation			Chi-square	.019*
% rely on governmental assistance	99	90		
Diagnosis (% schizophrenic)	95	90	Chi-square	.481
Period of Illness (mean year)	19	21	Student t-test	.348
Number of hospitalizations (mean)	4	4	Student t-test	.921
Period of latest Hospital stay (mean year)	8	7	Student t-test	.2

* <.01 **<.05

Below describes the characteristics of the studied sample which came from two LSCHs, i.e. LSCH1 group (n=77) and LSCH2 group (n=69). Results showed that these two groups of respondents did not differ in almost all demographic factors, except in age and financial situation. Taking together, the whole studied group had slightly more male than female. Most of them were aged under 60 (mean 53 years), schizophrenic, single and had reached primary school level. Their illnesses were so chronic that most of them had been ill for more than 20 years and had a mean continuous hospital stay of 7.5 years just before admitting into LSCH. Half of them had admitted into mental hospital for three times or more. Also, about two fifth of them had at least one physical illness. Most were single or divorced, and had few contacts with their families. They did not have any friends outside the hospitals and LSCH. Most of them were lack of employable skills and attended some forms of vocational training. Almost all of them had to rely on governmental social security schemes to support their lives.

Social Functioning and Current Psychiatric Symptoms

Social functioning of the studied group was measured by the Specific Level of Functioning (SLOF) scale. About half of them showed at least one functioning problem or disability and (i.e. score < 4). Many of them had impairments in their work skills, community living skills, and interpersonal relationships. On the other hand, current psychiatric symptoms of studied group were measured by Social Behavioural Schedule (SBS). More than half showed at least one significant behavioural problem (i.e. score >1) that needed staff's intervention, while one third showed three psychiatric symptoms or more. About one third (30%) showed at least one positive symptoms such as laughing and talking to themselves, while one fifth showed at least one negative symptoms such as poor personal appearance and hygiene.

Research Results

Table 2 Subjective Satisfaction of LSCH residents in various life domains

Subjective QoL (Score between 1-7 with 7 means most satisfactory)	Mean score	Standard Deviation
Living Situation	5.3	0.889
Daily Activities & Functioning	5.3	1.133
Family	4.7	1.840
Social Relationship	5.0	1.180
Financial Situation	4.9	1.450
Legal and Safety Issue	5.4	1.081
Health	4.8	1.330
Overall	5.5	1.1473

On each life domains, two thirds or above of studied group expressed satisfaction. In particular, they were most satisfied with the living situations, followed by leisure activities and personal security, while they were least satisfied with their family relationships and financial situations (please refer to Table 2 for your reference). Moreover, their reported overall life satisfaction was satisfactory (mean score >5). According to these research results, the studied group viewed their lives as positive at LSCH and community after their discharge from mental hospitals.

B. Perceived Freedom

Almost all (97.9%) LSCH resident reported that they were restricted in at least in one area of their lives. About half of them reported there were restrictions in four areas mostly involving: managing pocket money, going out, sleeping time and attending vocational training. Although there were restrictions, most restrictions were not strict, and so most residents (72.2%) reported that could enjoy freedom in their overall life at residential home.

C. Perceived Freedom and Overall QoL

Correlation and regression analysis was performed with the data of 146 respondents by using SPSS for Windows. Overall life satisfaction was found to relate to individual's overall perceived freedom (Pearson correlation coefficient=.385, p=.000), but not related to the total number of perceived restrictions. By using regression analysis, perceived freedom could explain 14.9 % of the variance in overall life satisfaction (Please refer to Table 3).

D. Comparison of predictive power of perceived freedom with other variables.

In order to explore the strength of relationship between perceived freedom with subjective life satisfaction, it is better to compare the predictive power of individual's perceived freedom with other variables such as demographic variables, medical variables, social functioning and current psychiatric symptoms. (Please refer to Table 3).

All of the demographic variables including sex, age, education, income, marital status, religion, place of birth, income, having a physical illness, and period of stay at LSCH were found not related to overall life satisfaction. Overall life satisfaction were found related to the following medical variables: having a diagnosis of schizophrenia (Cramer's V =.351, p=.030 < .05), number of hospitalization (Pearson correlation coefficient =-.330, p=.000), and hospitalization period just before admission to LSCH (Pearson correlation coefficient =-.170, p=.046 < .05). By using regression analysis, medical variable could explain 2.79 % of the variance in overall life satisfaction. (Please refer to Table 3).

On the other hand, most current psychiatric symptoms as measured by Social Behavoural Schedule were not related to overall life satisfaction. Only one symptoms, i.e. hostile social contacts, was found to be moderately correlated with overall life satisfaction (Pearson correlation coefficient =-.324, p=.007). Besides, overall life satisfaction is weakly correlated with physical functioning (Pearson correlation coefficient= .183, p=.027 < .05) and inter-personal skills (Pearson correlation coefficient= .164, p=.048 < .05), but not in other skills including: personal care, social acceptability, community living and work as measured by SLOF. By using regression analysis, current psychiatric symptom (i.e. hostile social contacts) and social functioning (i.e. physical functioning and inter-personal skills) could explain 4.2 % and 4.8% of the variance in overall life satisfaction respectively (Please refer to Table 3).

Based on the above research results, among all the variables discussed above, perceived freedom was found to have the strongest predictive power for overall life satisfaction.

Table 3 Independent Predictive Power of various variables and Overall Life Satisfaction

	Variable	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	Medical Variables (i.e. number of hospitalization & latest hospitalization period)	.165	.027	.012	1.1008
2	Psychiatric Symptoms	.204	.042	.035	1.1271
3	Social Functioning	.219	.048	.035	1.1272
4	Perceived freedom	.385	.149	.143	1.0692

Discussion

Perceived Freedom and Overall life satisfaction

In this study, it is found that individual's perceived freedom is found to be good predictor the subjective overall life satisfaction for people with long-term psychiatric illness. This finding is supported by other research studies. For example, Rosenfield [17] identified sense of mastery, while Zissi et al. [16] identified autonomy as good predicator for subjective life satisfaction. Moreover, in this study, individual's perceived freedom is found to be a stronger predictor than other variables including: demographic variables, medical variables, social functioning and current psychiatric symptoms.

After identifying individual's perceived freedom as good predictor for overall life satisfaction, program elements in enhancing individual's perceived freedom should be included in residential home care. This suggestion is supported by the study done by Timko et al. [11] who reported that the policy of encouraging residents' control on management of residential home was found to be related to residents' reported life satisfaction for people with mental illness.

Other predictors of overall life satisfaction

In this study, a number of demographic and social variables are found relating to and predicting overall life satisfaction. These research findings are reviewed as below.

All of the demographic variables including sex, age, education, income, marital status, religion, place of birth, income, having a physical illness, and period of stay at LSCH are found not related to subjective overall life satisfaction. Thus none of these demographic variables is predictor of overall life satisfaction. These research findings are supported by a number of research studies which have found that demographic variables are unrelated or at most weakly related to overall life satisfaction [21, 25-29].

Overall life satisfaction is found related to having a diagnosis of schizophrenia and number of hospitalization. These results are supported by other studies [19, 26, 30]. However, the finding that latest hospitalization period just before admission to LSCH is related to overall life satisfaction is not supported by other studies [21, 26].

Consistent other studies, overall life satisfaction is found to be negatively correlated with current psychiatric symptoms [19, 21, 26, 29].

With regard to correlation between social functioning and overall life satisfaction, there are inconsistent in research studies. Some studies reports that overall life satisfaction is positively related to social functioning [11, 21, 31], while some studies do not confirm this result [13, 28]. This research study adds evidence to the finding that overall life satisfaction is positively related to social functioning.

Conclusion

In mental health field, few studies have been done in identifying program elements which predict or lead to individual's life satisfaction. This research study has demonstrated that individual's perceived freedom is a good predicator for subjective life satisfaction for people with long-term mental illness. Program elements in enhancing individual's perceived freedom are suggested to be included in residential home care. In this study, research design is based on cross-sectional study. In future, a large-scale longitudinal study should be carried out in order to confirm the above research findings.

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Promoting the Psychosocial Functioning of Young Adults through Psychiatric Residential Rehabilitation: A Qualitative Evaluation of the Making a Significant Change (MASC) program

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Abstract

Aims and purpose of the study

This research evaluated the Making a Significant Change (MASC) program – the only residential psychosocial rehabilitation program for young adults in the Grampians region of Victoria, Australia. The program provides intensive support and rehabilitation services to young people aged 16 to 24 years who have a mental illness and are at risk of developing further mental health disabilities. This evaluation aimed to establish a holistic view of the program with a focus on the process of rehabilitation rather than a pure examination of the outcomes. The purpose of the evaluation was to provide descriptive data for key stakeholders in the service so that the impact of intervention approaches could be gauged.

Methods

A qualitative methodology explored the attitudes and perceptions held by consumers and staff of the MASC program. Data were collected through in depth semi-structured interviews with seven participants (four consumers and three staff). These data were triangulated with consumers' case histories and individual program plans.

Findings

The evaluation found that all of the domains of psychosocial functioning were covered efficiently within the MASC program and that skills learnt during this process built resiliency enabling most consumers to obtain a comfortable lifestyle for themselves. Areas of program delivery which could benefit from revision included modification of the initial stages of entry into the program

and immediately after discharge from acute inpatient hospital admissions. The importance of considering the needs of staff to overcome feelings of frustration and complacency was also highlighted.
Key Words: Psychiatric Residential Rehabilitation, Young Adults, Qualitative Methods

Introduction

An estimated 634,000 young adults in Australia experience a mental health disorder (Blair, Burthon, Silburn & Zubrick, 2000). The issues related to mental illness for young adults are complex and reach into many domains of an individual's life. The first episode of a disorder can exacerbate normal developmental issues experienced during this life stage, affecting psychosocial functioning that is critical to an individual's social and emotional wellbeing (Harrop & Trower, 2003). Studies have indicated that psychotic disorders, anxiety disorders and mood disorders produce deficits in psychosocial functioning in adolescence and adulthood. Such deficits include impaired academic and occupational functioning, social difficulties, poor peer relationships, lowered life satisfaction, increased adversity, increased treatment utilization, criminal arrests and reduced global functioning (Gotlib et al., 2003; Reinherz, Giarconia, Carmola Wasserman & Silverman, 1999).

High-risk behaviours can foster further serious deficits in psychosocial functioning for young adults experiencing mental illness (Davis et al., 2000). Such high-risk behaviours include increased alcohol and drug use, self-harming, unsafe sexual behaviour, reckless driving, aggression toward others and an increased risk of suicide (Drake, McLaughlin, Pepper & Minkoff, 1991; Siegfried, 1998; Rayner & Warner, 2003; Burnely, 1994). The risk of suicide is exacerbated by complex social issues such as family breakdown, unemployment, low self-esteem, homelessness, poverty and drug and alcohol abuse (Burnely, 1994). Further disabilities once established can prove to be resistant to change in later adulthood (Blair et al., 2000).

Promoting Psychosocial Functioning as a Treatment Modality

Findings from past research suggest that effective intervention with young adult consumer groups require approaches that target multiple complex domains in order to foster resilience and build skills (Fuller, 1998; Fuller, McGraw & Goodyear, 2002; Kosky, 1992 & Nemec & Furlong – Norman, 1989). A large Australian found young people perceived support, belonging, sense of citizenship, ability to contribute, a sense of mastering and connectedness to family and peers as important skills for promoting resilience and well being (Fuller, 1998). When effective, such intervention approaches act to reduce the impact of suicidal ideation, self-harming behaviours, aggression, substance abuse and mental health issues (Kosky, 1992; Nemec et al., 1989). Psychosocial interventions employ techniques aimed at decreasing symptoms and maladjustment by improving adaptive and social functioning (Gotlib et al., 2003; Geller, Zimmerman, Williams, Bolhofner & Craney, 2001). Such processes include the attainment and development of skills through learning and motivation to improve affect, cognitive processes, behaviour, interpersonal interactions and self-confidence.

The Making a Significant Change Program

The 'Making a Significant Change' program (MASC) is provided by Centacare in Victoria within their psychiatric disability rehabilitation and support service (PDRSS). Such programs are designed to compliment clinical mental health services by providing psychosocial assessment, rehabilitation and support (Department of Human Services, 2003). Non-government organisations in the community manage these programs statewide (Department of Human Services, 2003). The MASC program services the Grampians region operating from the regional city of Ballarat. The total population of the Grampians region is estimated at 202,952 residents (Australian Bureau of Statistics, 1999). Of the total population, an estimated 23,888 residents are aged between 16 and 24 years (Department of Infrastructure, 2000).

The MASC program provides intensive support and rehabilitation services to young people aged 16 to 24 years who have a mental illness and are at risk of developing further mental health disabilities. Examples of common illnesses within the consumer group are schizophrenia, bipolar affective disorder, and depression. The MASC program is a relatively new program, operating since 1999. The program aims to provide short-term intensive support to improve the mental health status and quality of life of consumers (Centacare & Ballarat Psychiatric Fellowship, 1998). The promotion of psychosocial functioning aims to decrease high risk behaviours, build skill mastery and improve self confidence before young adults are supported to reintegrate into their own rural communities (Centacare & Ballarat Psychiatric Fellowship, 1998). A solution-oriented approach is adopted to compliment the framework of psychosocial rehabilitation in order to guide “the process of facilitating an individual’s restoration to an optimal level of independent functioning in the community…” (Cnaan et al., 1988).

There are three levels of support offered by the MASC program: Intensive rehabilitation is provided within a residential rehabilitation setting that is staffed seven days per week from 8 am to 10.30 pm, with the option of twenty-four hour support if the need arises (Thorne & Davis, 2000). The second level of support involves home-based outreach in which consumers work with staff on a less intensive basis. Support is offered to assist consumers and where necessary carers, with the transition phase of returning to local communities (Thorne & Davis, 2000). The third level of support involves,secondary consultation, where staff work closely with rural providers of services to establish continuity of care throughout the transition phase and to ensure ongoing care where necessary after the consumer exits the program (Thorne & Davis, 2000).

Each level aims to support consumers maintain their mental health and overcome high-risk behaviours by building skills in the areas of mental health, budgeting, recreation, social skills, motivation, education, employment, working toward living independently, utilizing community services and family reconciliation (Thorne & Davis, 2000). Individual program plans are used to explore and identify the goals of consumers, establish a plan of action and to monitor progress (Thorne & Davis, 2000).

Aims of the Study

This study aimed to establish a holistic view of the program with a focus on the process of rehabilitation rather than a pure examination of the outcomes. The first aim was to determine the attitudes and perceptions that participants had toward the role of rehabilitation within the recovery process for young adults experiencing mental illness. The second aim was to identify the attitudes and perceptions participants had toward the intervention strategies currently employed. The third aim was to ascertain the extent to which it is perceived that the lives of consumers had changed from participating in rehabilitation. The fourth aim was to explore the participant’s perceptions of what the future holds for consumers.

Method

Participants

The study involved seven participants, three staff members and four consumers. Demographic information obtained from consumers included age, gender, primary diagnosis, secondary diagnosis, identified high-risk behaviours and length in program. To build a profile of the MASC consumer population, demographic information was obtained for each individual who had accessed the program during the time of its existence (i.e., 1999 to 2004). The mean age of all consumers was 21.16 years of age (N=57). The mean length of time spent in the program was 8.42 months. The most commonly occurring primary diagnosis was schizophrenia (45.6%), followed by a drug induced psychotic episode (19.3%), depression (15.8%) and bipolar affective disorder (8.8%). Co-occurring mental illness was noted in 45.6% of consumer cases. Drug induced psychotic episodes (30.8%) were the most common co-occurring diagnosis followed by depression (19.2%). The most frequent high-risk behaviours acknowledged at time of entry into program for all consumers were drug and alcohol abuse or dependence (82.5%), previous acute inpatient admissions (73.7%), previous suicide attempt (42.1%), self-harming behaviour (36.8%) and history of aggressive acts towards others (36.8%).

Materials

Semi structured Interviews

Semi-structured interviews were considered to be the most effective method of acquiring an overall view of the program whilst allowing the exploration of alternative issues if they arose.

Case Histories

ndividual program plans, activity timetables and communication notes that record the daily activities of consumers were used to produce a series of case histories. Individual program plans are a mandatory component of the program and reflect a number of the programs' key aspects. These aspects include mental health, drug dependencies, physical health, family, education, personal appearance, hygiene, diet, budgeting, creative personal expression, vocational training, exit plan and are used to identify difficulties for consumers, set goals, monitor current status and record action taken to date. Individual program plans are reviewed on a six monthly minimum basis.

Data Triangulation

Data triangulation refers to the use of multiple sources of data for providing information (Flick, 2002; Goodrick, 2004; Patton, 2002). For the purpose of this study, the process involved building thematic conceptual matrices of the information obtained from staff interviews, consumer interviews and case histories (see Miles & Huberman, 1994 for more on matrix displays).

Procedure

Ethical approval was granted by the University of Ballarat's Human Research Ethics Committee. All ethical principles were followed in the course of conducting research.

Interviews were conducted for approximately an hour and a half and were audiotaped. Interviews were conducted by the first author, who was also a casual employee within MASC at the time. This dual role was managed by stressing to all participants that the research was being conducted by the University of Ballarat and not the researcher's employer. It was also emphasised that any information that the researcher gleaned would only be used for the study and not by the program. Participants were informed that the only accessible data to any person other then the researchers would be in a general format in the final copy of the thesis or journal article.

The staff interviews were performed on an individual basis by the first author. Interviews with consumers were conducted as a group interview at the request of participants. The audio recordings of interviews were transcribed following completion. Transcripts were compiled following the qualitative data preparation and transcription protocol developed by McLellan, MacQueen and Neidig (2003).

Process of Data Analysis

An approach to thematic coding based on constant comparative methods was used to analyse the transcribed interview data (see Dye, Schatz, Rosenberg, & Coleman, 2000 for description of this processs) . Data analysis was carried out by the first author and revised in consulation with the second author who acted in a supervisory capacity. In addition to the data obtained from interview, summaries of communication notes and activity timetables obtained from individual program plans were made. Data were then built into matrix displays to allow ease of comparison across cases and cross-referencing between program documents and the attitudes and perceptions of participants. The final results comprise a series of thematic descriptions, incorporating data from these multiple sources as well as selected quotations from the study's participants. Themes also relate back to the study's four main research aims.

Results

Theme 1: Attitudes and Perceptions Participants Had Toward the Role of Rehabilitation within the Recovery Process

They wouldn't be in this program if they hadn't had a major psychiatric episode…that they didn't have high-risk behaviours like drug abuse or self harm or suicidal thoughts…or all of the above (staff)

Perceived Purpose of Rehabilitation

Participants perceived the purpose of the program was to restore consumer's previous levels of overall functioning to enable them to live independently within the community. It was perceived that to achieve this, the program served as a place to establish social networks within a supportive and non-judgemental environment free from stigma.

Some of these guys have done some pretty horrific things in the past and been in some really quite… antisocial settings so to actually be accepted for some of that stuff where no one else has accepted them is a really good starting point" (staff).

It pulls people out of holes a lot you know… someone I knew was like… in real trouble and MASC pulled em out of trouble and gave em a fresh start in a new place" (consumer).

Programs like ours are there to transit these kids through that pretty rough stage and they come out the other end… having learnt to be independent (staff).

The Perceived Role of Rehabilitation in Overcoming Mental Health Issues and High Risk Behaviours

I didn't even know what psychosis was I just thought things (laughs) weren't going well (consumer).

Common perceptions of the role of rehabilitation in overcoming mental illness were to restore self-esteem and confidence through support and education on precipitating factors. Prevention and intervention to overcome high-risk behaviours and links into other agencies were identified as being important within the recovery process. Cross references with individual program plans highlighted the role of the program in supporting consumers through the differing phases of illness.

Yeah I lost a lot of confidence from my last…psychosis so… I gotta build it back up again (consumer).

It's been like a year now and I haven't used em coz I know if I do I will probably get sick again and end up in psychosis and end up back in the psych ward and I will probably never come good again (consumer).

There's a lot of agencies and things that they've got access to that help you in a lot of different ways (consumer).

If there's drugs and stuff happening…if you're at home and you stuff up a couple of times and you're gone, but you get a few chances to realize what's the right thing to do (consumer).

Promotion of Daily Living Skills and General Health and Well-being

Daily living skills identified as being promoted within the program were cooking skills, personal hygiene, personal care, budgeting, and cleaning skills. Cross references with individual program plans also identified physical health, personal appearance and diet.

So, the funding is around daily living and ensuring that they've got the skills to look after themselves. So, it'd be you know making sure that they learn how to cook, clean…" (staff).

To get you into things you got to do to get into the normal rhythm of what you have to do in life (consumer).

It was acknowledged that the promotion of well-being worked to rebuild trust, overcome fear and hopelessness. Techniques used to do this incorporated the encouragement of positive family relationships, re-establishing social networks, participation in recreational activities, vocational and educational support.

You do a bit of fun stuff and give yourself good ideas of what to do in the future, have a few experiences, you know always having people there to talk to that are intelligent and know what you're talking about (consumer).

I liked being the footy head and knowin' a lot of people I like that, I really did like getting along with heaps of people and havin' lots of friends and stuff n I think that's what broke me for ages (consumer).

Theme 2: Attitudes Participants Had Toward the Intervention Approaches Currently Employed and the Perceived Effectiveness of Those Interventions

If you can't build that rapport with the young person then really you're not going to be able to work on any of the other issues. You get a small window and as soon as that window opens, you need to jump in, get in before they shut the window and hopefully you can actually get on with it and move forward (staff).

Attitudes towards the Program as an Intervention Strategy

Recurring patterns of consumers feeling 'pushed' whilst in the program occurred across participants. It was identified that the reactions to being pushed were dependent on the phase of illness. Other patterns indicated that interventions employed mostly made consumers feel safe, supported, and secure. Consumer participants expressed appreciation toward the program for aiding participants to feel well again.

It's pushing you to be doing stuff and that's when it sucks, when your in the depths of depression and you just want to be sitting there (consumer).

I really didn't like being pushed much… but it is a good thing coz it keeps you active… it keeps your mind active, keeps you healthy (consumer).

It was good for me in the whole sense of I wanted to get to a safe place, MASC felt like a very safe place coz like you were being supervised sort of… (consumer).

They definitely helped me out a lot just to get well again after the psych ward basically (consumer).

Formal Strategies

Formal strategies explored were the use of a solution-oriented approach and individual program planning. Attitudes toward these approaches varied across cases. Issues influencing the effectiveness of individual program plans included time availability and motivation. Cross-referencing indicated that they were particularly useful in exploring creative personal expression, family relationships, physical health and budgeting. Substance use and mental health components had mixed outcomes. Education and training had poor outcomes with cross-referencing demonstrating a lack of interest in pursuing these goals any further.

The workers are too busy to pull out everybody's IPP everyday to have a look and read through four pages (staff).

It's mainly just paperwork really, at least that's what I seem of em (consumer).

I thought IPPs helped… I had to do things a certain way and I got it done and I got it done the way I wanted it coz it helps you to set goals. Oh, but sometimes when you don't want to do anything, when you don't want to be doing anything it sucks (consumer).

We are not dwelling on what happened in the past or what the problem is… we're actually trying to look at you know achieving goals for the future (staff).

Informal Strategies

Numerous informal strategies were identified. These included activity timetables that were recognised across cases as effective on a day-to-day basis, role modelling, psychoeducation and the use of general discussion. Cross-referencing with individual program plans identified the use of ultimatums, intensive key support, music groups, accessing short courses, liaison with other agencies, redefining self-boundaries, intensive communication, identity kit lists and stress management sessions.

With your work timetable, on a weekly basis you can pull from that IPP and ***actually*** *keep it active on a weekly basis (staff).*

Role modelling is the big thing for this program, staff are expected to role model socially acceptable practice (staff).

Earlier on I used to talk to [name] every morning for two hours, every morning we used to sit down and have a cup of coffee and a smoke and just talk (consumer).

Specialised Strategies

Across cases, harm minimisation approaches were consistently reported as an effective way of reducing the severity of high-risk behaviours. Other interventions identified were the use of urine screens, drug diaries and consultancy and collaboration with external specialised services. External services included a drug and alcohol withdrawal unit, drug and alcohol counsellors, peer support networks, community psychology services and the utilisation of case management from psychiatric services. Cross-referencing further revealed the use of alcohol agreements, random breath testing, and implementation of post withdrawal strategies.

You know it relaxes me I enjoy it but only in moderation. It fucks me up if I have too much… (consumer).

It's quite strange that three pieces of paper and a little coloured book may be the answer for some of these young people (staff).

Depending on what the consumers needs are quite often find that they don't want extra people. They would rather… deal with their issues in house and you know that is a concern because the staff aren't actually employed as drug and alcohol workers or dual diagnosis workers (staff).

Perceptions of the Work Carried Out by Staff

Across cases, it was perceived that staff members were conducting their work well. Staff participants identified that the area was frustrating and that the work was difficult. However, their responses indicated that they perceive their positions and the work that they conduct as rewarding. Consumer participants described feelings of admiration of the staff's ability, feelings of grief during periods of staff turnover and that they are very involved in the lives of consumers.

I don't know if they could improve, they interact unreal I reckon, they really get in-depth in all their lives pushin' the right directions and stuff you know, they do a good job I reckon (consumer).

One of the big things for staff is that we get complacent with what we're working with. We forget that these people are in the program for a reason and they are the extreme end of the scale and I mean we're working with them everyday (staff).

Strategies Employed by Staff to Overcome Feelings of Frustration

Strategies that were reported as useful for staff were the feedback from external sources, the role of supervision, using a positive outlook, and the ability to separate professional and personal roles.

I've learnt that what I thought were the important issues sometimes aren't the important issues (staff).

I think over that five year period I learnt to look for more positive then I have negatives (staff).

It's extremely important that staff actually meet supervision guidelines (staff).

I have learnt over the years that you have to have a cut off point between your life and the young people that your working with (staff).

Theme 3: Extent to Which the Lives of Consumers Had Changed Resulting From Participating In Rehabilitation

I guess making friends in new places is good and figuring out them people aren't everything in your life and other things are more important like your actual proper friends and your family and that you're living a good life and stuff is better then worrying about a handful of people and what they dislike about ya (consumer).

Short Term Impact

The expansion of social networks was identified by all participants in the study. Other persistent patterns emerging across cases were improved family relationships, restoration of confidence, a sense of belonging, attachment and acceptance and the development of positive outlooks, which included hope for the future, aspirations, and goals.

That was the most important thing, finding companionship and good friends really (consumer).

So, I've always wanted to do something with my music so in the next however long if something happens and I actually get to play somewhere that will be a good thing (consumer).

We've actually taken them out and done stuff like jumping off cliffs with all the safety harnesses on and all that sort of stuff. So that they can actually experience you know that it's ok to jump off a cliff… its safe, you know it's just as safe to go out and go for a job (staff).

Long Term Impact

Perceived changes that continue to influence the lives of consumers into the future included improved employment prospects, relocation from their place of origin, obtaining a sense of achievement and the establishment of family relationships in situations where they previously did not exist. Cross-references with individual program plans showed consistent changes across cases showing that participants were maintaining healthy family relationships, completed training programs, and currently living independently with intensive outreach support.

They've actually achieved stuff and they're actually happy with their lives. And there's people out there who are still using drugs but their living independently and they're happy with their lives and they're actually moving forwards (staff).

This young person actually sess their child on a monthly basis now with supervision and that child is actually going to have a father in his life (staff).

Some of the guys leave the Grampians region altogether, they decide that it's better to have a fresh start (staff).

Influence on Well Being and the Daily Living Skills of Consumers

Improved overall functioning and improved nutrition and diet were reported across all cases. Other consistent patterns were improved physical health, overcoming fears and improved levels of life satisfaction. Cross references with individual program plans highlighted changes across cases related to improved personal hygiene and physical health and an ability to manage own finances.

The feedback that we get from family and other people are that yes this person is doing really, really well compared to what they were before they came into the program (staff).

We can go shopping, we can get videos, we can drive down the street, we can get takeaway, we can go away, we can go back to [town] but leave whenever we want, we can go on a holiday up the Murray and go fishin' (consumer).

Influence on the Management of Mental Health Issues and High Risk Behaviours

A theme that emerged across all cases was that the mental health status of consumers improved with a reduction in high risk behaviours. Furthermore, raised awareness of the impact of high risk behaviours was thought to improve insight and assist consumers to overcome negative issues related to mental illness. Cross-referencing indicated that all participants showed a reduction in substance use over the course of their time in the program and that their illnesses were currently in remission.

Feeling healthy like you know I'm not sick in the head or the body or anything like that and I've got friends and social networks and I've got family (consumer).

He's reduced his drug use… his mental health improved, and his social shills improved… so it was working on drugs worked into mental health worked into social skills (staff).

Theme 4: Participants' Perceptions of What the Future Holds For Consumers

Immediate Future

A theme that emerged across all cases was that participants perceived a future for consumers where they would have to deal with a lack of anonymity and social stigma. For example, there was a perceived inability for consumers to return to their place of origin. Other patterns across staff cases was the perception that some consumers will be able to overcome their mental illness and others will need long term psychiatric care in the future.

I hate it now, I just go there and I get this eerie feeling, I'm avoiding people and I don't want to go up the street coz I might see em and I might have to talk to em (consumer).

I'm just thinking of a couple of people who have been through this program and they've ended up in longer term psychiatric facilities (staff).

Long Term Future

Reported consumer hopes for the future were similar across cases; these included gaining employment, developing romantic relationships, having a license and a vehicle. Other emerging patterns included relocation from place of origin and the resolution of issues after leaving the program.

…get another car and get back on the road again, bit more freedom, maybe get a girlfriend one day… maybe have a family one day, buy me own house… yeah… it'd be good (consumer).

For years I've wanted to move away somewhere real far away (consumer).

Some of the feedback from families… are actually saying hey look, I know it was traumatic when our son or daughter was here but they've followed through you know (staff).

Mental Health Status

The overcoming of mental illness and resolution of mental health issues in the future was a recurring pattern across cases. Consumer responses indicated that they would not disclose their past psychiatric history to others in the future. Staff responses suggested that it was perceived that the prognosis for consumers was either remission or long term psychiatric care.

If I had a girlfriend one day or I just met someone who know nothin' about mental illness I wouldn't be saying this *sort of stuff (consumer).*

I actually see a good prognosis for most of the people who come through (staff).

You can't underestimate that some people do need to have longer term support and you know we support… in mental health terms two years is a very short period of time (staff).

Well Being and Daily Functioning
Participants perceived that consumers would feel comfortable with their lifestyles, have an improved level of self-esteem and confidence and lead an active lifestyle. It was also perceived that the impact of societal pressure would produce additional challenges for consumers to overcome in the future.

So I don't think its going to get any easier… there may be more challenges (staff).

It might not be the way that I see it as ideal or the staff see it as ideal or someone else looking into it but I think that the majority of people will actually achieve something and be living the life they want to live (staff).

He just can't wait to zoom off into the night and go camping all over the different parts that he wanted to see… and he's you know, I'm well I can do this, I can go and see outside the west Grampians area (staff).

Discussion

This study aimed to establish a holistic view of the MASC program with a focus on the process of rehabilitation rather than a pure examination of the outcomes. Overall, the evaluation revealed that all of the domains of psychosocial functioning were covered efficiently within the MASC program and that skills learnt during this process built resiliency enabling most consumers to obtain a comfortable lifestyle for themselves. Specific themes emerging from the data enable each of the study's four main aims to be addressed.

Shared and differing perspectives of the impact of psychosocial rehabilitation on the lives of consumers
The first aim of the research was to determine the attitudes and perceptions that participants had toward the role of rehabilitation within the recovery process for young adults experiencing mental illness. The broad range of themes and patterns emerging from the data demonstrated, from a holistic perspective, the impact of psychosocial rehabilitation on the lives of young people with a mental illness. Overall, the program was seen as a place that was non-judgmental in which young people could feel safe, supported, and rebuild their confidence. This was perceived as serving an important role in alleviating anxiety and fostering an environment where consumers can work on personal issues without the added burden of feeling unsettled. All participants in the present study provided positive feedback regarding the program as a whole. The emphasis of such feedback was on the achievements of the individual consumers. Such positive responses may be a reflection of the use of a solution-oriented approach within the program. Using this approach within the program has trained staff and supported consumers in assessing situations and reframing issues from a positive viewpoint on two levels: first, within the program and second, in the other areas of consumer's lives.

Consumers also commented on the expansion of their social networks, benefits of keeping active, the overcoming of fears, and the restoring hope for the future within a supportive environment. In comparison, staff emphasised issues related to the restoration of overall functioning, equipping consumers with skills to enable them to live independently and the development of positive outlooks. Such differences in the perspectives of staff and consumers may be explained in terms of motivation. Participants within the program are motivated to participate in the program for individual reasons that reflect their stage of psychosocial functioning, i.e., identity formation (Davis et al., 2000). Staff tended to identify in their responses issues that reflect the values reinforced through employment conditions and professional development training.

In terms of consumer satisfaction, consumers reported feeling that the site of the program was a good place, and the experience of participation overall was also good. They felt safe, secure and supported most of the time. Such feelings have been described as protective or resilient factors against such high-risk behaviours as self-harm, substance abuse and aggression (Fuller et al., 2002). Contradictory responses from consumers pointed to feelings of frustration during certain stages of the program. In particular, a number of consumer responses described a feeling of being pushed. While this is perceived as beneficial by consumers in hindsight, it was not appreciated by them during the initial stages on the program or after being discharged from psychiatric services. Feeling pushed can leave consumers feeling frustrated and misunderstood. These feelings have the potential to interfere with building rapport with young people who have particularly complex needs and prolong the time it takes to realise the therapeutic benefits of the program (Fuller, 1998). Despite this, consumers who participated in this study have passed through all of the stages of the program and reported feeling satisfied with the program overall. Consumers also indicated their respect and admiration regarding the role that staff play within the program.

Two opposing viewpoints emerged from the responses of staff regarding levels of their satisfaction with the program. On one hand, it was recognised that day-to-day work is largely stressful with staff working long hours, combating frustration and feelings of complacency. On the other hand, the attitudes of staff were positive in nature and it was recognised that, although the day-to-day work was challenging, as a whole the work was rewarding. Staff emphasised the role of looking for positives, recognising small achievements and establishing day-to-day living skills as the most rewarding components of the program yet little recognition was given to these issues by consumers. The emphasis staff placed on these issues may arise from a need to define achievable goals in which success can be measured to gain job satisfaction from a challenging work environment.

Shared and differing perspectives on intervention approaches and program delivery

The second aim of this study was to identify the attitudes and perceptions participants had toward the intervention strategies employed by the MASC program. Consumers highlighted feelings of being pushed during the initial stages of the program as a limitation of service delivery. Entry into the program is often a period where discharge from acute services has recently occurred and psychosocial functioning is at its lowest point. The impact of acute mental illness during this time affects most psychosocial domains on a social, emotional, physical and cognitive level. Factored into this is the perceived effectiveness of individual program plans as an intervention approach as well as staff feelings of frustration and complacency.

Complacency and high levels of frustration affect the patience of staff and the time management of day-to-day tasks. As a result, individual program plans can be neglected. Complacency may be the consequence of a small team working long hours with complex consumer needs on a day-to-day basis. These issues combined with the mandated use of an intervention approach (individual program plans) that are perceived as limited, could further exacerbate staff-related frustration and complacency.

Individual program plans were recognised as the most limited intervention approach employed in the program by both staff and consumers. This formal approach tends to be effective only when consumers' mental health status is stable and they are motivated to reach defined goals. Setting goals related to education and employment is not particularly realistic when basic psychosocial domains are underdeveloped. These two areas of functioning, employment and education are not perceived as important by consumers at this stage in their lives. The lack of interest and motivation from consumers in setting and reviewing goals can frustrate workers when time is limited and goals are being ignored or not being reached.

Frustration and feelings of inadequacy in managing the difficulties posed by consumers can lead to negative professional attitudes (Richmond & Foster, 2003). Addressing substance use and misuse puts additional pressure on staff and consumers when staff members are not trained in this area, and external sources employed to deal with such issues may not be well received by staff or consumers. For the future of the MASC program, it will important that staff are trained further in issues of substance use and abuse and be involved in continuing education on the effects of mental illness and its treatment.

As a whole, the program as an intervention approach was perceived by staff and consumers as considerably effective in supporting young people with mental illness to obtain improved family relationships, extended social networks, improved confidence and greater self-esteem. Development of these particular areas of a young adult's life is particularly important to aid consumers in overcoming high-risk behaviours and the impact of mental illness. The rebuilding of skills and informal approaches to intervention were considered to be positive strengths of the MASC program.

Whilst working on the complex issues experienced by consumers, obtaining day-to-day functioning skills further promote psychosocial functioning and build resilience for consumers. Interventions that promote and develop skills in daily living and creative personal expression were identified by staff and consumers in this study as important. Improved psychosocial functioning and resilience act as prevention measures against the development of further disabilities in adulthood (Harrop & Trower, 2003; Fuller et al., 2002; Davis et al., 2000). The program appears to foster a positive environment within which consumers feel safe and secure. Feelings of safety and security allow consumers a freedom to develop the differing psychosocial domains, learn about themselves and explore different worldviews influenced through the diversity of staff backgrounds and personalities, social relationships through feelings of belonging and connectedness, and culture through challenging activities and regular meal and movie nights (Gotlib et al., 2003). These facets of self and world exploration are integral components of identity formation that are an important developmental task for young adults as they step into adulthood (Arnett, 2000).

Extent of recovery

The third aim of this study was to ascertain the extent to which it is perceived that the lives of consumers had changed from participating in rehabilitation. All of the consumers interviewed had accessed the program for more than two years. During this time, they had all had at least one further acute hospital admission. At the time of being interviewed, their mental illnesses were in remission. The extent of recovery reported by the consumers who participated in this study was positively perceived, ,with most young adults living in a way in which they felt comfortable. Improvements were reported in each of the key psychosocial domains of emotional, social, cognitive and physical development. Perceived levels of recovery were mostly at a basic level, providing a strong foundation for further development and recovery at a later stage. Developing strong hopes and dreams for the future further fosters positive steps in the direction of recovery. For those consumers who do not reach a level of recovery within the program, the alternative is long term psychiatric care and alternative support services.

Hopes for the future

The fourth aim of this study was to explore the participant's perceptions of what the future holds for consumers. Consumer hopes for the future largely reflect the 'typical Australian dream': independence, full time employment, romantic relationships, later marriage and home ownership . These hopes were largely unchanged from those that existed before participants became unwell. Whilst these hopes were relatively unchanged, the consumers interviewed in this study acknowledged that they may require extra support at times in their lives in order to maintain stable mental health if they are to realise these hopes in the future. The staff at MASC who participated in this study expressed support of these dreams, hoping that consumers receive opportunities free from stigma, with a sense of anonymity and independence. Whilst staff appear supportive, they are also wary of the reality for consumers who experience frequent periods of acute illness requiring future long term support within intensive psychiatric rehabilitation programs.

Methodological limitations of the study

Whilst the use of a qualitative research paradigm has provided a data set rich in information, these data are limited to the specific point in time participants were interviewed and as such the context of perceptions are strongly influenced by individuals who do not necessarily reflect the views and opinions of existing and previous members of the MASC community. The group method of interviewing the participants who were also consumers was adopted at the request of participants, and this raises questions regarding the validity of reported perceptions. Furthermore at the time of the study, the researcher occupied a dual role as both a student of the University of Ballarat and also as a casual employee of the MASC program. Whilst this served as beneficial as rapport had already been established with participants, the dual role may have influenced responses from participants and later the interpretation and discussion of results. The personal philosophical commitments of both the researcher and supervisor to this form of intervention and evaluation technique may have potentially influenced the objectivity of data analysis. The qualitative method of evaluation used to conduct the research also limited the scope of the research project as it proved to be time consuming limiting its capacity to include other important stakeholders such as carers in the interview process.

Recommendations

The present study found the MASC program to be an effective intervention approach for young adults experiencing mental illness. Perceptions of staff and consumers toward the program were largely positive; however, areas of program delivery that could benefit from revision in aid of further strengthening the therapeutic impact of the MASC program were also identified. The following two recommendations are made, based on the results of this evaluation.

Recommendation 1 - Modification in the initial stages of entry into the program and immediately after discharge from acute inpatient hospital admissions.

Consumers in this study felt particularly vulnerable during the initial period of entry into the program and negative interactions or interventions at this time have the potential to prolong the time it takes therapeutic benefits to have an influence. The interactions and interventions employed during these stages depend strongly on building rapport with consumers. Currently consumers are feeling pushed in a negative way during these times due to the emphasis on formal intervention approaches. Informal approaches were highlighted as the most beneficial and well-received interventions during these times. It is recommended on the basis of this evaluation, that staff revise current practices during the earlier stages of entry into the program and incorporate informal approaches to ensure consumers perceive all stages of program participation in a positive light.

Recommendation 2 – Staff support and professional development

It is important within such a program not to overlook the needs of staff to overcome feelings of frustration and complacency. The results of this evaluation highlighted a particular need for staff to receive specialised substance use and dependence training. Obtaining qualifications in this area may improve the ability of staff to deal with the issues related to substance use and dependence, decreasing frustration levels as a result.

Conclusions and directions for future research

The strength of a qualitative research project is that it provides a data set that is meaningful and information-rich. The present study provides useful data regarding the perceived impact of rehabilitation in promoting psychosocial functioning in the lives of young adults with a mental illness. In addition, the study has generated a series of themes and patterns to be explored in future research. These future research directions include (1) determining the prevalence and impact of dual diagnosis within psychosocial rehabilitation programs for young adults, (2) comparing of the effectiveness of alternative interventions, and, (4) investigating relationships and transitions between acute psychiatric services and psychiatric disability rehabilitation and support services,and (4) exploring the impact of rural issues and stigma on the recovery process for young people who access services in a rural setting.

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Social Support and Life Satisfaction

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Abstract

This study aims at exploring the relationship between social support and life satisfaction for people with long-term mental illness. Research sample included 146 subjects, coming from two large residential homes in Hong Kong. Results show that different sources of social support have different effects on individual's life satisfaction. Supports from staff and friends, but not from family, predict individual's life satisfaction well. Emotional and instrumental supports from staff and friend have different predictive power and importance on individual's life satisfaction. These findings suggest that strengthening staff and friends' support could improve life satisfaction for people with long-term mental illness.

Key words: Life Satisfaction, Social Support, Mental Illness

Introduction

Although many researchers concern with the significant effect of social support on individual's mental heath (e.g. Brown et al. [1]), few research studies have been done in exploring the relationships between social support and life satisfaction for people with long-term mental illness. Baker et al.'s study [2] is one the few studies giving a detailed analysis in this area. In his study of 844 people with chronic psychiatric illness receiving community support services, case management service, as one type of social support, was shown to improve respondents' subjective overall life satisfaction over the nine months period. Moreover, the increase of social support was related to the increase of subjective overall life satisfaction.

While acknowledging the existing relationship between social support and life satisfaction for people with long-term mental illness, little is known on how social support system affects life satisfaction. There are several important issues in the investigation of this area which are discussed below.

Firstly, in social support research, there is a distinction between received support and perceived support. Received support is a measurement of the actual support received from supportive members, while perceived support is typically measured by asking people to what extent they believe in their network are available to help them. For example, Earls et al. [3] found that frequency of social support (actual received support) was related to individual's life satisfaction for people with psychiatric illness. On the other hand, Turner et al. [4] reported that perceived social support was correlated with psychological well-being for people with psychotic mental illness. Research evidences tend to suggest that perceived social support, but not received support, is more strongly related to life satisfaction [5].

Secondly, some researchers further examine the different modes and functions of perceived social support on individual's life satisfaction. Although there are different categories regard to the functions of social support, social support could simply be categorized in two aspects: emotional or instrumental support [6]. Different modes of social support seem to meet the needs of people with different types of psychiatric illness. For example, while people with depression need emotional support [7], people with schizophrenia need a combination of problem solving and low level emotional support [8]. Thus it seems that different modes and functions of social support, i.e. emotional or instrumental support, may have different effects on individual's life satisfaction.

Thirdly, research studies consistently found that the sources of supportive network of people with mental illness are different from that of the general population [8, 9]. While, their supportive networks are smaller in size [10], they are more likely to emphasize non-family support, such as: social service providers [11, 12]. For example, when facing with stressful life events, people with psychotic mental illness were found to seek support from mental health professionals, rather than from family [8]. It seems that different sources of support (i.e., family and non-family) may have different effects on individual's life satisfaction.

Finally, some researchers have tried to investigate about the complex process how social support interacts with psychological well-being. Several theoretical models have been developed in this area. The first model is called stress buffering model. This model assumes that social supports have an effect upon the individual's psychological well-being only in the presence of certain social conditions, such as stressful life events [13]. The second model is the direct or main effect model. The model suggests that social support has independent effects on individual's psychological well-being [14]. The third model is the indirect model. It assumes that social support exerts an indirect effect on individual's psychological well being by directly reducing perceived stress, which in turn, promote individual's well-being [15]. Although many empirical research studies have been carried out to test these models, research evidences for these models was inconsistency [13, 14, 15, 16]. More research needs to be done before reaching any firm conclusion in this issue.

Research Objective

The aim of this research study is to explore the effects of different sources of social support (i.e. family, friends and staff) and functions (i.e. emotional support and instrumental support) on individual's life satisfaction for people with long-term mental illness.

Research Design and Sample

This study has adopted a cross-sectional research strategy. The studied group of people with long-term mental illness came from two large residential homes in Hong Kong. In each residential home, four to five residents lived in the same bedroom. Various kinds of professional and non-professional staff had been employed to provide 24-hour personal care services for its residents. Staff to resident ratio is about 1:4. Those residents, who were being assessed by registered psychiatric nurse as mentally stable, had suitable comprehensive and communicative skills, and discharged from mental hospitals and then lived at the residential home for one year or more, were eligible for being selected into the studied sample. Finally 146 residents had given their written consent and were interviewed by the author successfully. The data of subjective life satisfaction and social support of the studied group were collected and completed in 1998.

Measuring Scales and Data Collection

1) Quality of Life Interview scale

In this study, Lehman's Quality of Life Interview [17] is adopted to measure the subjective life satisfaction of the studied group. The reliability and validity of the scale are well established [17, 18] and the scale has been widely used [19, 20]. In this study, there is no modification in this scale, and the reliabilities of sub-scales of overall life satisfaction as well as subjective satisfaction in various life domains have been tested to be satisfactory (Cronbach's a= .73 for overall life satisfaction sub-scale; and Cronbach's a range from .75 to .91 for subjective satisfaction indicators in various life domains).

Multi-Dimensional Scale of Perceived Social Support

With regard to the measurement of different sources and functional aspects of social support, the Multidimensional Scale of Perceived Social Support (MSPSS) [21] is modified and adopted in this study. The validity and reliability of the scale has been reported to be satisfactory [5, 21]. However, this scale is originally designed for people without mental illness. So this scale is modified so as to be more relevant and applicable for people with long-term mental illness living in residential home. Two modifications have been made. Firstly the scale has been shortened, and respondent is asked whether supportive persons would provide assistance in seven occasions instead of twelve. These seven occasions included: financial support; using public transport and community facilities; giving advice; going out for tea; sharing pleasant and unpleasant feelings; comforting; and giving concern. Assistances to the first four occasions refer to instrumental support, while assistances to last three occasions refer to emotional support. Secondly, "significant others" of the original scale is replaced by staff of residential home. So, in this scale, respondents would rate and compare their perceived social support from family members, friends and staff. A typical question is: "Would your family member / friend / staff provide financial support to you?" Each item is rated in a 4-point scale: "1" Not at all; "2" Sometimes; "3" Often; "4" Certainly.

In this study, the reliabilities of MSPSS and its subscales have been tested to be satisfactory (Cronbach's a was .90 for whole scale, and ranked from .98, .86 and .85 for the subscales of perceived support from family, friends and staff respectively). In addition, factor analysis has been carried out for this scale by using principal component analysis through Window SPSS program. Results shows that each items of this scale are satisfactory explained by three factors (please refer to Table 1 & 2). So this scale can be grouped into three factors as if the original scale [5, 21] and these three factors are: family support (item S1 to S7), friend's support (item S8-S14) and staff support (item S15-S21).

Table 1 Total Variance Explained for each item of MSPSS

	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
Component									
Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	
S1									
7.267	34.603	34.603	7.267	34.603	34.603	6.588	31.373	31.373	
S2									
5.768	27.465	62.068	5.768	27.465	62.068	4.953	23.587	54.960	
S3									
1.225	5.833	67.901	1.225	5.833	67.901	2.717	12.940	67.901	
S4									

1.118	5.324	73.225							
S5									
.905	4.311	77.536							
S6									
.770	3.669	81.204							
S7									
.573	2.728	83.932							
S8									
.556	2.649	86.582							
S9									
.482	2.297	88.878							
S10									
.433	2.060	90.939							
S11									
.396	1.888	92.826							
S12									
.343	1.632	94.458							
S13									
.291	1.384	95.842							
S14									
.285	1.358	97.200							
S15									
.221	1.054	98.253							
S16									
.116	.553	98.807							
S17									
6.951E-02	.331	99.138							
S18									
6.494E-02	.309	99.447							
S19									
5.125E-02	.244	99.691							
S20									
3.625E-02	.173	99.864							
S21									

2.860E-02	.136	100.000							

Extraction Method: Principal Component Analysis.
S1 to S21 refer to the questionnaires items of MSPSS

Table 2 Structural Matrix of MSPSS

Items	Component		
	1	2	3
S1			
-.952			
S2			
-.970			
S3			
-.972			
S4			
-.977			
S5			
-.969			
S6			
-.975			
S7			
-.961			
S8			
	.809		
S9			
	.772		
S10			
	.742		
S11			
	.339		
S12			

	.480		
S13			
	.605		
S14			
	.481		
S15			
		.472	
S16			
		.651	
S17			
		.668	
S18			
		.733	
S19			
		.624	
S20			
		.688	
S21			
		.799	

Extraction Method: Principal Component Analysis.
Rotation Method: Oblimin with Kaiser Normalization.
S1 to S21 refer to the questionnaires items of MSPSS

Characteristics of the research sample

Below describes the characteristics of the studied sample which came from two large residential homes, i.e. home A group (n=77) and home B group (n=69). Results showed that these two studied groups did not differ in almost all demographic factors, except in age and financial situation. Taking together, the whole studied group had slightly more male than female. Most of them were aged under 60 (mean 53 years), schizophrenic, single and had reached primary school level. They had a mean continuous hospital stay of 7.5 years just before admitting into residential home. Most were single or divorced, and had few contacts with their families. They did not have any friends outside the hospitals and residential home. Almost all of them had to rely on governmental social security schemes to support their lives.

Research Results

A. Subjective Life Satisfaction

Table 3 Subjective Satisfaction of Studied Sample in various life domains

Subjective Life Satisfaction (Score between 1-7 with 7 means most satisfactory)	Mean score	Standard Deviation
Living Situation	5.3	0.889
Daily Activities & Functioning	5.3	1.133
Family	4.7	1.840
Social Relationship	5.0	1.180
Financial Situation	4.9	1.450
Legal and Safety Issue	5.4	1.081
Health	4.8	1.330
Overall Life Satisfaction	5.5	1.1473

Most residential home residents (82%) were satisfied with their overall life. So the studied group viewed their overall lives as positive at their current places after their discharge from mental hospitals. The reported level of life satisfaction of the studied group is found to be similar to that reported in other studies [20, 22].

B. Social Support

The social supports of the studied group are found to be weak. About 80% of respondents were single, divorced or widowed. The majority of the studied group had few or nor contacts with their family members, and less than one fifth of respondents had weekly contacts with their families. Comparatively, the studied group had more contacts with other residents living at the same residential home. Over one third of respondents talked with other residents at least weekly. Most of the respondents (80%) rated their perceived total social support as fair and weak, while more than seventy percentage (76%, 88% and 72% respectively) rated their perceived support from family, friends and staff as fair and weak (score <3).

C. Subjective Life Satisfaction and Social Support

1. Effects of different sources of support on individual's Overall QoL

Overall life satisfaction is significantly related to and predicted by individual's perceived support from friends (Pearson correlation coefficient (r) =.260, p=.002) and staff (r=.280, p=.001), but not from family. (Data of regression analysis please refer to Table 4 for reference).

2. Effects of emotional and instrumental support on individual's Overall QoL

Overall life satisfaction is significantly related to and predicted by individual's instrumental support from friends (r=.215, p=.009) and emotional support from friends (r=.266, p=.001), instrumental support from staff (r=.262, p=.001) and emotional support from staff (r=.291, p=.000).

In particular, individual's overall life satisfaction is found to be significantly correlates with support from friends in their company for going for tea (r=.239, p=.004) and comforting (r=.224, p=.007) concern (r=.332, p=.000). In addition, it is found correlated with almost all items of support from staff including: financial support (r=.206, p=.013), assistance in using community facilities (r=.216, p=.009), advice (r=.207, p=.012), sharing of feeling (r=.196 p=.018), comforting (r=.242, p=.003) and concern (r=.296, p=.000).

For support from friends, emotional support from friends could explain 6.4% variance of individual' life satisfaction, while instrumental support could explain 4%. (Please refer to Table 4 for reference). So for support from friends, emotional support seems to have higher predictive power than perceived instrumental support for individual's life satisfaction. For support from staff, emotional support from friends could explain 7.8% variance of individual' life satisfaction, while instrumental support could explain 6.2%. (Please refer to Table 4 for reference). So for support from staff, instrumental support and emotional support seems to have similar predictive power for individual's life satisfaction.

Table 4 Independent Predictive Power of Social Support variables and Life Satisfaction

	Dependent Variable	Independent Variable	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	Overall Life Satisfaction	Total Support from friends	.260	.068	.061	1.1117
2	Overall Life Satisfaction	Instrumental support from friend	.215	.046	.040	1.1244
3	Overall Life Satisfaction	Emotional support from friend	.266	.071	.064	1.1097
4	Overall Life Satisfaction	Total Support from staff	.280	.078	.072	1.1053
5	Overall Life Satisfaction	Instrumental support from staff	.262	.069	.062	1.1111
6	Overall Life Satisfaction	Emotional support from staff	.291	.085	.078	1.1048

3. Mediating Effects of Satisfaction with Friend

As discussed above, overall life satisfaction is significantly related to individual's support from friend. Interestingly, after controlling subjective satisfaction with friend, this correlation becomes non-significant (Please refer to Table 5 for reference). This result shows that subjective satisfaction in friend has mediating effects on the relationships between overall life satisfaction and support from friend.

Table 5 Correlation of Overall QoL with Perceived social supports

Item	Test	Without controlling any variables		Controlling Subjective Satisfaction in friends and staff	
		Value	Significance	Value	Significance
Perceived Support from friends	Pearson correlation coefficient	.260	.002*	.022	.796

Remark : significance <=.001

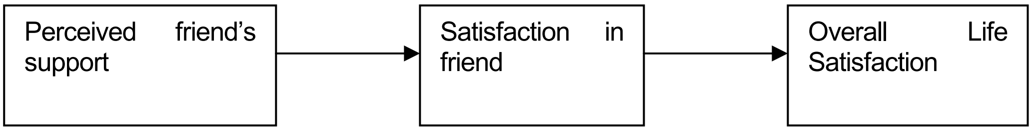
Discussion

In this study, several interesting findings are found. Firstly, it is found that different sources of social support have different effects on individual's subjective life satisfaction. Perceived support from friend and staff are found to predict individual's overall life satisfaction. However, perceived family support is found not related to individual's overall life satisfaction. These findings are supported by Lehman's study [17] which has found that intimate social relationships, rather than family relationships, predict individual's overall life satisfaction. People with long-term mental illness are so impaired and disabled that they emphasize and rely more on non-family support rather than family support in their daily lives [11, 12]. Moreover, the majority of them have few or even no contacts with their family members, and so non-family support play a more significant role in their daily lives. Thus it is not surprising to find that perceived support from friends and staff, rather than family support, play a more important role in enhancing individual's overall life satisfaction for people with long-term mental illness.

Secondly, both emotional support and instrumental support are found to predict individual's overall life satisfaction. Thus although emotional support is repeatedly cited in literature as an important correlate of psychological well being, people with long-term mental illness may need a combination of both instrumental and emotional support in enhancing their life satisfaction.

Furthermore, support from staff and friends are found to affect individual's life satisfaction through different ways. For support from friends, emotional support seems to have higher predictive power than instrumental support for individual's life satisfaction. So, emotional support from friends is more important in enhancing individual's life satisfaction. For support from staff, both instrumental support and emotional support seems to have similar predictive power as well as importance in enhancing individual's life satisfaction.

Finally, it is found that subjective satisfaction with friends has mediating effect on the relationship between overall life satisfaction and perceived support from friend. This interesting and preliminary finding indicate that perceived support from friends lead to a better overall life satisfaction *indirectly,* i.e. by improving the subjective satisfaction in friend. That is to say: perceived support from friend leads to a better subjective satisfaction in the domain of friend which in turn leads to a better overall life satisfaction. This preliminary finding suggests that social support interact with life satisfaction in an indirect way and so it is in favor of the indirect model. However, as the underlying interaction between perceived staff support and life satisfaction needs further exploration, more research is needed in this area.



The above findings have important service implications. According to the above findings, in order to enhance individual's overall life satisfaction, it is important for mental health professionals to strengthen the social support system of our service users. It could be done in several ways. Firstly, it is important to strengthen the support of staff in all aspects of the daily life of our service users, including both instrumental as well as emotional support. As staff becomes the main source of social support and has daily contact with individual service user, so it is important to strengthen staff support first. According to the above research results, in order to enhance individual's life satisfaction, staff support could be strengthen in the following ways: financial support; use of public transport; use of community facilities; giving advice; sharing pleasant and unpleasant feelings; comforting; and giving concern, etc. On the other hand, in order to strengthen support from friends, it is important to encourage service users to have more social gathering with other residents, especially in going out for tea; and to encourage service users to have emotional sharing and support towards each others.

Conclusion

This study aims at exploring the relationship between individual's social support and life satisfaction for people with long-term illness. In this study, several interesting findings have been found. Different sources of social support have different effects on individual's life satisfaction. Supports from staff and friends, but not family support, are found to lead to a better overall life satisfaction. For friends' support, emotional support seems to have a higher predictive power than instrumental support for individual's life satisfaction. For staff support, instrumental and emotional supports have similar predictive power for individual's overall life satisfaction. Finally, perceived support in friend leads to a better subjective satisfaction in friend which in turn leads to a better overall life satisfaction. The above findings suggest that strengthening individual's social support, especially staff and friends' support, could improve life satisfaction for people with long-term mental illness. In addition, based on the research results, effective ways of strengthening social support have also been discussed.

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