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IJPR Volume 15, Number 1

Feature Articles Page

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Dr. A.J. Anderson
Managing Editor - IJPR
8 Devonshire Place, London W1G 6HP, UK

Feature Articles

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Innovation in the Group Home Design:

Applying ‘Group-as-a-Whole’ to a Fairweather Lodge

Diana J. Semmelhack, Psy.D., L.C.P.C.
Midwestern University

Larry Ende, Ph.D., MSW
Therapist

Tanya Gluzerman, MA
Doctoral Intern

Karen Farrell, Psy.D.
Director of Training, Midwestern University

Clive Hazell, Ph.D.
DeVry University

Theresa Schultz, Ph.D.
Midwestern University

Dr. Diana Semmelhack is an Associate Professor in the Department of Behavioral Medicine at Midwestern University.
Dr. Larry Ende is a therapist, writer and group facilitator.
Tanya Gluzerman, MA, is a doctoral intern in clinical psychology at Midwestern University.
Dr. Karen Farrell is Director of Training at Midwestern University.
Dr. Clive Hazell is a senior professor at DeVry University who specializes in group work.
Dr. Theresa Schultz is an Associate Professor at Midwestern University.

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Correspondence: Dr. Diana Semmelhack, Psy.D., L.C.P.C., Department of Behavioral Medicine, Midwestern University, 555 31st , Downers Grove, IL 60515.

Abstract

This study explored the impact of a modified Fairweather Lodge on the development of group cohesion and self-efficacy for nine severely mentally-ill clients. The Fairweather Lodge model is a psychosocial rehabilitation model combining congregate living with collaborative employment. It differs significantly from traditional group homes with "Lodge" members assuming almost complete autonomy with regard to establishing rules and procedures, as well as in taking primary responsibility for site operations. Employment and Lodge member independence are emphasized. Our modified version of the model highlights the group-as-a-whole therapeutic position. This perspective, originating in the Tavistock tradition, focuses on the group-as-a-whole's contribution to the tasks of connection and rehabilitation versus any given individual's actions. Consultant interpretations address processes operating outside the current awareness of the group that might impede the task (anxiety, depression, etc.). Group members work together to promote growth. Ten subjects completed the 16-week evaluation period in the Control Group setting (standard group home) and nine subjects were evaluated under the modified Fairweather Lodge Model. Baseline measures of self-efficacy and cohesiveness before the start of treatment were compared between groups by unpaired t-tests. Significant changes from baseline were determined in each group by repeated measures analysis of variance with Tukey Tests used for post-hoc testing. There was no difference between the Control and Experimental Groups at baseline. After the 16 week treatment, an individual's sense of self-efficacy (on average) did not change in the Control Group, but increased by 45% in the Experimental Group. The Lodge setting also produced a 35% increase in cohesiveness from baseline to 16 weeks of treatment.

Introduction

Group homes were developed by mental health workers in the 1960's and 1970's as part of the deinstitutionalization movement. This movement involved the closing of public hospitals and the transfer of services for the mentally ill into the surrounding community, where they could be provided in "the least restrictive environment" (Bachrach, 1980). Group homes are typically small residential facilities located within a community. They are intended to simulate family life.

Unfortunately, the deinstitutionalization process fell short. According to the National Alliance on Mental Illness (NAMI, 2008), of those individuals with a severe mental disorder only 40% receive needed treatment services on any given day. This results in homelessness, imprisonment, and at times violence. Forty-two of the fifty states have less than half the minimum number of beds needed to house the mentally ill. Many severely mentally-ill individuals are forced to reside in long-term care facilities or nursing homes (highly restrictive environments), designed to provide care for people unable to care for themselves (National Center for Health Care Statistics, 1999). The population of mentally-ill individuals residing in these facilities is growing. Many of these individuals are under the age of 65 and have few other housing options. The lack of housing and treatment for the mentally ill, in our view, is a national crisis.

In response to this crisis, we propose that, contrary to what is implied by existing opinion, the application of an analytic "group-as-a-whole" model of therapeutic treatment to community living (in the context of a Fairweather Lodge) can improve the basic effectiveness of the group home design. This conclusion in turn may help strengthen the argument for developing new group homes. Our study suggests that clients with severe mental illness can benefit from treatment often considered intellectually and emotionally beyond them. We examine our approach to treatment as it positively affects two key factors of group home life: group cohesion and the self-efficacy of group members. We applied group-as-a-whole treatment to a group home (a Fairweather Lodge) partly because the treatment appears well designed for alleviating and responding to the severe isolation which individuals with mental illness tend to suffer from. Group homes are intended to counteract this isolation.

The Fairweather Lodge

A typical group home stresses maintenance and provides 24 hour supervision. There are few treatment options offered beyond medication management. There is limited focus on developing group cohesion or self-efficacy through team building, vocational training or psychotherapy. Typical group homes offer residents few opportunities for exploring their need for positive relationships, or the impact of isolation and depersonalization (due to mental illness) on their psychological well-being (Edelson, 1970).

Recently, two U.S. organizations devoted to advocacy and housing for the mentally-ill population (we shall leave them nameless) collaborated to bring about a Fairweather Lodge group home (the first of its kind in its state). A group-as-a-whole treatment model was gradually introduced, creating the basis for this study. The Fairweather Lodge group home model was developed by Dr. George Fairweather in 1963 in response to the deinstitutionalization movement. His is a psychosocial rehabilitation model, combining congregate living with collaborative employment. The model focuses on rehabilitation and the promotion of autonomy for Lodge members (Fairweather, 1964; 1980). A “Lodge” is an affordable dwelling whose members share running the home, including domestic chores and the purchase and preparation of food. Unlike in most traditional group homes, Lodge residents make their own house rules and manage their own activities. Moreover, they collaboratively design and run a small business. Such businesses may offer cleaning services, printing, furniture building, etc.

The Lodge model stresses part-time employment and Lodge member interconnectedness. Unlike in traditional group homes, where staff members provide 24 hour on-site control over the day-to-day operations of the facility, Lodge staff duties are limited to mentoring, advising, mediating, and helping in emergencies. Lodge staff includes one Lodge coordinator and one vocational trainer, who remain on-site during weekday hours only. A Lodge thus costs much less to run than a typical group home. Research supports the effectiveness of the Lodge model (Fakhoury et al., 2002).

The Group-as-a-Whole Model

This study explores the impact of a modified Fairweather Lodge on the development of group cohesion and self-efficacy for nine severely mentally-ill clients. The modification consists in applying the group-as-a-whole treatment model to the Lodge. This model, rooted in the Tavistock tradition, focuses on the group-as-a-whole’s contribution to the group and to individuals’ actions.

According to the group-as-a-whole model, staff interpretations of group behaviors take into account unconscious group processes (anxiety, depression, etc.) that operate outside the current awareness of the group, processes that may interfere with the major tasks of connection and rehabilitation. Interpretations are made by a “consultant.” These interpretations teach group members to become more sensitive to underlying group dynamics and one’s own role within them. A group-as-a-whole therapeutic perspective was fostered through 1) bi-weekly group psychotherapy sessions and 2) a social psychological perspective maintained by staff that any given individual’s behavior is influenced by the whole group, and not solely by individual psychodynamics. The group-as-a-whole model involves some integration of psychodynamic theory. The exact nature of this theory is not prescribed, but one quite frequently finds elements of traditional and object-relations theory in Tavistock consultations (Hazell, 2005).

The group-as-a-whole process refers to those conscious or unconscious dynamics relevant to the group as a specific psychological construction. One of the most extensively discussed group-as-a-whole processes in the empirical literature is group cohesion. As we will consider shortly, group cohesion plays a fundamental role in the ability of a group to be therapeutic. In our study, without prompting, the Experimental Group (the group applying the group-as-a-whole model) began to explore dynamics that interfered with group cohesion and worked to overcome them. Beyond considerations of cohesion, the group-as-a-whole can be perceived, experienced, and represented in the minds of the members with a range of positive and negative qualities (Greene, 1999). The group can be experienced, for example, as the unconscious “good mother” with protective and holding abilities (Scheidlinger, 1974). The group can be experienced as the unconscious “bad mother,” who can annihilate an individual (Agazarian, 1989). These opposite experiences of the group, formed from shared projections, have been well described in the literature. Other group processes examined serve defensive or work-avoidant needs (Bigelow, 1998). Bion (1951) explored fundamental assumptions of unquestioned dependency (for example, on the consultant), fight–flight, or again the delegation of a strict, turn–taking pattern of exchange of ideas, all often arising due to anxiety among the group members (Rioch, 1970). Such assumptions and processes need to be dealt with via interpretation or confrontation by the consultant in order to shift the group toward more task-oriented and less defensive behavior (Ettin, 1992; Yalom & Leszcz, 2005).

A consultant working in the Tavistock tradition might, for example, sense that a group that is discussing the desire to go on a trip may be avoiding the task at hand. The consultant may address this discussion with a group-as-a-whole interpretation by stating, "This group is uneasy about dealing with something in this room and desires to move away from it, to go on a trip instead, rather than to address this uneasiness." The consultant became aware of the group's escape from the task through members' comments on events outside of the group's process. The consultant's interpretation was intended to re-focus the group's discussion back on the dynamics developing in the here and now.

To deal with anxieties, groups can form us– versus–them, or in–versus–out polarities where some members disown aspects of themselves and project them into some other part of the group, or into an external group. (Agazarian, 1997). These externalizations are usually a defensive means that can undermine accomplishing the group's task. The process of splitting and externalizing needs to be dealt with by the consultant.

The approach of the consultant interpreting the dynamics of the group stresses the interconnectedness among members. This appears to reduce the tendency for scapegoating when discussing particularly controversial subjects. In addition, the approach contributes to the development of a holding environment, which encourages clients to share and to face painful issues. (Semmelhack, Ende, Hazell, Hoffman, and Gluzerman, 2009).

Group Cohesiveness

Our study measured the effects of group-as-a-whole treatment on group cohesion and self-efficacy. Group cohesion can be defined as feelings of trust, belongingness, and togetherness experienced by group members (Burlingame, Earnshaw, Hoag, Barlow, Richardson, Donnell, 2002). There is increasing agreement that cohesion is the best definition of the therapeutic relationship in a group (Burlingame, et al., 2002). Cohesiveness appears to be as important, if not more important, in describing a patient's improvement, than what theoretical orientation a therapist adheres to (Norcross & Godfried, 2001). Cohesion is defined in a group setting as to multiple alliances (e.g. member-to-member, member-to-group, member-to-therapist, group-to-therapist) (Burlingame, et al., 2002). We examined group cohesion both because of its importance for group therapy and because of its ability to counter the isolation characteristic of the severely mentally ill.

Bion (1951) has stated that we are group animals at war with our groupishness. He suggests that while as group animals we desire to be in groups, we also fear groups and what they can do to us and others. There is a field of forces that each human being must negotiate--forces pulling us towards the group and forces pulling us away from the group. The net effect of this force field results in the individual's level of membership or belonging to a group. When this force field is aggregated across all of the members of a group, one could call the result the group's cohesiveness. According to Yalom, Houts, Zimerberg, and Rand (1967), group cohesiveness predicts successful outcomes in group therapy. The development of cohesiveness appears to have a curative effect (Yalom, 2005). Marmarosh, Holtz, and Schottenbauer (2005) agree, finding cohesion to be a primary group factor, "'directly related to curative group factors such as "collective self-esteem" (i.e., the self-esteem one gains by being a member of a group) and "hope for the self" (similar to optimism) (p. 36).

Self-efficacy

We also examined the effects of group-as-a-whole treatment on self-efficacy in members. Self-efficacy is a crucial concept in the work of psychologist Albert Bandura. According to Bandura, self-efficacy indicates "the belief in one's capabilities to organize and execute the courses of action required to manage prospective situations" (1999, p.2). In more common language, this means that self-efficacy represents an individual's belief in her ability to succeed in the situations she encounters. Self-efficacy affects our motivation, behavior, and emotional states.

We examined self-efficacy because it is key to the development of autonomy, a major issue for the Fairweather Lodge, as well as for the group home in general. We believe group-as-a-whole treatment improves self-efficacy because it raises self-esteem and helps members to internalize the group as a soothing object which can be called upon in times of stress. These factors can reduce anxiety and thereby increase both ego functioning and task orientation.

Most individuals have goals they would like to achieve and aspects of their lives they would like to change. Bandura (1999) has found that self-efficacy plays a vital role in how people approach their goals, tasks, and challenges. He suggests that individuals with a strong sense of self-efficacy tend to view challenging problems as tasks to be mastered; tend to develop a strong commitment to their activities; and tend to recover quickly from setbacks. On the other hand, Bandura suggested that individuals with weak self-efficacy tend to avoid challenging tasks, focus on personal failings, and quickly lose confidence in their abilities.

According to Bandura, self-efficacy begins to form in early childhood. It then develops throughout life as we process new experiences and acquire new skills. Bandura has pointed to four major sources of self efficacy: mastery experience, social modeling, social persuasion, and psychological responses. He proposed that in mastery experiences we perform a task successfully, which strengthens our sense of self-efficacy. On the other hand, continuous failure in responding to challenges weakens self-efficacy. As for social modeling, Bandura suggested that witnessing others successfully completing a task strengthens the observer’s belief that she can master it. In social persuasion, the encouragement of others convinces people that they have the skills to succeed. Finally, psychological responses play an important role in self-efficacy. Bandura suggested that emotional states, moods, physical reactions, and stress all affect how we feel about our abilities.

Previous Research

Some key problems have confronted researchers studying group home effectiveness. Most of the studies have been non-controlled follow ups, cross sectional surveys, or non-randomized controlled trials (Fakhoury, Murray, Shepherd, & Priebe, 2002). There have been few outcome studies regarding the effectiveness of housing. There are difficulties due to practical and ethical problems that make randomized controlled trials hard to conduct. Fakhoury and colleagues report that the most common type of research has been cross-sectional, but one cannot determine causality from this research (Fakhoury et al., 2002). Despite growth in group housing, little research has been done on the effects of living arrangements, or the support available to residents (Nelson, Walsh-Bowers, & Hall, 1998).

Tornatzky, Fegus, Avella, and Fairweather (1980) showed that the Lodge provided a better track record in terms of recidivism and employment than most other forms of community aftercare. Persons who were members of the Lodge on average remained within the community much longer than their matched pairs in other community treatment programs. Lodge residents were more frequently employed, and the cost of operating Lodge programs was less than that of other programs. When the Lodge became completely self-governed by the members, it also could be somewhat self-supporting by the employment income of members, which provides a further measure of the cost-effectiveness of establishing a Lodge (Tornatzky et al., 1980).

Though there has not been extensive research done on the effectiveness of the Fairweather Lodge model, some other research has been compiled. Onaga, McKinney, and Pfaff (2000) examined the variables behind the success of the model by looking at 74 Lodges throughout the nation. One main theme that surfaced was that Lodges were similar to families in that they emphasized mutual support, shared resources, common goals, a sense of community, a nurturing environment, and an integration of values.

Haertl (2004) explored factors contributing to the success of clients in a Fairweather Lodge through a mixed design study. The results indicated that success in the Fairweather Lodge model depended on the following variables: willingness to work, assimilation to the community environment, receptivity to peer support, work and living skills, ability to experience a higher quality of life, empowerment, sense of community, and independence.

Limited research has been conducted on the utility of the group-as-a-whole model in creating a sense of cohesion or self-efficacy with severely mentally-ill populations housed in community based settings (Hazell, 2005; Semmelhack, Hazell & Hoffman, 2008). Most of the work available on the group-as-a-whole methodology provides qualitative descriptions of group process, not empirical studies conducted with control groups. According to Kapur, Ramage and

Walker (1986), since the 1960s analytic group work with institutionalized populations has been de-emphasized. The analysis of transference issues and in-depth emotional material is deemed largely inappropriate and impractical. A study by Semmelhack, Hazell, and Hoffman (2008) suggests outcomes to the contrary. They found a significant decrease in anxiety and a trend toward decreased depression after 30 weeks of group-as-a-whole work with severely mentally-ill individuals residing in an inpatient setting. A significant increase in cohesiveness after group-as-a-whole work under these circumstances was also found (Semmelhack, Hazell, Ende, Hoffman, & Gluzerman, 2009).

Method

Setting

The Experimental Group resided in a Fairweather Lodge located in a home in a middle-class neighborhood. The home had four bedrooms, four bathrooms, a living room area, TV room, large kitchen, dining room and recreation area. The Control Group members resided in a typical group home setting in the state where the study took place.

Participants: Experimental Group

There were nine residents in the Experimental Group, all of whom had been given a major Axis I diagnosis according to the Diagnostic and Statistical Manual of Mental Disorders Text Revision (DSM-IV-TR) (American Psychiatric Association, 2000). The population ranged from 40 to 60 years of age. Three members were diagnosed as having Paranoid Schizophrenia, two Major Depression, and four Schizoaffective Disorder. None of the participants was diagnosed with an Axis II disorder. All of them had experienced childhood trauma, including sexual, emotional, or physical abuse, or neglect. Additionally, all had made at least one suicide attempt. All members had at least average intelligence, measured upon admittance into the facility through the administration of a Kaufman Brief Intelligence Test (K-BIT) (Kaufman & Kaufman, 1990).

Participants: Control Group

The ten members of the Control Group were matched with the Experimental Group on gender, age and intelligence. Members of the Control Group had similar Axis I diagnoses. They too showed an absence of Axis II diagnoses. Like those in the Experimental Group, all individuals had a history of suicide attempts and childhood trauma. Control Group members were engaged in traditional group home treatment, which included training or psychotherapy on an as needed basis in addition to medication management.

The total sample consisted of nineteen clients (eight men and eleven women). The Control Group included five men and five women, the Experimental Group five men and four women. All participants were European American.

Instruments

Group Attitude Scale (GAS). The study measured cohesiveness using the Group Attitude Scale (Evans & Jarvis, 1986). This questionnaire consists of 20 self-report items. The items relate to several aspects of cohesiveness, including attractiveness, belongingness, and well being. They address the broadness of the concept of cohesiveness. The measure requires the participants to respond to statements such as, "People in my work group work together well," and, "I feel like I am really part of my group" before and after the 16-week treatment period by placing an "X" on a continuous scale labeled from 0 to 100. Members of the Experimental and Control Groups were asked to indicate how they felt about group membership (the group being the members of their group home).

In several studies of the original Group Attitude Scale, the measure coefficient alpha has ranged from .90 to .97 at various points in the lives of groups studied. The validity and reliability data obtained to date on the scale suggest that the instrument has promise as a measure of sense of belonging to a group (Evans & Jarvis, 1986). General Self-Efficacy Scale (GSES). We measured self-efficacy using Jerusalem and Schwarzer's (1992) General Self-Efficacy Scale (GSES). The GSES has been used to measure improvements over time in self-efficacy. It was developed in Germany in 1979 by Matthias Jerusalem and Ralf Schwarzer and was later revised and adapted to 26 languages (Jerusalem & Schwarzer, 1992). The scale was originally created to assess a general sense of perceived self-efficacy and to predict coping with daily hassles, as well as to determine how one adapts to stressful life events. The GSES was designed for the general adult population, including individuals age twelve and up. The scale is self-administered. It takes, on average, four minutes to administer. As regards scoring, responses are made on a 4-point scale. After administration, the responses to all 10 items are summed up and yield a composite score ranging from 10 to 40. Higher scores indicate stronger patient belief in self-efficacy.

The items on the GSES relate to several aspects of self-efficacy, including belief in one's capacity to perform novel and difficult tasks and cope with adversity in various areas of human functioning (Jerusalem & Schwarzer, 1992). Perceived self-efficacy aids in goal setting and persistence when faced with a setback. Each of the items on the scale points to successful coping while attributing this success to one's internal ability.

In regard to the scale's reliability, in samples from 23 nations Cronbach's alphas ranged from .76 to .90 (Jerusalem & Schwarzer, 1992). As regards validity, criterion-related validity has been acknowledged in a variety of correlation studies where positive coefficients were correlated with favorable emotions, dispositional optimism, and work satisfaction, and negative coefficients were correlated with depression, anxiety, and stress.

The strengths of the GSES are that the measure has been used internationally with success for two decades and that the measure is suitable for a broad range of applications and populations, including the elderly population, minorities, and others. (Jerusalem & Schwarzer, 1992). The weakness of this measure is that it does not necessarily assess behavioral change (Jerusalem & Schwarzer, 1992). Thus the measure may need to be used concurrently with an additional one.

Procedures

Administration of study measures. Participants in the treatment group were given the GAS (Evans & Jarvis, 1986) and the GSES (Jerusalem & Schwarzer, 1992) by a member of the Lodge staff before the group began (Time 1). The group ran for 16 weeks, at the conclusion of which participants were again given the GAS and GSES (Time 2). A member of the staff distributed the scales to group members immediately after the end of the 16-week module. She read the explanation of each measure written on the examination form with no other promoting of which answer would be the correct or more appropriate one. She collected the scales within two hours after the end of the group. Members of the Control Group were assessed at the same two points by a group home staff member, who distributed the measures following the same protocol as with the Experimental Group.

Statistical Analyses

Data are presented as mean and standard deviation. Baseline measures of self-efficacy and cohesiveness before the start of treatment and at 8 and 16 weeks of treatment were compared between groups by unpaired t-tests. Changes from baseline were determined in each group by repeated measures ANOVA with Tukey tests used for post-hoc testing.

Results

Ten subjects completed the 16 week evaluation period in the Control Group settings and nine subjects were evaluated under group-as-a-whole treatment. There was no significant difference between the groups in self-efficacy or cohesiveness determined as baseline measures before the start of treatment (Table 1). (This equality at baseline was particularly surprising since while Experimental Group members had only recently met, Control Group members had resided together for thirteen years.) However, the level of both self-efficacy and cohesiveness were significantly higher for the modified Fairweather Lodge than for the Control Group at 16 weeks of treatment.

Table 1. Agency and cohesiveness during 16 weeks with control and Group-as-a-whole Lodges.

Group	N	Treatment	Agency	Cohesiveness
Control	10	Baseline	61.2 + 17.6	67.1 + 15.9
		8 weeks	62.4 + 14.0	69.8 + 16.8
		16 weeks	61.7 + 12.5	67.7 + 15.1

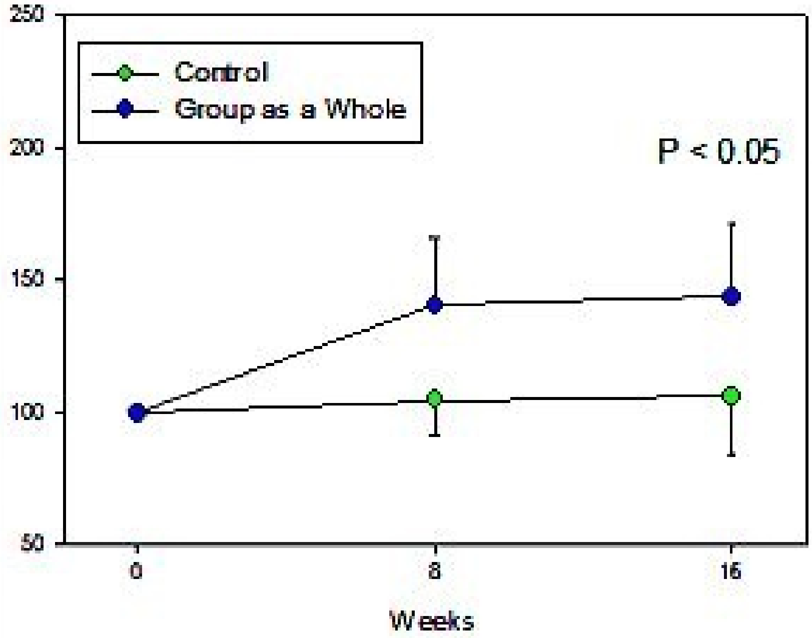
Group-as-a-whole	9	Baseline	54.2 + 17.3	61.8 + 9.3
		8 weeks	68.4 + 12.7	76.5 + 14.9
		16 weeks	73.8 + 12.5*	83.2 + 12.8*

Mean + standard deviation
* = P < 0.05 compared to Control Group

Self-efficacy did not change in the Control Group, but increased 45% in the Experimental Group from baseline to 16 weeks (figure 1). The group-as-a-whole setting produced a 35% increase in cohesiveness from baseline to 16 weeks of treatment (figure 2). In contrast, the Control Group showed no significant change in cohesiveness.

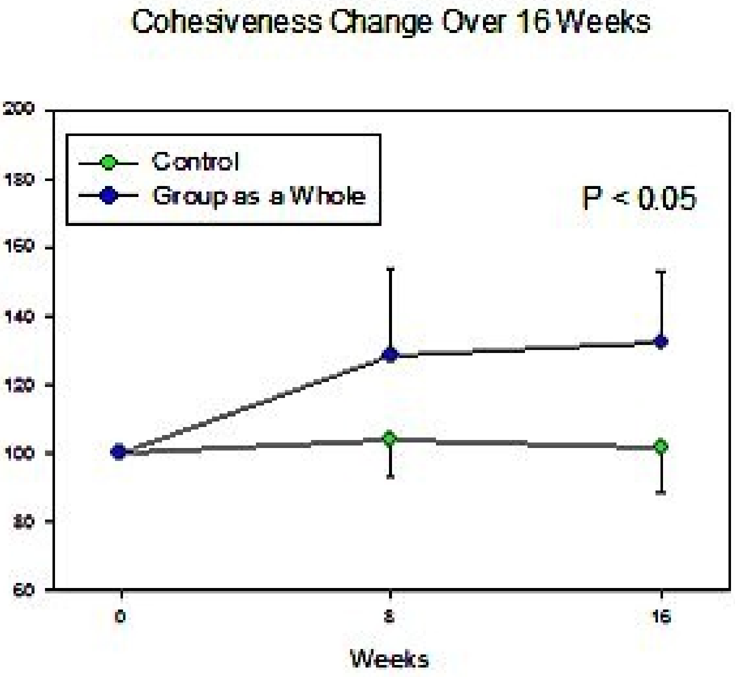
Figure 1.

Agency Change Over 16 Weeks



Agency (self effectiveness) changes over 16 weeks of Group-as-a-whole or Control treatment. Data are shown for each group as percent of baseline measured at the start of testing. Group-as-a-whole treatment produced a significant increase in self effectiveness over the 16 week period as determined by repeated analysis of variance. There was no significant change in self effectiveness in the Control Group.

Figure 2



Cohesiveness changes over 16 weeks of Group-as-a-whole or Control treatment. Data are shown for each group as percent of baseline measured at the start of testing. Group-as-a-whole treatment produced a significant increase in self cohesiveness over the 16 week period as determined by repeated measures analysis of variance. There was no significant change in cohesiveness in the Control Group.

Casually collected qualitative feedback from Experimental Group members suggests the apparent utility of the modified Fairweather Lodge model, as well as showing concretely some of its apparent effects. A few examples suggest the tenor of a variety of comments. One member stated,"For the first time in my life, I feel like part of a group." Another one said, "You know, we are a part of a team. We are all together and for better or worse we can make things happen. I'm not alone. I have you guys backing me." A third member stated, "I need this group. I've never before been understood as a person." And another remarked, "Coming here makes me feel more confident to face my day."

Discussion

The findings suggest that individuals with chronic mental illness can benefit from a group-as-a-whole treatment (in this case in a Fairweather Lodge) that speaks to them as human beings who can learn from their relationships. Despite society's preoccupation with this population's having limitations, individuals with severe forms of mental illness are human beings who know what it is like to feel validated and connect with others. This is a major factor that group-as-a-whole treatment brings to the table so that group members can connect with each individual member as part of a larger community.

Too many approaches to individuals with mental illness minimize the humanistic aspect with regard to symptom management. While psycho-education plays an imperative role in allowing one to understand and manage symptoms of mental illness, being able to connect with and relate to others raises self-esteem and improves the ability to connect with and reintegrate into society as a whole.

We need not only to teach social skills and to encourage community, but to learn overall how to create the conditions which foster human connectedness. Group-as-a-whole work and the Fairweather Lodge are designed to do this.

In addition to applying the group-as-a-whole treatment approach, we might consider such questions as, how can we provide interpersonal direction? What does it mean to be part of a group? What does it mean to be validated and understood? And, how can we facilitate these crucial social processes?

When individuals feel like part of a community, they can act more like one. Group cohesion appears to increase self-efficacy in the world. The group becomes internalized as a validating and a soothing object--rather than an alienating one. This raises self-esteem while reducing anxiety. Group cohesion, it appears, helps those with mental illness become more effective actors in the social world.

Study Limitations

Limitations to this study can be addressed in future research. Reactivity within the repeated measures design may have been a weakness influencing outcomes. For example, results may have been influenced by the fact that members gained familiarity with the tests given and an awareness that they were part of a study. Another weakness is the small sample size because it may have attenuated our ability to see significant differences between groups. Additionally, the small sample size allowed for less reliable measurement and could have affected the results by showing significance where in reality there is none, or obscuring effects that were present. Because the group of participants was not ethnically diverse, the ability to generalize the results to diverse populations is limited. Finally, as suggested in the “Results,” it may be necessary to add an element of qualitative research to a study like this one in order to establish more clearly the relationship between the concrete Experimental Group process and the statistical results of the study.

Conclusion

Our society in the United States creates very limited housing options for people with mental illness. The society places many such people in long-term care centers with few options for treatment other than medication management. Yet many of these individuals can develop the skills they need to integrate into the community. Individuals with severe mental illness need permanent housing options which, like the modified Fairweather Lodge model, are designed to help bring about the conditions required for client growth. Given the thoughtful cultivation of community and skills, these individuals can learn to meet the harsh demands of the social realities outside the group home.

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The Clubhouse Family Legal Support Project: A Framework for Replication and Development

Stephanie Hartwell, PhD
Associate Professor and Graduate Program Director
Department of Sociology
UMass Boston
100 Morrissey Blvd.
Boston, MA 02125-3393

Laura Watts, MA
Applied Sociology
UMass Boston

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Abstract

This report highlights the Clubhouse Family Legal Support Project (CFLSP) that provides support and resources to parents with psychiatric disabilities facing legal barriers to participation in the parenting role. The purpose is to describe the program and its potential for and barriers to expansion. Two months of intensive observation in civil court and interviews with key program practitioners were conducted culminating with the presented logic model and case examples. Taken together, both articulate the program framework and the complex custody issues experienced by parents with psychiatric disabilities. Taken together both and provide an initial framework for program replication and future development.

Key Words: parents with psychiatric disabilities, legal barriers, custody, logic model

Introduction

Over the last decade there has been a trend toward an increased restriction of familial rights, including marriage and parenting, for individuals with psychiatric disabilities (Hemmens, Miller, Burton, & Milner 2002). Yet women and men with psychiatric disabilities are likely to be parents (Nicholson & Biebel, 2002). Research on parents with psychiatric disabilities describes difficulties in managing: (1) the stigma of psychiatric disabilities; (2) day-to-day parenting; (3) psychiatric symptoms; and (4) contact or custody issues (Nicholson et al., 1998). Park and Solomon (2006) report that mothers with psychiatric disabilities are three-times more likely than other parents to be involved with child welfare agencies and resultant out-of-home placements. Parents with psychiatric disabilities are at a greater risk of losing custody of their children due to beliefs that they are inadequate parents (Jacobsen, 1998).

Current research is beginning to question the perception that having a psychiatric disability is incompatible with parenting and is delineating models to aide and support the parenting role (see for example Hinden et al., 2006). The Clubhouse Family Legal Support Project (CFLSP) is a statewide program in Massachusetts that provides legal representation, support and advice to low-income parents with psychiatric disabilities at risk of losing custody and/or all contact with their children. The program was created through collaboration between Employment Options, Inc., and the Mental Health Legal Advisory Committee (MHLAC) and funded by the Department of Mental Health (DMH) and Massachusetts and Boston Bar Associations.

While it seems to make sense that parents with psychiatric disabilities need support and services to manage their psychiatric illness and parenting role, existing services are sparse (Brunette, 2002; Park & Solomon, 2006). Guided by the principal that relevant service interventions can improve parenting skills, the CFLSP has anecdotally demonstrated that integrated legal services have a positive impact on the preservation of families and parenting roles (Nemens & Nicholson, 2006). This report builds an evidence base (Nicholson et al., 2007) for program replication and development by identifying the program's logic model (Appendix A) and providing examples of actual parents served.

Methods

Ethnographic methods including family/civil court observations, unstructured and informal qualitative interviewing, and record reviews were used to craft representative case examples and identify the program logic model to highlight variables for program evaluation, replication and development. This study was approved by the University of Massachusetts Boston Institutional Review Board.

Findings

The CFLSP began in 1999 with the Employment Options, Inc. strategic planning committee's recognition of the need for legal consultation, representation, education, and advocacy for parents with psychiatric disabilities involved with their Options Clubhouse. The Options Clubhouse is one of more than 30 community-based psychiatric rehabilitation programs in Massachusetts that provides individuals the opportunity to participate in meaningful work and social relationships. The non-profit organization is also at the forefront of providing a continuum of Family Initiatives programs for custodial and non-custodial parents that combine adult and child supports as well as legal services via the CFLSP.

The target population of the CFLSP is low-income or indigent parents with psychiatric disabilities at risk of losing custody and/or all contact with their children. Referrals are made to the CFLSP program via outreach to the Department of Mental Health (DMH), Department of Children and Families (DCF), bar associations, legal services and private bars, judges, courts, and community clubhouses across the state. Staff lawyers visit clubhouses monthly to educate staff and clubhouse members about CFLSP services. During these visits they compile client intake lists. Finally, MHLAC has an intake referral phone line that can direct individuals to the CFLSP.

The CFLSP project staff includes 2 full-time lawyers who serve clients across Massachusetts. From September 2008 through August 2009 the CFLSP opened 42 cases—20 "brief service" and 22 "full service." During that same timeframe the program closed 40 cases – 18 "brief service" and 22 "full service" for a total of 63 clients served during the year. Brief service cases are triaged with service information and brief advice. Full service cases include parent representation in substantive areas including divorce with custody and visitation features, custody and visitation for unmarried parents, and, to a lesser extent, guardianship and child support cases. The legal processes for full cases include motion sessions, case management conferences, status conferences, pre-trial conferences, settlement negotiations, and trial. The content of each case involves brokering, including explaining to parents, arrangements of court orders regarding custody and visitation as well as assuring the parent's perspective is represented as a part of the court decision-making processes (see Appendix A).

The CFLSP integrates the principles of the legal system and public mental health services to protect the rights of parents with psychiatric disabilities. Specifically, the program assures just legal representation within the framework of an accessible service with the goal of increasing self-sufficiency and psychiatric rehabilitation potential. However, the program confronts parent and program barriers (see the Logic Model in Appendix A). Parents with psychiatric disabilities are a diverse group with varying health and legal problems, cultural and religious beliefs, and resources. The two examples below illustrate this and are representative of CFLSP full service cases. Sixty-five percent of the full service cases (65%) are female and 35% are male. Most involve increasing visitation for non-custodial parents with multiple complicating factors including employment, substance abuse, transportation, and housing problems.

Example One

Parent is in her mid thirties and has been diagnosed with bipolar and substance abuse disorders and major depression. She has three children; a teenage son from a previous relationship and two young daughters ages six and eight. She has part-time custody of her son and was reduced to supervised visits with her daughters after a suicide attempt. She was referred to the CFLSP by a clinician who called legal aide on her behalf. She believes her mental health issues have been "used against her" in court. She is currently living in a homeless shelter because she was asked to leave her mother's nursing home where she was living previously due to age restrictions. Before going into court, the lawyer from the CFLSP informs the mother of the best and worst case scenarios of going before the judge and concludes by encouraging the mother that she has demonstrated everything she was suppose to including participating in daily dialectic behavioral therapy. The CFLSP lawyer also advises the mother that their goal is to demonstrate to the court that both parents can "cooperatively parent" and have a "history of decision making that is in the best interest of the children." When they go before the judge for a status modification, the CFLSP lawyer informs the judge that the mother has been in treatment for more than 10 months, continues more than 6 months of supervised visits with her children, and that she has been a consistently "loving and appropriate" parent. The mother tells the judge, she'd like unsupervised visitation, but knows she needs a place to live. The judge responds, "You could be living out of the back seat of a car and still be an appropriate parent." The judge grants unsupervised visits, but for limited increments of time so the mother can "ease into it" and adjust to unsupervised time with her daughters.

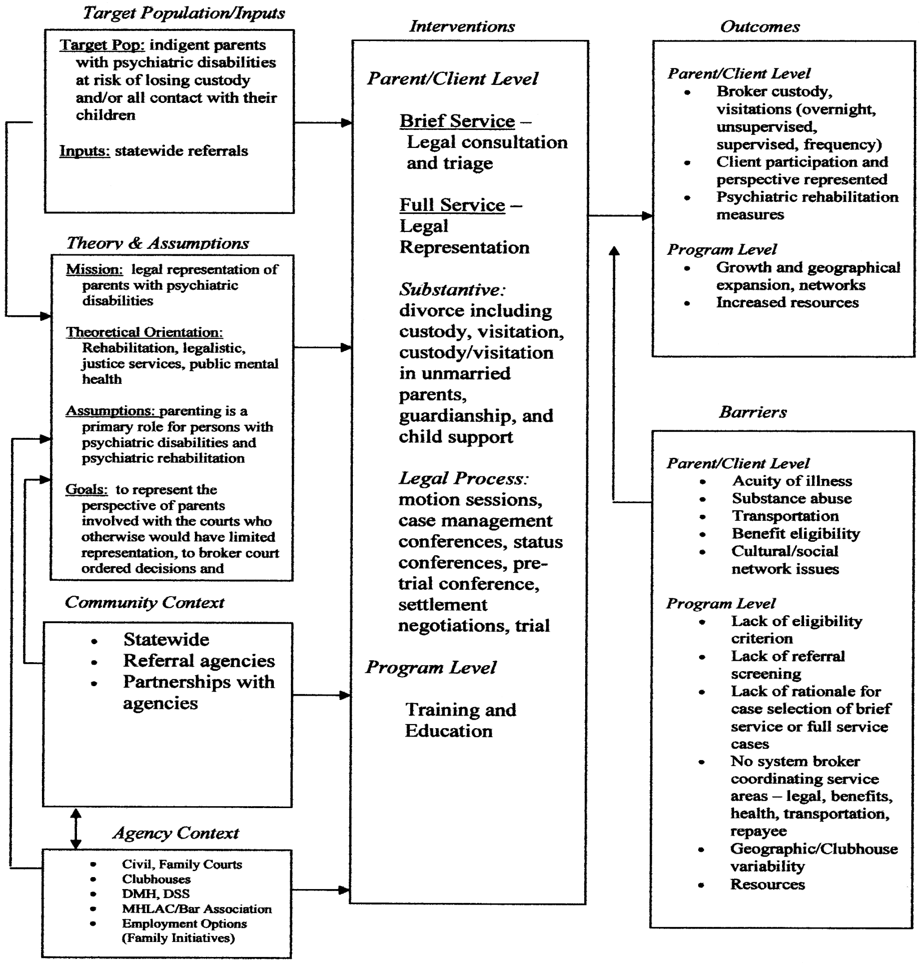
Example Two

This father is in his thirties and was recently diagnosed with Bipolar Disorder. He has a history of incarceration and alcohol and drug abuse but has been sober 4.5 years. He was born congenitally deaf and communicates solely by American Sign Language (ASL). He is seeking visitation with his children (six and eight years old). Because neither child 'speaks' sign language, an interpreter must be available to translate when the father visits with them. Currently the father's ex-wife both supervises and interprets for the visit. The father is seeking both the discontinuation of his ex-wife supervising visits and a transition towards unsupervised visits with an alternative interpreter. In a lobby conference with legal counsel and the Judge, the Judge stated 'nothing in the Guardian Ad Litem report indicates client is unfit to be with kids.' The Judge advised counsel that both parties move towards a slow integration of unsupervised visits and that both attorneys 'work out their client's problems or go to trial'. The CFLSP lawyer explained to the father what occurred in lobby conference adding the judge's statement that 'if the client does not maintain medication and treatment compliance', he (the judge) will move for swift and severe consequences regarding the parent's visitation. A trial date was set, prior to which, both the father and his ex-wife were ordered to go to 'Conciliation', which is non-binding mediation.

Barriers

CFLSP program development barriers include limited funds for program evaluation and personnel. Additionally, the program has had difficulty identifying point persons (or boundary spanners) to coordinate and broker services across multiple agencies – clubhouses, legal services, child and parent services (Steadman, 1992). Other program barriers include the lack of client eligibility criterion, a screening process, or a protocol for triaging brief and full service cases. Finally, because the program is statewide, increasing increased attention should be paid to the diversity of referral sources, resources, and clubhouse populations. A logic model was created (see Appendix A) that integrates the theory behind the program and its core features. The model articulates program variables (intervention, outcomes, and barriers) relative to representing parents (clients) and future program development.

APPENDIX A: CFLSP Logic Model



Target Population/Inputs

Target Pop: indigent parents with psychiatric disabilities at risk of losing custody and/or all contact with their children

Inputs: statewide referrals

Theory & Assumptions

Mission: legal representation of parents with psychiatric disabilities

Theoretical Orientation: Rehabilitation, legalistic, justice services, public mental health

Assumptions: parenting is a primary role for persons with psychiatric disabilities and psychiatric rehabilitation

Goals: to represent the perspective of parents involved with the courts who otherwise would have limited representation, to broker court ordered decisions and

Community Context

- Statewide
- Referral agencies
- Partnerships with agencies

Agency Context

- Civil, Family Courts
- Clubhouses
- DMH, DSS
- MHLAC/Bar Association
- Employment Options (Family Initiatives)

Interventions

Parent/Client Level

Brief Service – Legal consultation and triage

Full Service – Legal Representation

Substantive: divorce including custody, visitation, custody/visitation in unmarried parents, guardianship, and child support

Legal Process: motion sessions, case management conferences, status conferences, pre-trial conference, settlement negotiations, trial

Program Level

Training and Education

Outcomes

Parent/Client Level
- Broker custody, visitations (overnight, unsupervised, supervised, frequency)
- Client participation and perspective represented
- Psychiatric rehabilitation measures

Program Level
- Growth and geographical expansion, networks
- Increased resources

Barriers

Parent/Client Level
- Acuity of illness
- Substance abuse
- Transportation
- Benefit eligibility
- Cultural/social network issues

Program Level
- Lack of eligibility criterion
- Lack of referral screening
- Lack of rationale for case selection of brief service or full service cases
- No system broker coordinating service areas – legal, benefits, health, transportation, repayee
- Geographic/Clubhouse variability
- Resources

Conclusions

Parents with psychiatric disabilities are at risk of losing custody and contact with their children because they lack representation in the family court system. Persons with psychiatric disabilities who are parents have identified the loss of contact with their children as a barrier to successful rehabilitation (Nicholson & Biebel, 2002). Thus, legal representation is a critical issue for both parents with psychiatric disabilities and psychiatric rehabilitation. The CFLSP attempts to assure the rights of parents with psychiatric disabilities are represented in the judicial system. This report highlights features of the CFLSP, and the parents the program represents, as well as the barriers to achieving the promise of the program for the preservation of the parenting role for parents with psychiatric disabilities involved with the legal system.

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Healing and Hope for the Homeless: An Evaluation of Project Excell

Medha Talpade
Clark Atlanta University

Salil Talpade
University of West Georgia

Barbara Lattimore
Fulton County Department of Behavioral Health and Developmental Disorders

Author Note:
Medha Talpade, Ph.D. is Associate Professor of Psychology. As the external evaluator of the project, her contribution to this manuscript included data collection, data mining, analyses, and report writing. Salil Talpade, Ph.D. is Professor and Chair of Marketing and Business Education. He provided direction into analyses of the data and editing/writing/converting reports into this manuscript. Barbara Lattimore, Ph.D. is the Director (Retired) of Behavioral Health and Developmental Disorders, Fulton county, Georgia, provided the blueprint for the rationale and initiation of Project Excell.

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Correspondence:
Dr. M. Talpade, Box 1603, Clark Atlanta University, 223 James P. Brawley Drive, Atlanta, GA. 30314

Abstract

Project Excell was an intensive outpatient treatment program initiated in Fulton county, GA. Individuals engaged in this project were 60 homeless males suffering from co-occurring substance abuse and mental health disorders. Clients were provided with services to match their physical, mental health, substance abuse treatment, job skills training needs. An evaluation of the data collected via the Family Assessment Questionnaire (FAQ), Addiction Severity Index (ASI), Multipurpose Information Consumer Profile (MICP), and protocol of the Georgia Performance Reporting Act (GPRA) revealed significant improvements in various bio-psycho-social measures over a period of 6-months. Improvements were found in employment status, recidivism, use of emergency room services for mental and physical health purposes. Thus, Project Excell's Best Practices Model of matching all the client needs with services and the Stages of Change substance abuse treatment model reaped positive client outcomes.

Keywords: outpatient treatment, homeless, males, co-occurring disorders, evaluation.

Introduction

"Addiction treatment providers are continually challenged to improve services. Often, these challenges occur in a fiscal growth environment that is not only flat, but in most instances, declining. Over the past decade, there has been an increased awareness of the common presentation of persons with co-occurring psychiatric disorders in routine addiction settings. National and state initiatives have been significant, and have stimulated considerable interest in providing better services for co-occurring disorders. Although clearly interested in doing so, addiction treatment providers have lacked pragmatic guidance on how to improve existing services (The Dual Diagnosis Capability in Addiction Treatment (DDCAT) Index, 2006, p.4; http://www.adp.ca.gov/COD/pdf/ddcat_toolkit.pdf)." A state survey report (Department of Human Services, 2008) asserted that individuals with co-occurring disorders are 20 times more likely to be hospitalized and use emergency services, show increased rates of homelessness, are vulnerable to housing instability, are susceptible to premature death, and are more likely to be incarcerated. Project Excell was a response to this need for services for the homeless males with co-occurring disorders in Fulton county, GA.

Project Excell

The greater metropolitan area of Atlanta, Georgia has a population of 3.5 million individuals. Included in this population are richly diverse communities of color, ethnicity and class distinction. About 20 percent of the area's population has no health insurance. One-half of those with insurance are African- American and 39 percent are between the ages of 25 to 44 years old.

Overall, 54% of Fulton County's residents are African American, 41% are European American, and three 3% are Hispanic. According to US Census Data, Georgia ranks 13th in the nation with people below the national poverty level. Georgia has a rate of 12.3 % as compared with the rate of 20 % for Fulton County residents. According to the Atlanta Regional Commission, 34% of individuals who are homeless are also mentally ill, often with a co-occurring diagnosis.

Project Excell was a program initiated by Fulton County Department of Behavioral Health and Developmental Disorders (Oct.2008 – Dec. 2009). Individuals targeted for this project were those who experiencing co-occurring substance abuse and mental health disorders. These individuals were homeless and found residence with Fulton County, Georgia. Project Excell engaged 60 homeless males suffering form co-occurring substance abuse and mental health disorders in intensive outpatient treatment.

Best Practices Model

DDCAT identifies the service types provided to individuals with co-occurring disorders, and that they range from consultation, collaborative, to integrative. The consultation end involves an occasional communication between the client treatment providers about the clients' status and progress, whereas the integrative end involves the provision of substance abuse and mental health services in the same treatment plan. Project Excell was based on the 'best practices model' and provided integrative services to their homeless clients with co-occurring disorders.

Another set of 'best practices' identified by the Substance Abuse and Mental Health Administration report (SAMHSA, 2003) was the staff training and utilization of motivational interviewing. Motivational interviewing is a counseling style designed to help clients change their behavior by exploring and resolving their ambivalence about that behavior. Project Excell staff were trained in this technique. Futhermore, process and outcome evaluations of Project Excell were conducted to evaluate client outcomes after each quarter over a one year period.

Trans-theoretical Stages of Change Model

The Trans-theoretical Model of Change, has been the basis for developing effective interventions to promote changes in health behaviors. The Transtheoretical Model (Prochaska & DiClemente, 1983; Prochaska, DiClemente, &

Norcross, 1992; Prochaska & Velicer, 1997) is a model of behavior change which integrates constructs from other theories. The central organizing construct of the model is the 'stages of change' which encompasses the model of intentional change. Intentional change involves decision making by the individual and also involves emotions, cognitions, and behavior. External influences such as social and physical environments are also considered as impacting through the individual. The model involves a reliance on self-report.

The trans-theoretical model construes change as a process involving progress through a series of five stages. The five stages are: Pre-contemplation, contemplation, preparation, action, maintenance. Pre-contemplation is the stage in which people are not intending to take action in the near future (6-months) because they are uninformed about the consequences of their behavior. Contemplation is the stage in which people are intending to change in the next 6-months. This is considered the procrastination stage. Preparation is the stage in which people are intending to take action in the immediate future (in a month). Action is the stage in which people have made specific overt modifications in their life-styles within the past 6-months. The action stage is also the stage where vigilance against relapse is critical. Maintenance is the stage in which people are working to prevent relapse. They are more confident that they can continue their change. The Trans-theoretical Model can provide sensitive measures of progress and a set of outcome measures that are sensitive to a full range of cognitive, emotional, and behavioral changes and recognize and reinforce smaller steps than traditional action-oriented approaches. Project Excell recognized that addiction treatment was not an all or none event, but a process which ebbed and flowed. The clinicians assessed the clients' stage of change and matched reinforcements and services to help the client move to the next level.

Treatment programs for homeless consumers

An overview of homeless programs and detoxification facilities indicates that the programs and facilities have different goals and provide varied services. For example, programs have been geared toward treating drunk drivers, homeless clients with mental health problems, homeless clients with poly-drug abuse, homeless clients with a history of alcohol abuse, or substance abuse treatment centers for any homeless clients. Services vary from basic detoxification, to detoxification followed by a short-term treatment program, or short-term treatment program followed by a long-term treatment program, residential programs or non-residential programs (Talpade, 2003)

Leon, Sacks, Staines, McKendrick (2000) identified successful outcomes in terms of longterm stability of a therapeutic community treatment program for treating mentally ill chemical abusing homeless clients. Dickey (2000) estimated that 25% of the homeless population was mentally ill and that this population was qualitatively different from those who are only mentally ill. Similarly, Kertesz et al. (2007) report findings of the national survey data, among homeless persons with a drug abuse history (58% of the total), 17% reported receipt of inpatient or residential treatment within the past year, projecting up to 1/2 million inpatient treatment episodes per year among homeless persons. Only a minority of participants achieved favorable employment or housing outcomes at one year. The authors acknowledge that this treatment, although resource intensive, was insufficient to help many participants with both homelessness and high levels of psychological distress. Thus, the need to acknowledge multiple needs and match the consumer profile with treatment services is imminent.

Dickey (2000) summarized the need for such disparity research by the following words:
Doing research, of course, is not the same as improving the lives of those who are mentally ill and homeless. However, as society becomes more attentive to evidence-based policy, the link between research and public support for policy initiatives grows stronger. Professionals and advocates can collaborate in a way that honors individual rights and contributes to the social good (p.8).

Project Excell was geared toward matching the client needs with services. Thus, it was predicted that Project Excell would improve the bio-psycho-social status of the clients in the program, the homeless males with co-occurring disorders, over a period of 6-months. Specifically it was expected that: (1) Alcohol and Drug use reports would decline, (2) Housing status, education, employment, and income would improve, (3) Crime and criminal justice status would improve, (4) Mental and physical health outcomes would improve, (5) risky behaviors would decline,

(6) Social connectedness would improve.

Method

Design and Participants

Participants. Consumers in Project Excell were all males, with 75% Black, 12% white, 2% Hispanic, and 11% reporting ‘other’ as their racial category. The age range of these males is 19 to 67 years, with a median age of 44 years. The majority (50%) range between the ages of 35-54 years. Archival data reports the following incidence of the consumers with co-occurring disorders (66%, n=40) in the program. Sixty-seven percent (n=41) had mental health needs, 100% (n=60) needed substance abuse treatment. Additionally, 90% of the clients were not enrolled in any training, 38% who were the majority, had 12 years of school, 76% were unemployed, 21% had been arrested, 41% reported poor to fair health; 15% had sought inpatient help for alcohol/drug problems and mental health needs; 10% had sought outpatient help for physical needs, 26% sought outpatient help for drug/alcohol abuse problems and mental health needs. Fifteen percent of the clients sought emergency room (ER) treatment for physical problems, 10% for mental problems, and 2% went to the ER for alcohol/drug problems. Twenty-six percent of the clients reported being depressed in the past 30 days, 21% of the clients reported being anxious in the past 30 days, 13% of the clients reported experiencing hallucinations in the past 30 days; 5% reported suicidal tendencies in the past 30 days. Thus, the clients of Project Excell had significant substance abuse, mental health, physical health, and housing challenges.

Materials

The assessment protocol of Project Excell included a Family Assessment Questionnaire (FAQ), Addiction Severity Index (ASI), Multipurpose Information Consumer Profile (MICP), record of the Georgia Performance Reporting Act (GPRA) data.

The FAQ was administered to all consumers at the Center for Behavioral Health and Addictive Diseases to assess why the consumers came to the center. The ASI, is a self-report measure which taps into the mental health and biopsychosocial needs of the consumers. This measure is based on the clear assumption that individuals entering treatment have a co-occurring psychiatric disorder. The MICP is a record of the consumers biopsychosocial and criminal history over one’s lifetime, whereas the GPRA is a record of the consumers’ biopsychosocial history over the past 6-months. The MICP tracks the participant’s biopsychosocial
history, many which are not reflected in the GPRA. For example, evidence of suicide attempts, spirituality, family support, family history of mental health and chemical dependence, and leisure activities are recorded and can be used by the counselor or case manager to facilitate treatment.

Procedure

Consumers of Project Excell came from the Fulton county homeless shelters, transitional houses, Mental health jail diversion services, and the Georgia Crisis Line. After the FAQ was administered, consumers were provided with informed consent and their signature was acquired on a SAMHSA approved consent form. Screening and assessment were conducted at intake, with the GPRA data collected at the same time. A psychiatric evaluation, nursing (medical) evaluation, urine test results were assessed and documented. The MICP and ASI were administered to the clients to determine current client needs and record the past biopsychosocial history.

Counselors kept track of individual attendance for group therapy. The clients had to attend 8-12 sessions, three hours per day for three days per week. Consecutive attendance was encouraged, however, if the participant missed any session, they had to complete the 8-12 recommended sessions. If participants missed three sessions consecutively, their file was deemed closed and ineligible for services.

The program manager and six staff members provided treatment services to the participants. This included three Licensed Professional Counselors, one licensed Addiction Professional Counselor, one M.S. in Human Services.

Additionally two psychiatrists, a nurse clinician evaluated the mental and physical health needs of the clients. Medical needs of participants were met by service providers of Fulton county.

Services

Clients in the Excell program were provided with intensive outpatient services with group counseling sessions held during the day at the Center for Health and Rehabilitation. More intensive individual counseling was provided for those needing such counseling, and Treatment planning was provided to all clients.

Screening and Assessment was conducted at intake, with the GPRA data collected at the same time. The Family Assessment Questionnaire was administered to all clients at the Center for Health and Rehabilitation to assess why the client came to the center. The MICP and ASI were administered to the clients to determine current client needs and record the past biopsychosocial history. Aftercare services were provided to clients who did not have such services at the place of referral. Sites with consistent follow up client services were identified for client placement.

Clients were provided with intensive outpatient day treatment, individual and group counseling and recovery support. Cooccurring treatment and recovery support were provided to those who needed such support. HIV/AIDS counseling was also provided. Case management services provided to the clients included family services, employment coaching, services. Medical services included alcohol/drug testing, HIV/AIDS services. Aftercare services included continues care, relapse prevention, recovery coaching. Educational services included substance abuse education and HIV AIDS education. The recovery support services included peer coaching and drug free socials. The cost per client was $722.

Results

Data from 60 homeless males with co-occurring/ substance abuse/mental health challenges were analyzed using the SPSS. A follow-up of 49 clients was conducted and the intake and follow-up data were compared to evaluate if the predicted outcomes were obtained. The follow-up rate for Project Excell was 94.2% compared to 67.7% for other grantees.

Alcohol/Drug Use in the past 30 days: Intake Versus at 6-months after intake

Data of 49 clients at intake and after 6-months was compared. Repeated measures MANOVA revealed significant decline over time on the measures of : Alcohol intake over the past 30 days, F (1,13)= 15.36, p = .002 Use of Illegal Drugs over the past 30 days, F (1,13)= 5.44, p = .036, Use of Alcohol and Drugs over the past 30 days, F (1,13)= 17.04, p = .001, use of Cocaine over the past 30 days; F (1,13)= 9.52, p = .009. See Table 1 for descriptive statistics.

Table 1

Alcohol and Drug Use over the past 30 days: Descriptive Statistics

Interview	Used Alcohol	Used Illegal Drugs	Used Both Alcohol and Drugs	Used Cocaine
Intake				
Mean				
N	3.77	5.44	14.55	2.44
SD	57	55	11	55
6-month follow-up	8.47	10.47	12.14	6.97
Mean	1.00	.75	5.67	.31
N	48	48	3	48
SD	3.35	2.56	7.23	2.02

Housing Status, Education, Employment, Income: Intake Versus at 6-months after intake

Nonparametric and parametric statistics were computed on the client reports. Chi square analyses of client reports at intake and after 6-months on housing and employment status revealed non significant improvements. Changes in housing status, with more clients in shelters, fewer on the streets and institutions, more residing in own apartments, were reported. Also, although non significant, more clients reported working part time after 6-months than at intake. Repeated measures MANOVA did not reveal significant differences on the variables of Income and Education.

Crime and Criminal Justice Status: Intake Versus at 6-months after intake

Improvements in criminal status (no arrests, drug related arrests), number of days confined, number of crimes, number of arrests, parole status, were noted 6-months after intake. Chi-square tests revealed significant differences/decline in drug related arrests, $\chi2$ (1, 19) = 4.05, p = .044. Although chi square analyses revealed non significant differences, there were positive changes in the number of clients awaiting trial and those who were on parole/probation. Pairwise comparisons on the number of arrests, number of days confined, and the number of crimes revealed non significant differences.

Mental and Physical Health Problems and Treatment:

Intake Versus at 6-months after intake

Positive changes in perceived impact of alcohol/drugs on brain function were found, F (1, 31) = 4.26, p = .047. Significant increases in stress, F (1, 31) = 24.24, p = .000; and emotions, F (1, 31) = 40.53, p = .000; were evidenced after 6-months.

Treatment for Alcohol/Drug related problems, Mental health, Physical health

Results indicate statistically significant reduction in reports of clients seeking Inpatient treatment for Mental problems, , $\chi2$ (1, N = 107) = 3.85, p = .050 (likelihood ratio); from 5% at intake to none after 6 –months, Emergency Room (ER) treatment for Physical problems, , $\chi2$ (1, N = 107) = 3.85, p =.050 (likelihood ratio); from 10% at intake to 1% after 6 –months, ER treatment for Mental problems, $\chi2$ (1, N = 106) = 5.06, p =.022, from 10% at intake to 1% after 6 –months.

Sexual Behaviors : Intake Versus at 6-months after intake

Sexual behaviors were evaluated by responses to questions regarding the number of sexual contacts in the past 30 days whereas risky sexual behaviors were evaluated as responses to questions such as engaging in sex without using condoms, sex with a HIV positive partner, sex with a partner when high on alcohol/drugs. Results indicated that although pairwise comparisons and chi square analyses did not reveal statistically significant differences, risky sexual behaviors reduced after 6-months.

Social Connectedness: Intake Versus at 6-months after Intake

Chi square tests and repeated measures ANOVA revealed non significant differences in social connectedness. Social connectedness behaviors were defined by attendance of organizations supporting recovery, attendance of self help groups, religious groups, interactions with family and friends, and the number of family members that clients could turn to when in trouble. Although non significant, clients reported having people such as clergy, family, friends, and sponsor to turn to when in need.

Age Group X Interview Type x Educational Attainment

A MANOVA conducted on target psychological variables such as reports of stress, educational level, depression, anxiety, hallucinations, brain function, violent behaviors, health status, and psychotropic medications as a function of Age Group (Younger versus Older) and Interview type, revealed significant interactions between the Educational level as a function of Age and Interview type; F (1,42) = 4.79, p = .035. Thus, educational level of older participants increased over time whereas the educational level of younger participants decreased over the 6 month period. See Table 2 for descriptive statistics.

Table 2

Education level as a function of Age and Interview type: Descriptive Statistics

Interview	**Age group**	**Educational Level**	**Descriptives**
Intake	18-44 years	Mean	11.94
		SD	1.85
		N	17
	45-65+ years	Mean	11.45
		SD	3.67
		N	11
6 month follow up	18-44 years	Mean	10.88
		SD	1.36
		N	8
	45-65+ years	Mean	14.00
		SD	2.53
		N	6

Employment Status X Interview Type x Stress level

A MANOVA conducted on target psychological variables such as reports of stress, educational level, depression, anxiety, hallucinations, brain function, violent behaviors, health status, and psychotropic medications as a function of Employment Status and Interview type, revealed significant interactions between the Employment Status (fulltime versus part time) as a function of Age and Interview type; F (1,39) = 6.91, p = .013. Thus, stress level of part time participants decreased over time (from Mean = 2.93, SD = 1.16 to Mean = 2.33, SD = 1.75) whereas the stress level of full time participants increased (from Mean = 2.33, SD = 1.30 to Mean = 4.14, SD = 1.46) over the 6-month period.

Use of Inpatient Services for Mental Problems X Interview Type x Psychological Problems

A Kruskall-Wallis analyses conducted on target psychological variables such as reports of stress, educational level, depression, anxiety, hallucinations, brain function, violent behaviors, health status, and psychotropic medications as a function of the use of Inpatient services for Mental problems and Interview type, revealed significant effects between the Use of Inpatient Services (yes versus no) Interview type, and Depression, Stress, Anxiety, Suicide, and Psychotropic Medications. Thus, the use of inpatient services for mental problems were significantly related to the experience of stress, $\chi 2$ (2, N = 48) = 6.15, p = .046, depression, $\chi 2$ (3, N = 99) = 8.29, p = .040, anxiety, $\chi 2$ (3, N = 102) = 9.57, p = .023, suicide, $\chi 2$ (3, N = 101) = 20.87, p = .000, and the use of psychotropic medications, $\chi 2$ (3, N = 102) = 16.67, p = .001. A comparison of the Mean Ranks (see Table 3) revealed that reports of depression, suicide, and the use of psychotropic medications at intake, was a predictor for the use of inpatient treatment for mental problems. Stress however was not a good predictor for the use of inpatient treatment for mental problems.

Use of Inpatient Services for Physical Problems X Interview Type x Psychological Problems

Table 3
Use of Inpatient Services for Mental Problems X Interview Type x Psychological Problems

Variables	Interview	Response	N	Mean Rank
Stress	Intake	Yes	8	30
	Intake	No	27	21
	6-months	No	14	31
Depression	Intake	Yes	8	72
	Intake	No	45	48
	6-months	No	46	50
				64
Anxiety	Intake	Yes	8	65
	Intake	No	46	46
	6-months	No	46	53
			2	85
Suicidal behavior	Intake	Yes	9	61
	Intake	No	45	51
	6-months	No	46	51
			2	51
Psychotropic Medications	Intake	Yes	9	75
	Intake	No	45	45
	6-months	No	46	53
			2	
				84

A Kruskall-Wallis analyses conducted on target psychological variables such as reports of stress, educational level, depression, anxiety, hallucinations, brain function, violent behaviors, health status, and psychotropic medications as a function of the use of Inpatient services for Physical problems and Interview type, revealed significant effects between the Use of Inpatient Services (yes versus no) Interview type, and number of violent acts in the past 30 days, $\chi 2$ (3, N = 103) = 12.15, p = .007. The Mean Ranks revealed that the number of violent acts in the past 30 days predicted the use of inpatient services for physical problems (see Table 4).

Table 4
Use of Inpatient Services for Physical Problems X Interview Type X Psychological Problems

Variables	Interview	Response	N	Mean Rank
Violent Acts	Intake	Yes	1	102
	Intake	No	54	53
	6-months	Yes	1	90
	6-months	No	47	49

Use of Inpatient Services for Alcohol/Drug related Problems X Interview Type X Psychological Problems

A Kruskall-Wallis analyses conducted on target psychological variables such as reports of stress, educational level, depression, anxiety, hallucinations, brain function, violent behaviors, health status, and psychotropic medications as a function of the use of Inpatient services for Alcohol/drug use problems and Interview type, revealed significant effects of the use of Inpatient Services (yes versus no) Interview type, on stress, $\chi2$ (3, N = 49) = 9.30, p = .026, and education level, $\chi2$ (3, N = 107) = 11.06, p = .011. A higher level of education and stress predicted the use of inpatient services for alcohol/drug problems (see Table 5).

Table 5
Use of Inpatient Services for Alcohol/Drug related Problems X Interview Type X Psychological Problems

Variables	Interview	Response	N	Mean Rank
Stress	Intake	Yes	5	28
	Intake	No	30	22
	6-months	Yes	3	46
	6-months	No	11	26
Education	Intake	Yes	8	83
	Intake	No	51	48
	6-months	Yes	8	65
	6-months	No	40	54

Use of Emergency Room Services for Mental Problems X Interview Type X Psychological Problems

A Kruskall-Wallis analyses conducted on target psychological variables such as reports of stress, educational level, depression, anxiety, hallucinations, brain function, violent behaviors, health status, and psychotropic medications as a function of the use of ER services for Mental problems and Interview type, revealed significant effects between the Use of ER Services (yes versus no) Interview type, and experiencing Stress, $\chi2$ (2, N = 48) = 8.26, p = .016; Hallucinations, $\chi2$ (2, N = 99) = 8.64, p = .013; Violent acts, $\chi2$ (2, N = 102) = 6.48, p = .039; Suicide, $\chi2$ (2, N = 101) = 31.98, p = .000; and Psychotropic medications, $\chi2$ (2, N = 102) = 14.48, p = .001; in the past 30 days. Thus, the presence of stress, hallucinations, violent acts, suicide, and use of psychotropic medications at intake predicted the use of ER services for mental problems. See Table 6 for Mean Ranks.

Table 6
Use of ER Services for Mental Problems X Interview Type X Psychological Problems

Variables	Interview	Response	N	Mean Rank
Stress	Intake	Yes	6	33
	Intake	No	28	20
	6-months	No	14	30
Hallucinations	Intake	Yes	5	71
	Intake	No	46	47
	6-months	No	48	50
Violent Acts	Intake	Yes	6	70
	Intake	No	48	51
	6-months	No	48	50
Suicidal behavior	Intake	Yes	6	67
	Intake	No	47	50
	6-months	No	48	50

Psychotropic Medications	Intake	Yes	6	83
	Intake	No	48	46
	6-months	No	48	53

Use of Emergency Room Services for Alcohol/Drug use Problems X Interview Type X Psychological Problems

A Kruskall-Wallis analyses conducted on target psychological variables such as reports of stress, educational level, depression, anxiety, hallucinations, brain function, violent behaviors, health status, and psychotropic medications as a function of the use of ER services for Physical problems and Interview type, revealed significant effects between the use of ER Services (yes versus no) Interview type, and experience of Anxiety, , $\chi 2$ (2, N = 102) = 6.22, p = .045 ; and Violent acts, , $\chi 2$ (2, N = 103) = 7.58, p = .023. Thus, anxiety and violent acts at intake predicted the use of ER services for alcohol and drug problems. See Table 7.

Table 7
Use of ER Services for Alcohol/Drug use Problems X Interview Type X Psychological Problems

Variables	Interview	Response	N	Mean Rank
Anxiety	Intake	Yes	1	100
	Intake	No	53	48
	6-months	No	48	54
Violent Acts	Intake	Yes	1	102
	Intake	No	54	53
	6-months	No	48	50

Discussion

Project Excell resulted in a substantial number of changes in the status of the clients. Project Excell improved the biopsychosocialstatus of the clients in the program. These findings are corroborated by reflections of the staff in direct contact with the clients of Project Excell who agreed that the program made a positive impact on the clients related to their addiction, mental health, employability, recovery/rehabilitation. Similar results have been evidenced by other treatment programs for clients with co-occurring disorders where receipt of professional service delivered superior outcomes (Gonzales & Rosenheck, 2002). They also indicated that short –term improvements were found across the board, and long-term improvements were deemed to persist with ongoing support systems.

Although improvements were not evidenced on all the measures, there were substantial changes toward the positive in client status over the short period of treatment and follow up time. Specifically, more clients were working part-time; these findings are positive considering the current employment conditions. This may explain the results related to stress where full time workers were more stressed (may have fear of losing their jobs) in comparison to part-time workers (who may just be thankful for finding a job). Drug-related arrests declined significantly over the period of 6-months (from n = 6 to n = 0). The use of ER services for Mental and Physical health purposes, and inpatient mental health services declined over time. More clients sought ER services at intake for varied problems and is attributed to the lack of insurance, lack of health care, lack of resources. Use of ER services reduced over time probably indicating an increase in support systems and coping strategies. Unlike what was found at intake, poor mental health status was associated with attendance of recovery groups, suggesting that the clients had probably learnt coping skills to aid their recovery.

Despite these positive outcomes, it is acknowledged that some of the findings were not as positive. That is more clients were housed in shelters after 6-months or were theoretically, homeless. These findings are attributed to the resources available at the shelters; food, shelter, treatment, vocational rehabilitation. In the absence of any financial resources, the shelters were thus the best available option. Also, as a clinician pointed out, shelters provide a sense of community instead of an apartment where they would feel isolated. Reports of stress and emotions increased with time. It is postulated that the encounter with outside environmental stressors and the lack of the controlled supportive environment may have caused these outcomes.

Age was negatively correlated mental health problems and with sexual activity. It is postulated that because of this relationship, older clients were more likely to keep up their psychotropic medication regimen, rather than younger clients who, according to the counselors, discontinued their medications due to a negative impact on sexual activity. This relationship may also explain why older clients continued to increase their educational level in contrast to the younger clients. This relationship between lack of education and homelessness has been corroborated by other researchers (Calsyn & Roades, 1994). Thus, as some of these findings indicate, this program had better outcomes for the older clients.

Future implications and improvements for programs such as this are derived from staff reflections. Staff made recommendations to enhance treatment outcomes. They were, incorporating a pretreatment component to educate clients about expected outcomes and benefit of program completion; transportation and meals continued for a longer period of time 6-12 months after discharge from program; healthcare on a sliding fee ; case management continued from nine months to one year based on the needs of the client, because clients with co-occurring disorders are the most difficult to rehabilitate and need more intensive case management and support. For clients with mental health issues, clients needed semi independent housing with ongoing support. Relapse is a part of recovery (85%) therefore the staff argued, enough time was important to rehabilitate the client. Also, motivation increased when the clients had fewer needs.

Staff also ascertained that one element ubiquitous for recovery, in addition to support systems available after leaving the program, was motivation of the client. To provide both, it was recommended that the follow up be continued in the community, with affordable housing, which is supervised by mental health professionals who could monitor and control negative client outcomes. Providing such a therapeutic community has delivered significantly positive outcomes especially among those with mental health issues (Leon et al., 2000). Improved outcomes for those with stable housing as a part of the treatment have been corroborated by others (Kertesz, 2007).

Thus, future interventions geared toward the homeless will benefit from the treatment model used by Project Excell and will reap long term benefits if the staff recommendations of extended treatment, follow-up, and support services are initiated. In summary, the brief intervention Project Excell improved client outcomes on several biopsychosocial measures and provided hope and healing for the homeless males in Fulton county, Georgia.

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Community Treatment Orders: The Service User Speaks

Exploring the Lived Experience of Community Treatment Orders

Karen Schwartz PhD (corresponding author)
Assistant Professor Carleton
University School of Social Work
1125 Colonel By Drive
Ottawa, ON, Canada K1S 5B6
Karen_schwartz@carleton.ca

Ann-Marie O'Brien MSW
Adjunct Professor
Carleton University School of Social Work

Vanessa Morel

Meredith Armstrong

Courtney Fleming

Patricia Moore

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Abstract

This study uses an exploratory qualitative design to examine the lived experience of one group of service users on community treatment orders (CTOs). The study was designed and completed by four graduate students at Carleton University School of Social Work.

Despite the unique features of CTO legislation in Ontario, many findings from this study are remarkably similar to findings of research conducted in other jurisdictions. What is unique in our findings is the lack of focus on the actual conditions and provision of the CTO. The issue for our participants was less about the CTO itself, and more about the labels, control and discrimination associated with severe mental illness.

Cette étude utilise un concept qualitatif et exploratoire pour examiner les expériences vécues d'un groupe qui utilise les ordonnances de traitement en milieu communautaire (OTMC). Cette étude a été designée et complétée par 4 étudiants de l'école de service social de l'université Carleton.

Malgré les nombreux aspects uniques de la loi gérant les OTMC de l'Ontario, plusieurs résultats de cette étude sont remarquablement similaires aux résultats découverts dans de différentes juridictions. L'élément unique de cette recherche est le manque de focus sur les conditions véritables et les provisions des OTMC. La problématique encourue par les participants n'était pas au sujet des OTMC en soi, mais plus tôt au sujet de l'étiquetage, du contrôle, et de la discrimination associé aux troubles de santé mentale sévères.

Keywords: Community Treatment Orders, Service User Perspective, Mental Health, Stigma

Introduction:

Prior to the introduction of Community Treatment Orders (CTOs) in the Canadian province of Ontario, service users were strongly opposed to this legislation arguing that it would contribute to the oppression of an already stigmatized and marginalized segment of society and violate a person's fundamental right to choose the kind of medical treatment in which they wish to participate. A review of submissions to the Ontario government's discussion paper on mental health reform found no consensus between the various stakeholder groups with the exception being advocacy groups for service users who were consistently opposed to this legislation (Boudreau & Lambert, 1993). More recently, the Ontario Ministry of Health and Long Term Care legislated review of CTOs found that : "If there was common ground among the consumers that we met, it was on the issue of respect for their dignity and autonomy, the necessity to provide proper services to them, the need for easy access to rights advice and advocacy, and most of all, the absolute imperative that their voices be heard and that they play a meaningful role in the events that affect their lives" (Dreezer & Dreezer, 2005). There have been no published studies that explore service users lived experience with respect to Community Treatment Orders in the Ontario context. This paper will begin to redress this gap.

What is a Community Treatment Order (CTO)?

Community Treatment Orders (CTOs) are one form of mandatory outpatient treatment that requires a person with serious mental illness to adhere to a plan of treatment or care and supervision while living in the community. CTOs exist in various forms in most parts of the developed world. Australia and New Zealand have well established CTO regimes (Brophy & Ring, 2004). Many American states have statutes for involuntary outpatient commitment, another form of mandatory outpatient treatment (Swartz & Swanson, 2004). CTO legislation has recently been introduced in Scotland (Campbell et al, 2006). Community Treatment Orders became part of the Ontario Mental Health Legislation in December 2000. The legislation was marketed as 'Brian's Law' in response to the murder of a popular sportscaster by a man suffering from untreated schizophrenia. Following this murder, the public demanded that criteria be established requiring some seriously mentally ill people released from institutional care to be compelled to receive treatment while they live in the community. The legislation targets those service users who have a history of noncompliance with recommended treatment that results in behaviour which leads to re-hospitalization. Opponents of the legislation state that the new law violates an individual's right to choose whether or not they wished to participate in treatment. Proponents of this legislation argue that requiring a person to follow a prescribed form of treatment while living in the community is less restrictive than being detained in a hospital. However, "their coercive nature is seen as a threat to the community mental health sector's firmly held values of egalitarianism and partnership" (Everett, 2001, p6). Moreover, the association of this legislation with an act of violence further stigmatizes an already marginalized segment of our society (Schwartz & O'Brien, 2009).

CTO legislation in Ontario is defined in the Mental Health Act (Ontario, 1990). The legislation attempts to balance the collective need for safety and order, and the individual right to freedom and autonomy. The legislation is unique in that it is consent based, and physician directed, not court ordered, as it is in most American states. If the person being issued a CTO has capacity to make treatment decisions they must consent to the CTO, otherwise the person making treatment decisions on their behalf provides the consent. Prior to the CTO being issued a plan of treatment or care and supervision is developed by the physician issuing the CTO, the service user, and community based service providers. All parties must agree to the plan, and the service user and Substitute Decision Maker (SDM) (if applicable) must receive independent rights advice prior to the CTO being issued. All parties named in the CTO must receive written copies of all CTO documentation pertaining to them, and information on how to request a consent and capacity board hearing. The Consent and Capacity Board is the mental health tribunal in Ontario that reviews all matters in the civil mental health system.

Literature Review: Community Treatment Orders

CTOs in Ontario have been described as having 'admirable respect' for service user's autonomy (Dawson, Romans, Gibbs, & Ratter, 2003). However respectful, CTOs do limit service users' civil rights and, therefore, their value ought to be measured in terms of relative benefits to service users (O'Brien, Farrell, & Faulkner, 2009). Ten years after the introduction of CTO legislation there remains a paucity of research on its usefulness (O'Brien, & Farrell, 2005; Hunt et al 2007). The most significant limitation of all existing studies of CTOs in Ontario is that they fail to include service users' perceptions.

Most research aimed at exploring the opinions and beliefs of service users has been conducted in the United States. Swartz, Swanson, Wagner, Hannon, Burns, Shumway (2003) examined the preferences of four stakeholder groups: persons in treatment for schizophrenia (n=104), family members, clinicians, members of the public, concerning outpatient commitment for persons with schizophrenia. The study concluded that 'stakeholders were willing to accept the coerciveness of outpatient commitment to gain improved outcomes for certain persons with schizophrenia and related disorders'. (Swartz et al, 2003). Borum, Swartz, Riley, Swanson, Hiday, Wagner (1999) examined consumer perceptions of involuntary outpatient commitment. In this study 306 people with severe and persistent mental illness were interviewed to determine their perceptions of the requirements of the court order and its effects in improving treatment compliance and community tenure. Eighty two percent of respondents believed that under PCT people are more likely to keep their appointments, take medication, stay out of hospital (Borum et al, 1999). Rain, Steadman, Robbins (2003) investigated whether mental health inpatients perceptions of coercion were associated with post discharge treatment adherence. One hundred and seventeen participants who were eligible for New York's OPC were interviewed and their perception of coercion was measured at 1, 5, and 11 months post discharge. These authors found no correlation between patients' perceived coercion and adherence as reported by service providers. (Rain et al, 2003). Van dorn , Elbogen, Redlich Swanson, Swartz, Mustillo (2006) explore the link between receipt of mandated treatment and reasons for avoiding or delaying treatment reported by persons with severe mental illness. These researchers found that "efforts to use leverage to improve treatment adherence may in some cases have the opposite effect by further alienating some individuals and strengthening the internal barriers that keep them from participating voluntarily in treatment." (Van Dorn et al, 2006). Scheid-Cook (1993) conducted an analysis of participant constructions of outpatient commitment. In general, he found that clinicians favoured the greater control over clients that an outpatient commitment provided. The clients in his study, on the other hand, were cognizant of the greater liberty it afforded them.

Brophy and Ring (2004) focus on both consumer and service provider perspectives of the efficacy of CTOs in Victoria, Australia. These researchers conducted three focus groups attended by 30 psychiatric consumers as well as conducting 18 interviews with service providers. Three themes emerged from the focus groups: understanding the purpose of CTOs; strengths and weaknesses of CTOs; knowledge about the discharge process. Most consumers expressed a general view that CTOs had a functional purpose, for example expedited access to inpatient services when required. However, the authors found that consumers are unsure about legal processes and their legally mandated rights (Brophy & Ring, 2004).

In New Zealand, Gibbs, Dawson, Ansley, Mullen (2005) conducted semi structured interviews with 42 of a possible 84 eligible service users who, in the past two years, had been subject to a CTO and not readmitted to hospital. Similar to Brophy's findings the usefulness of CTOs was generally accepted by most service users. In contrast to Brophy's findings that a CTO might be useful in accessing inpatient services, the New Zealand findings suggest that CTOs are viewed as being useful in avoiding an inpatient admission. In the interviews, service users discussed the themes of "autonomy and dependence, freedom and control, power and powerlessness, medication and its side effects, and the desire of patients to achieve stability, meaningful relationships, and a better quality of life" (Gibbs et al, 2005).

Gibbs, Dawson, Forsyth, Mullen, Tanga (2004) conducted a similar study focusing on Maori patients. In general, CTOs were seen to enhance the mental health, wellbeing, and social relationships of Maori patients.

Canvin, Bartlett, and Pinfold (2002) conducted a qualitative investigation into service users' perceptions and experiences of living with supervised discharge orders (SDO) in London, England. They found that service users were able to communicate their understanding of why mental health professionals placed them on the order and how their lives have been affected. Interestingly, individual service users were found to be capable of seemingly contradictory responses, simultaneously accepting and resisting the orders (Canvin et al, 2002).

One study has been completed in the Canadian province of Saskatchewan. O'Reilly, Keegan, Corring, Shrikhane, Natarajan (2006) interviewed 11 patients on a CTO and three patients who had been on a CTO. Most participants reported experiencing some degree of coercion while on the CTO, but many believed that the CTO was necessary to provide structure to their lives. (O'Reilly et al, 2006). "Many of the themes that emerged from this study were similar to those from non-Canadian jurisdictions despite the use of different models of CTOs in those jurisdictions" (O'Reilly et al, 2006).

In summary, studies of service users' perceptions of CTOs reveal, at best, ambivalence toward CTOs and their inherent coercion. Of concern is the somewhat hopeless resignation service users expressed. Given the unique features of CTO legislation in Ontario, and the dearth of information of service users' lived experience, the current study will redress this gap in knowledge. This exploratory study will discuss service users' perceptions of the impact CTOs are having on their lives, and offer suggestions for future studies.

Methodology

Service users living with a severe and persistent mental illness, subject to a community treatment order, and receiving services by the Royal Ottawa Mental Health Centre (ROMHC) including two ACT teams were eligible for inclusion (n=51). The availability of student researchers, as this project was not externally funded, was the primary factor that required a convenience sampling method to be used. Service users who presented at the mental health centre for their scheduled appointment with their treatment team were approached by the CTO coordinator and asked if they would be willing to discuss their experience with the students. Of the 51 service users subject to a CTO, 14 presented for their scheduled appointments during the students' availability. Of these 14 people, 6 agreed to be interviewed by the students. The students discussed the project with prospective participants and obtained written consent, prior to commencing with the interview. This research protocol was approved by the University of Ottawa Institute for Mental Health Research (IMHR), research ethics board.

Participants were involved in a semi-structured interview, with two student researchers, which lasted approximately thirty minutes. Interview questions were developed from a review of the literature, and included asking the service users' perceptions on the impact that the CTO was having on their lives (work, relationships, and housing); their ideas for improvements, as well as any areas of concern about CTO's.

An interview guide approach was used in the interviews, so that the order and wording of questions were flexible, allowed to emerge through conversation (Patton, 2003). A semi-structured face-to-face interview was used to collect data on the opinions of service users regarding their experiences with CTOs. Tutty and colleagues (1996) explain that semi-structured interviews, which use "predetermined questions or key words" as a guide, "are particularly appropriate when you want to compare information between and among people while at the same time you wish to more fully understand each person's experience" (p.56).

Audio recordings of the interviews were transcribed and reviewed by pairs of student researchers. Thematic analysis (Braun & Clarke, 2006) was used in this exploratory study. Thematic analysis is useful in analyzing narrative material from in-depth interviews and focus groups (Dudley, 2009). We employed an etic perspective in identifying categories in our analysis; the categories were identified by the researchers (Rubin & Babbie, 2008). Researchers organized "the raw data into conceptual categories" in order to "create themes or concepts" to analyze the data (Neuman & Kreuger, 2003, p. 436). We looked for common patterns or themes presented in the transcribed notes of the interviews. We began with open coding to locate themes and assign "initial codes or labels in a first attempt to condense the mass of data into categories" (Neuman & Kreuger, 2003, p. 438). At least two independently evaluated the themes in order to insure inter-rater reliability, (Dudley, 2009).

Results

1) Demographics

This exploratory study included six interviews with six participants. Participants consisted of five males and one female, whose ages ranged from their early 20s to mid-50s. Five were interviewed at a mental health center. One was interview in their home. Length of time on a community treatment order for participants ranged from four months to over seven years. None of the participants had capacity to make treatment decisions and each had substitute decision makers (SDM) consent to the CTO.

2) Housing

All participants are currently living in independent housing that they find satisfactory. Three participants discussed the challenges that they faced in the past in obtaining and maintaining safe and stable housing in the past. Being on a CTO did not appear to have an impact on housing.
"My father kicked me out, my mother kicked me out, and so between them I was going back and forth. I found an apartment, and then I had a problem keeping the crack heads out of my house. Then the hospital, then the group home, then I found a place to stay"

"That's how I was in the hospital for like two months. They left me in there for a month and a half, they told me I had to go to a group home, I didn't like that idea. That was recently, like two years ago."

2) Employment

Two participants are currently working part-time, and four participants discussed issues relating to employment, in general. There were different opinions held by participants with regards to the impact of their CTO on employment and employability. Some of the participants experienced difficulty getting time away from work to keep appointments and others experience difficulty due to the mandate to comply with medications.
"You know, I can't drive a forklift, 'cause my job says I can't be medicated, you know what I mean?"

"I have had to modify my work schedule… yeah, you've got to juggle back and forth just have some days off, … keep up with your appointments and other things"

"I've had a couple of jobs that have tried to work out. Pretty hard to get up in the morning and go to work for me. So anyway, I have a job now, on the CTO, and I didn't have one before."

3) Personal Relationships

Participants were asked about the impact of their mental health and the CTO on their relationships with friends and family. This was not an area of questioning that participants seemed interesting in engaging in, and most responses were brief and provided minimal detail. From the responses given, the families of participants viewed their community treatment orders favorably, and felt that there had been positive changes in the lives of the participants.
"My mom, she mentioned that maybe they're just watching over you, my dad says, yeah, they're just watching over you."
"They said when I was 17, 16, I was really sick, and they say I'm doing great now, and sometimes they give a bit of input like you better be careful not to get sick again."

"They listen more, since the CTO."

4) Reason for CTO

The participants cited various reasons for their CTO being initiated. The two major reasons that were discussed were not taking medication, and not engaging in self-care.

"I was not taking my medication, and I was living by myself in a rooming house, and I guess that's about it, I just didn't get activities, didn't care for myself, do the groceries and stuff".

"I don't know why they put me on a CTO. But I think it might have been because I am so alone, so I have the contact".

5) Information Provided

Many participants were vague about the amount of information provided by their service providers, and their understanding of that information. The few participants who had strong opinions regarding information provided to them believed service providers did not ensure they had a clear understanding of the legal processes.

"My rights? I don't know about my rights…but I was given a folder with information and other changes"

"Yeah, I understand my rights. It's a CTO, there's no real lawyer that's gonna help you out, he just explains to you the CTO. The CTO is like law, its law and uh, you can't defeat unless you make like another act, or change the CTO, and then it's like for 6 months."

"Did she explain the reasons? Yeah, poorly, you know, with poor explanation, and poor, misinterpreted information."

6) Understanding of Legal Processes

There was more variation amongst participants' responses concerning the legal aspects of CTOs, particularly the appeal process. Participants who had been on the CTO for longer periods of time (in excess of two years) expressed that they understood the appeal process, and had been involved with the appeal process, but did not have confidence in their ability to successfully change or end their order.

"Appeal? To go to the review board is kind of risky you know? They don't see you, they just see the CTO"

"Well in the beginning I did appeal, I started to appeal but I decided to go along with the program because the office threatened to take my driver's licence away, so I thought I better be cooperative. They took my driver's licence away anyways."

"Have you done an appeal before? Yeah, I've done several"

7) Stigma

Participants discussed the different ways in which the label of mental illness creates experiences of stigma. These experiences were described as occurring in the community through labels, scrutiny and isolation, and in the stigmatizing behaviour and attitudes of their professional service providers.

Community-based stigma was described by participants as a feeling that they were feared and isolated within their communities. Service users discussed the difficulty of feeling the constant gaze of the community judging their behaviour and deeming them something to be wary of.

"So it's like the community is judging you, you know? To see if you're safe to live in the community I guess"

"Police involvement, and then the neighbours are watching, then you're scared, and you're medicated. You wake up, and you don't know where the fuck you are, and there's dirty people around, and you're not in your clothes. Or you get up, and you just take another medication, you know?"

"I think the people across the hallway are getting suspicious of me. People coming in and leaving (ACT team workers), and we go out, you know? But I don't say anything."

Professional stigma was identified as a sense of de-personalization as a result of the use of diagnostic language, and paternalistic ideologies when working with consumers. Historically, the mental health system has been operating under a hierarchical "expert doctor"-patient relationship, commonly referred to as the medical model (Campbell, 2006). CTO service users discussed how this attitude still permeates many of their interactions with helping professionals. Mental health consumers, in general, often resist the diagnostic labels placed on them, and resent losing their identity to the illness within the institutional (i.e. hospital) settings and when receiving treatment while living in the community.

"I went, they told me I was schizophrenic, and I said I wasn't, and there was a dispute, and from there on I've been taking medication."
"I don't want somebody calling me schizophrenic."
"I went to the doctor to get sleeping pills, and he tells me I'm schizophrenic, I was like listen mother-fucker, I don't have schizophrenia. And he goes, "you know what, I'm gonna pick my nose, and I'm going to spit on the floor, and I'm going to say you have schizophrenia "…and he told me I got to agree to disagree."

8) Negative Feelings Regarding CTOs

Participants expressed some overall negative opinions about CTOs. Feelings of being controlled and labeled as mentally ill were dominant themes. Within our sample, there appears to be a connection between disagreeing with the diagnosis of mental illness (particularly schizophrenia) and negative statements regarding the conditions of their CTO, most frequently the condition of mandatory psychotropic medication.
"Well I think the psychiatrist who took my driver's licence away, I think he had too much power, he didn't even know me, because he was a new doctor at the hospital, when I had never been there before, and I had never talked to him for a long period of time. And he made an instant diagnosis that I might be a bad driver, and he took my driver's licence away by sending a letter to the ministry of transports, saying I was a threat to society or something, and actually I don't have any demerit points on my licence, I'm a good driver and I found that to be really bad."

"I think it's a hassle, I don't need a contract or law to tell me to take my medication and come for blood work. I think it's just; the big thing I think is coming in for programming every day. I just can't be bothered… Now that I'm on a community treatment order I have to follow and abide by it"
"What gives the CTO the power? It's the power of medication to our culture, crime, people, normal people, who are not alert to you, some guy. And after everything some crazy guy, some cop, some psychiatrist, some nurse, some shrink, some whatever you're on some medication you know, can you cook dinner for yourself, can you? Are you going to clean yourself, can you? Or you didn't do the laundry, and you're in public, and you stink, cause you don't have a washing machine or no car, or no job "

9) Positive Feelings Regarding CTOs

The positive statements made by participants were usually associated with positive outcomes associated with the implementation of the CTO. These outcomes include increased supports, employment, self-perception of improved mental health, and positive interactions with professional, family and friends.
"Yeah, yeah. It changed my whole life around. I went from a paranoid freak, to a well groomed individual"
"All I know is, I come in and see my doctor, and he gives me medication, and it keeps me healthy. So that's good, he was doing his job, and I'm getting my help."
"Now I've got a doctor, I've got a social worker, I've got a nurse who gives me medication, I got peer support, a lot of people. Yeah"
"Well I like to have it (the CTO) it's kind of nice to have the attention at the end of the day"

Discussion

Service users frequently discussed concerns regarding a lack of control over various aspects of their lives. The impact of the CTO on the daily lives of service users is apparent. Issues such as having their drivers' license revoked, being mandated to take medication that has unpleasant side effects, and frequent appointments at the hospital were discussed by participants as negatively impacting the amount of control they hold over their own lives. This is consistent with the literature, as most studies found that community treatment orders were perceived as coercive by service users (Brophy, 2004; Gibbs et al, 2004; Gibbs et al, 2005; O'Reilly et al, 2006; Scheid-Cook, 1993; Cavin et al, 2002; Dreezer & Dreezer, 2005).

Service users with negative feelings about their CTOs spoke more often about the labels placed on them, and the ways in which they felt they were perceived by the community and their service providers, than about the actual conditions of the CTO. The stigma associated with having a severe mental illness is of obvious concern to all participants interviewed. The term "schizophrenic" was particularly disliked by service users. This speaks to the need for professionals to provide space for self-definition. As stated by Campbell in his article about psychiatric survivors' perceptions of the mental health system,
"self-definition is an essential part of changing the lives of people with a mental illness diagnosis and choosing a self-description is an element in this. All service user action is concerned directly or indirectly, with changing the ways we think about ourselves and others think about us." (Campbell, 2006, p. 578)

The stigma experienced by service users from the community was articulated as a feeling of being under surveillance. The "othering" of individuals with severe mental illness is well documented in the literature, and it is implied in the results of this research which suggest that the CTO further builds on this feeling of being identified as having a mental illness, in that it legally defines an individual as mentally ill (Scheyett, 2006). The feelings of stigma felt by service users from community members were further compounded by the stigmatizing attitudes that participants perceived in their interactions with their service providers.

Professionally based stigma manifested itself in the participant's narratives through the acts of diagnosis, coercion, and authority. Service users discussed the inability of professionals to empower them to participate in the decision making process, or move away from an 'expert-patient' model of care. Participants, when talking about feelings of being controlled, most often discussed medical professionals such as family doctors and psychiatrists. This is probably reflective of the fact the CTOs in Ontario are issued by physicians, not courts. If a service user is noncompliant with the order, it is the physician who has the responsibility to issue at form for psychiatric assessment that authorizes the police to apprehend the person to bring them to the physician for assessment. Moreover, if the person appeals their CTO to the consent and capacity board it is the physician who has the burden of proof to demonstrate that the requirements for a CTO have been met. Service users only occasionally mentioned the role of social work, and this was generally more positive, noting that ACT teams were often adaptable to the service users' needs and schedules.

Service users, when asked about their understanding of their legal options and the process of CTOs were unclear about the amount of information that had been given to them by service providers. All service users stated that the processes had been explained to them, but several stated that they did not understand their order, the appeal process, or how the CTO would end. This limited understanding of the CTO suggests that service providers should review the information, policies and rights of the service user with them on a regular basis. This is necessary due to the varying levels of wellness that service users may experience, along with documented side effects of medication such as reduced attention span (Dreezer & Dreezer, 2005).

Limitations

This pilot study was limited due to time constraints and difficulty accessing participants. All of the participants were deemed incapable with respect to treatment decisions regarding their mental health. This group of service users may experience a CTO as more coercive than service users who are deemed capable of making decision for themselves. It would have been beneficial to conduct several interviews over time with each applicant, as this would increase rapport with the interviewer. It would also provide the opportunity to revisit certain questions with the participants in order to clarify or elaborate on their previous answers. The challenges of interviewing individuals living with severe and persistent mental illness, such as side effects of medication, or difficulty-focusing attention, occasionally caused researchers to ask questions that may have influenced participant's answers. Due to the difficulty of interviewing a population living with varying levels of wellness over time, multiple interviews may better reflect the overall perceptions of participants.

Conclusion

The findings of this study have been consistent with the published literature regarding the perceptions of service users of community treatment orders. Similar themes emerged across the literature in which participants report feelings of coercion and powerlessness, but also recognize some positive aspects of CTOs (Brophy, 2004; Gibbs et al, 2004; Gibbs et al, 2005; O'Reilly et al, 2006; Scheid-Cook, 1993; Cavin et al, 2002; Dreezer & Dreezer, 2005). What is unique in our findings is the lack of focus on the actual conditions and provision of the CTO. Our research suggests that the CTO adds to already problematic feelings of stigma and powerlessness that are associated with living with a mental illness. The issue for our participants was less about the CTO itself, and more about the labels, control and discrimination associated with severe mental illness.

There is limited research in Ontario on the topic of service users' experience of CTOs, and no study to date that has been completed in collaboration with service users. A participatory action research (PAR) project would be ideal in conducting anti-oppressive research, and supporting the goal of empowerment of individuals on community treatment orders (Tew, 2008).

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Motivation to physical activity in non-psychotic psychiatric inpatients

Julie Raepsaet
University Psychiatric Centre-K.U.Leuven, campus Kortenberg

Jan Knapen
Davy Vancampfort
Michel Probst
University Psychiatric Centre-K.U.Leuven, campus Kortenberg
K.U. Leuven, Faculty of Physical Education and Rehabilitation Sciences, Department Rehabilitation Sciences, Belgium

Corresponding author:
Julie Raepsaet
University Psychiatric Centre K.U. Leuven, campus Kortenberg
Leuvensesteenweg 517
3070 Kortenberg
Mail: julie.raepsaet@uc-kortenberg.be

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Abstract

Objective: To examine whether motivation to physical activity is related to different physical and psychological variables of physical activity, in a sample group of non-psychotic psychiatric inpatients.
Methods: In this explorative cross-sectional study, one hundred and twelve patients with different diagnoses were examined, using six questionnaires, at the University Psychiatric Centre K.U. Leuven, Campus Kortenberg, in Belgium.
Results: Two factors of motivation to physical activity, namely interest/enjoyment and competence, are significantly related to a higher physical activity level (respectively r = 0.46 and r = 054). Physical activity is significantly related to perception of physical fitness (r = 0.47). Perception of physical fitness is significantly related to general well-being and activity (r = 0.37), and perception of physical well-being (r = 0.68). Psychosocial adaptations related to body weight, body-image and self-worth and a perception of subjective well-being (physical and psychological well-being) are negative significantly related to trait anxiety (r = -0.60, r = -0.66 and r = -0.82).
Conclusion: It is important to motivate to physical activity those people with a low physical activity level, a low psychosocial adaptation level, a negative physical and psychological well-being, or a negative perception of physical fitness.

Keyword: motivation to physical activity, mental health disorders, physical activity level

Introduction:

Physical inactivity represents a serious physical and mental health problem. It not only increases the risk of cardiovascular diseases, osteoporosis, breast and colon cancer, type 2 diabetes and obesity, but also the risk of depression, anxiety disorders and other mental health problems (Hu et al., 2005; Knapen et al., 2009; Yates et al., 2009). Physical inactivity increases the morbidity and the mortality (Knapen et al., 2009).

Otherwise, physical activity has both a preventive and curative effect (Warburton et al., 2006; Knapen et al., 2009). It improves quality of life, physical health and fitness, and reduces mental health problems (Goodwin, 2003; Van Hees et al., 2005; Ussher, 2007).

In general, people with a psychiatric disorder show a less active lifestyle and have poor physical health compared with the general population (Sørensen, 2006; Ussher, 2007). In these patients, different symptoms of psychiatric disorders, such as psychosomatic complaints and hypochondria, lack of energy, general fatigue and a low physical self-concept in interaction with a poor physical health and fitness may lead to a vicious cycle of loss of self-confidence, an increased avoidance of physical activity and decreased levels of physical and mental health. For that reason, the incorporation of exercise therapy into the comprehensive treatment programs for psychiatric patients is highly recommended (Knapen et al., 2007).

Several meta-analyses examined the effects of exercise on depression and anxiety. The most recent meta-analyses of Rethorst et al. (2009) examined the effects of exercise on depression/depressive symptoms in 58 randomized controlled trails. It can be concluded that exercise therapy, within clinically depressed patients, seems to be at least as effective as antidepressant medication and psychotherapy (Rethorst et al., 2009).

Wipfli et al. (2008) analysed the results from 49 randomized controlled trials in the area ‘exercise and anxiety’. From the results it can be concluded that exercise therapy is more effective than stress management education, slightly more effective than group therapy, stretching and yoga, relaxation and meditation, and as effective as cognitive behavioural therapy (Wipfli et al., 2008).

These positive effects of physical activity on depression and anxiety were obtained by following guidelines; exercise 45-59 minutes a day at a moderate intensity, with a frequency of 3 or 4 times a week, for 10 to 16 weeks. Exercise programmes that combined aerobic and anaerobic exercise resulted in larger effects than aerobic or anaerobic training alone (Wipfli et al., 2008).

The term motivation indicates all the processes that deal with the stimulus, the direction and the retention of physical and mental activities (Johnson, Weber & Zimbardo, 2005). Several theories might guide our understanding of the motivation to physical activity by psychiatric patients, and give directions or practical approaches for increasing motivation (Sørensen, 2005). Deci and Ryan (1985) described a self-determination theory (SDT), which is a contemporary framework that is increasingly being used to understand exercise motivation and adherence (Thøgersen-Ntoumani & Ntoumanis, 2005). Specifically, SDT proposes that behavioural regulation towards physical activity can be amotivated, extrinsically motivated, or intrinsically motivated. These classifications of motivation differ in the extent to which they are self-determined, because they represent different degrees of internalization of external values and goals (Thøgersen-Ntoumani & Ntoumanis, 2005). Amotivation refers to any intention to change behaviour. Intrinsic motivation comes from the inside: you do something because you like it, without an external reward. Extrinsic motivation comes from the outside and can be divided into four types of regulation: external (for an external reward), introjected (avoiding negative feelings), identified (for the positive effects related to the activity and the appreciation of others) and integrated regulation (to perform personal goals) (Deci & Ryan, 1985). Amotivation and external regulation are negatively associated with the physical activity level. Introjected, identified, integrated regulation and intrinsic motivation are positively associated with the physical activity level (Thøgersen-Ntoumani & Ntoumanis, 2005; Sørensen, 2006) . A study of Sørensen (2006) demonstrated that intrinsic motivation to physical activity is related to a 57,4 % symptom reduction in a group of psychiatric patients with different diagnoses.

The aim of the present study was to examine whether motivation to physical activity, level of physical activity, psychosocial adaptations related to body weight, body image and self-worth, anxiety, subjective well-being, perception of physical fitness and trait anxiety are related to each other, in a sample group non-psychotic psychiatric inpatients. The hypothesis of this study was, that there will be an association between motivation, level of physical activity, and physical and psychological variables of physical activity, in a sample group non-psychotic psychiatric inpatients.

Method

Subjects

In this explorative cross-sectional study, one hundred and twelve non-psychotic psychiatric inpatients (45 men and 67 women), of the University Psychiatric Centre K.U. Leuven Campus Kortenberg, were examined during a period from 1/01/2009 to 13/02/2009. The average age for women was 31.82 years (SD = 11.85) and for men 39.71 years (SD = 13.29). The patients were diagnosed by psychiatrists according to the Diagnostic and Statistical Manual for Mental Disorders, Fourth Edition for syndrome diagnosis (axis I) and diagnosis of personality disorders (axis II). Multiple diagnoses were possible on both axes and mostly psychiatrists made three or more diagnoses. The principal diagnoses were: mood disorders (n = 34), anxiety disorders (n = 25), personality disorders (n = 21), eating disorders (n = 25) and substance related disorders (n = 7). Patients were individually invited to participate in the present study. All subjects signed the Informed Consent according to the standards of the Ethics Commission of the University Psychiatric Centre K.U.Leuven, Campus Kortenberg, Belgium.

Measures

Six questionnaires were used. The selection of the questionnaires was based on the reliability and validity of the questionnaires in the research domain of physical activity in mental health. An independent examinator collected the results in a closed envelope.

Baecke Questionnaire (Baecke, 1982)

The Baecke questionnaire evaluates the level of physical activity at work, including studying and housework (work index), in sports (sport index) and during leisure time (leisure time index) in the last year. The questionnaire consists of 16 items and each item is scored using a 5-point Likert scale. The maximum score for each of the three domains is 5. The total physical activity level is the sum of work, sport and leisure time indices. The total score varies between 3 and 15. A higher score means a higher physical activity level. The test-retest reliability coefficients for work, sport and leisure time indices in the present study are respectively 0.80, 0.90 and 0.74.

Motivation for Physical Activities Measure-Revised: MPAM-R (Ryan & Frederick, 1993, 1997)

The motivation to physical activity was measured by means of the Motivation for Physical Activities Measure-Revised by Ryan and Frederick (1993, 1997). This questionnaire contains 30 items divided into five categories: interest and enjoyment (7 items), competence (7 items), physical appearance (6 items), fitness (5 items) and social contact (5 items). The items are scored using a 7-point Likert scale. There are two distinct types of motivation: intrinsic (interest, enjoyment and competence) and extrinsic motivation (physical appearance and social contact). Fitness includes both intrinsic and extrinsic motivation.

This questionnaire was translated into Dutch through the back to back translation procedure by two independent translators. The Dutch version of MPAM-R showed the same factor structure as the original questionnaire (Vancoillie, 2007). The test-retest reliability measured with the intraclass correlation coefficient was 0.90, indicating that the Dutch version of MPAM-R is useful to examine the motivation to physical activity by psychiatric patients.

Body weight, image and self-esteem evaluation questionnaire: B-Wise (Awad & Voruganti, 2004)

The B-wise evaluates psychosocial adaptations related to body weight, body image and self-worth. The questionnaire consists of three factors: negative body image and stress, general well-being and activity, and knowledge and actions about body weight. The scores are scored on a 3-point Likert scale. The total score ranges from 12 to 36. High scores indicate better psychosocial adaptations. De Hert (2006) translated the original version of the B-Wise in Dutch. The back translation procedure was approved by the original authors of the scale (De Hert et al., 2006).

Trait Anxiety Inventory: T.A.I. (Spielberger, 1984)

The T.A.I. examines the trait anxiety. The 20 items are scored using a 4-point Likert-scale. The total score ranges between 20 and 80: the higher the score, the more anxious the person is in general. The Trait Anxiety Inventory was translated by Van der Ploeg (2000). The test-retest reliability ranges from 0.76 to 0.86.

Questionnaire on subjective well-being (Marcoen et al., 2002)

A selection of 8 items of the Marcoen questionnaire for subjective well-being (Marcoen, Van Cotthem, Billiet & Beyers, 2002) was used to measure well-being. Four items were selected out of the psychological scale and four out of the physical well-being scale. The selection was based on factor loadings and internal consistency scores (Opdenacker et al., 2009). The items are scored on a 7-point Likert scale. A higher total score means a better subjective well-being.

Visual Analogue Scale: V.A.S. scale: perception of physical fitness

A 100 mm Visual Analogue Scale examines the perception of physical fitness. At the opposite ends of the line are keywords ‘very bad’ and ‘very good’ were used.

Data-analysis

Data were analyzed using Statistica 9. The relationship between the variables was examined using Spearman rank order. Spearman rank order is a non-parametric measure of statistic dependence between two variables with a not-normal distribution (Portney & Watkins, 2000). The significance level in all of the tests was set at 0.0001 (two-tailed). The internal consistency of the questionnaires was measured by Chronbach’s alpha coefficients (Cohen, 1988).

Results

Internal consistency

The internal consistencies for the questionnaires from Baecke and B-wise are respectively $\alpha = 0.58$ and $\alpha = 0.65$. This is a moderate internal consistency. The Dutch versions of the motivation questionnaire from Ryan and Frederick (1993, 1997), the Trait Anxiety Inventory and the questionnaire on subjective well-being show a good internal consistency, respectively $\alpha = 0.95$, $\alpha = 0.94$ and $\alpha = 0.88$.

Correlation between variables

The five factors of motivation are interest and enjoyment, competence, appearance, fitness and social contact. Only two factors of motivation, namely interest and enjoyment and competence are significantly related to sport index, leisure time index and total physical activity level (table1). Motivation is not significantly related to psychosocial adaptations, trait anxiety, subjective well-being and perception of physical fitness (table 2). Physical activity level is significant related to perception of physical fitness (table 4). There is no significant relationship between physical activity and psychosocial adaptations, subjective well-being and trait anxiety (table 3 & 4). Perception of physical fitness is significantly related to psychosocial adaptations and physical well-being (table 5). Psychosocial adaptations and subjective well-being are significant related to trait anxiety (table 6).

Table 1: The correlation between motivation and physical activity level.

Measuring	Baecke work	Baecke sport	Baecke leisure time	Baecke total
Ryan interest and enjoyment	0.03	**0.43**	**0.39**	**0.46**
Ryan competence	0.12	**0.47**	**0.45**	**0.54**
Ryan appearance	-0.02	0.25	0.34	0.31
Ryan fitness	-0.06	0.28	0.24	0.28
Ryan social contact	0.04	0.13	0.09	0.13

p < 0.0001

Table 2: The correlation between motivation, psychosocial adaptations, trait anxiety, subjective well-being and perception of physical fitness

Measuring	B – Wise	T.A.I.	Marcoen factor 1	Marcoen factor 2	V.A.S.
Ryan interest and enjoyment	0.15	-0.06	0.27	0.07	0.33
Ryan competence	0.02	-0.01	0.17	0.02	0.26
Ryan appearance	-0.24	0.22	-0.14	-0.12	-0.04
Ryan fitness	0.06	0.04	0.09	0.09	0.09
Ryan social contact	0.33	-0.31	0.34	0.32	0.20

p < 0,0001; B – Wise = psychosocial adaptations related to body weight, body-image and self-worth; T.A.I. = Trait Anxiety Inventory; Marcoen factor 1 = physical well-being; Marcoen factor 2 = physiological well-being; V.A.S. = Visual Analogue Scale = perception of physical fitness.

Table 3: The correlation between physical activity and psychological adaptations.

Measuring	B-Wise factor 1	B-Wise factor 2	B-Wise factor 3	B-Wise totaal
Baecke work	-0.11	-0.13	0.07	-0.12

Baecke sport	-0.02	0.01	0.12	0.04
Baecke leisure time	-0.09	0.00	0.24	0.04
Baecke total	-0.08	-0.02	0.19	0.01

p < 0.0001; B-Wise factor 1 = negative body image and stress; B-Wise factor 2 = general well-being and activity; B-Wise factor 3 = knowledge and actions about body weight; B-Wise total = psychosocial adaptations related to body weight, body-image and self-worth.

Table 4: The correlation between physical activity , trait anxiety, subjective well-being and perception of physical fitness.

Measuring	T.A.I.	Marcoen factor1	Marcoen factor2	V.A.S.
Baecke work	0.07	-0.14	-0.02	0.02
Baecke sport	0.10	0.26	-0.04	**0.43**
Baecke leisure time	-0.08	0.22	0.07	**0.44**
Baecke total	0.05	0.24	-0.01	**0.47**

p < 0.0001; T.A.I. = Trait Anxiety Inventory; Marcoen factor 1 = physical well-being; Marcoen factor 2 = physiological well-being; V.A.S. = Visual Analogue Scale = perception of physical fitness.

Table 5: The correlation between psychosocial adaptations and trait anxiety, subjective well-being and perception of physical fitness.

Measuring	T.A.I.	Marcoen factor 1	Marcoen factor 2	V.A.S.
B – Wise factor 1	**-0.50**	**0.54**	**0.41**	0.35
B – Wise factor 2	**-0.63**	**0.61**	**0.56**	**0.37**
B – Wise factor 3	0.18	-0.17	-0.17	-0.01
B – Wise total	**-0.60**	**0.63**	**0.51**	0.39

p < 0.0001; B-Wise factor 1 = negative body image and stress; B-Wise factor 2 = general well-being and activity; B-Wise factor 3 = knowledge and actions about body weight. B-Wise total = psychosocial adaptations related to body weight, body-image and self-worth; T.A.I. = Trait Anxiety Inventory; Marcoen factor 1 = physical well-being; Marcoen factor 2 = physiological well-being; V.A.S. = Visual Analogue Scale = perception of physical fitness.

Table 6: The correlation between trait anxiety, subjective well-being and perception of physical fitness.

Measuring	T.A.I.	Marcoen factor 1	Marcoen factor 2	V.A.S
T.A.I.	1.00	**-0.66**	**-0.82**	-0.34
Marcoen factor 1	**-0.66**	1.00	**0.63**	**0.68**
Marcoen factor 2	**-0.82**	**0.63**	1.00	0.33

P < 0.0001; T.A.I. = Trait Anxiety Inventory; Marcoen factor 1 = physical well-being; Marcoen factor 2 = physiological well-being; V.A.S. = Visual Analogue Scale = perception of physical fitness

Discussion

The aim of the present study was to examine whether motivation to physical activity is related to different physical and psychological variables of physical activity, in a sample group of non-psychotic psychiatric patients. Motivation, especially intrinsic motivation (interest, enjoyment and competence), is positive related to a higher physical activity level. Our finding is similar to that of the study of Sørensen (2006), who investigated the relationship between level of physical activity and intrinsic and extrinsic motivation to physical activity in a group of psychiatric patients. They also reported an association between intrinsic motivation and physical activity level and that intrinsic motivation was related to a 57.4% symptom reduction (Sørensen, 2006).

The present findings demonstrate that physical activity level is related to a positive perception of physical fitness. Perception of physical fitness is positively related to psychosocial adaptations related to body weight, body-image and self-worth, and to physical well-being.

Psychosocial adaptations related to body weight, body-image and self-worth, and subjective well-being are negative related to trait anxiety. Van de Vliet et al. (2002) investigated the relationship between self-perceptions and negative affect in adult Flemish psychiatric inpatients suffering from mood disorders. Their conclusion, which is similar to our findings, was that the relationship between physical self-perceptions and negative affect might be considered as a valuable framework for furthering our understanding of the depression and anxiety reducing potential of exercise and physical activity in clinically depressed individuals (Van de Vliet et al., 2002).

The results should be cautiously interpreted as there are some limitations in the study. First, an explorative cross-sectional study has methodological limitations. No causal relationship or effect can be found. Therefore, we plan a longitudinal study in order to investigate the association between the changes in the variables. Secondly, the study worked with principal diagnoses; no subdivision can be made for the different diagnoses for the reason that most patients in the sample had three or more diagnoses. Thirdly, the results come from a single psychiatric centre. Finally, questionnaires were used to measure the patients' physical activity. Questionnaires have limitations, can be time consuming and are know to be less accurate than more objective techniques, such as pedometers and accelerometers (Van Hees et al., 2005).

Conclusion

Psychiatric patients accumulate a lot of barriers to participation in exercise such as a low self-worth and self-confidence, loss of energy, interest and motivation, generalised fatigue, poor physical fitness and health condition, fear of moving, social fear, overweight a low feeling of personal control concerning own fitness and health, and helplessness and hopelessness. For these reasons, it is very important to motivate these patients to be physically active. The physical activity has to be self-determined and focused on the positive experience of the activity itself. It is also important that the activity is individually adapted in order to prevent negative experiences with physical activity and drop-out. The therapist should give information about the health benefits of physical activity to both mental and physical health. Knowledge can reduce the anxiety about participation in physical activity. Physical activity itself can improve the perception of physical fitness which in turn improves the self-concept. A better self-concept reduces symptoms of depression and anxiety. It is important to motivate to physical activity those people with a low physical activity level, a low psychosocial adaptation level, a negative physical and psychological well-being, or a negative perception of physical fitness. To experience the positive effects of physical activity, some guidelines have to be followed: exercise 45-59 minutes a day at a moderate intensity, with a frequency of 3 or 4 times a week, for 10 to 16 weeks. Exercise programmes that combined aerobic and anaerobic exercise resulted in larger effects than aerobic or anaerobic training alone (Wipfli et al., 2008).

Further research is needed to examine specific types of motivation to physical activity related to different kinds of diagnoses. It is also important to do research into specific guidelines on physical activity in mental health and the extension of the data for a larger audience.

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Dialectical Behavior Therapy for the Treatment of Borderline Personality Disorder: An Evaluation of the Evidence

Jordan E. DeVylder, M.S.

School of Social Work
Columbia University

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Correspondence:
Jordan DeVylder, M.S.
Columbia University School of Social Work
1255 Amsterdam Ave., New York, NY 10027
jed2147@columbia.edu

Abstract

Dialectical behavior therapy (DBT) is a treatment developed for borderline personality disorder (BPD) in which the clinician attempts to motivate the client towards change in behavior while simultaneously validating existing thoughts and feelings. The goal of DBT is to minimize maladaptive behaviors related to impulse control and emotion regulation, especially those that may result in self-injury or death. Eleven studies supporting the efficacy of DBT for BPD are reviewed and found to provide the highest level of evidence using previously established guidelines for the evaluation of evidence-based practice (Foa, Keane, & Friedman, 2000). Implications for current practice as well as for future research are discussed in the context of the presented studies.

Keywords: DBT, borderline personality disorder, evidence-based practice

Introduction:

Dialectical behavioral therapy (DBT) is a form of cognitive-behavioral therapy developed specifically for borderline personality disorder (BPD; Linehan, Armstrong, Suarez, Allmon, & Heard, 1991; Linehan, Tutek, Heard, & Armstrong, 1994). The word "dialectical" in DBT comes from its focus on providing motivation for change in behavior while simultaneously validating the client's thoughts and feelings. Changes are enacted through the teaching of skills in core areas where people with BPD typically have difficulty. In order to improve treatment adherence and to reduce the risk of sudden drastic reactions to the introspection brought on by therapy, validation must be used to show acceptance of the individual even while the individual is being pushed towards restructuring deeply ingrained patterns of behavior.

Individual therapy

Individualized therapy sessions focus on the client's progress over the past week in three key areas, organized in a hierarchy of importance. The therapist first focuses on reduction of parasuicide and life-threatening behaviors if these have been a problem over the past week. The term parasuicidal behavior refers to "intentional, acute self-injurious behavior with or without suicidal intent, including both suicide attempts and self-mutilative behaviors" (Linehan et al., 1991, p. 1060). If there have been no such self-injurious behaviors since the prior session, the therapist then shifts focus onto the reduction of behaviors and thought patterns that interfere with the process of therapy. Once these issues have successfully been addressed and the client is compliant with treatment, focus can shift to reduction of behaviors that seriously interfere with the client's quality of life. The client must learn "radical acceptance" in order to accept his or her present situation as it is, and use that as the starting point for change rather than letting the emotions associated with that situation take over and leave the client feeling trapped and incapacitated.

Group sessions

Whereas individual sessions focus on the current events and personal progress, group sessions teach the core skills that facilitate change by improving the client's view of his or herself while simultaneously improving the client's ability to interact with others. These skills are taught in four areas; mindfulness, interpersonal effectiveness, emotion regulation, and distress tolerance (Lynch, Chapman, Rosenthal, Kuo, & Linehan, 2006). Mindfulness skills address the tendency in BPD to make habitual defamatory self-judgments, while allowing the client to focus on the present moment without dwelling on past trauma or apprehension regarding the future (Robins, 2002). Interpersonal effectiveness skills teach clients how to negotiate and solve their problems with other people in their life, addressing the instability of interpersonal relationships that is a common feature in BPD. Emotion regulation skills allow the client to accept rather than become overwhelmed by emotions, allowing the person to process and act on emotions rather than to be made helpless by extreme all-encompassing feelings. Distress tolerance skills allow the client to build resiliency to be able to better cope with stressful situations (McKay, Wood, & Brantley, 2007; Linehan et al., 1991).

Additional therapeutic interventions and fidelity of treatment

In addition to individual therapy and group sessions, clients in DBT programs typically have emergency access to their therapist by telephone. The client can make brief phone calls to the therapist in moments of crisis, generally to prevent self-harm. Restrictions are placed on hours and frequency of telephone use, and are generally respected by clients regardless of the severity of the disorder (Lynch, Trost, Salsman, & Linehan, 2007).

DBT does not only include therapy for the client, but for the therapist as well. BPD can be considered a very difficult diagnosis to work with, and therapist burnout is a major risk. To address this, sessions are typically included to address therapist concerns and to insure treatment model fidelity, thereby allowing more consistent care with a relatively inconsistent population (Linehan, Schmidt III, Dimeff, Craft, Kanter, & Comtois, 1999).

DBT practice with good fidelity includes all four components just described. In most research studies, treatment lasts one year and consists of an hour of individualized therapy and 120-150 minutes per week of group sessions; however, this can be adjusted without major sacrifices in fidelity as clients generally respond to treatment well before one year (Linehan et al., 1991).

Strengths and limitations of DBT

The primary strength of DBT is that it has been shown through randomized control trials to be an efficacious treatment for BPD, a severe and persistent mental illness without prior evidence-based treatment. The treatment is well-received by clients and has a high rate of treatment adherence among this population (Lynch et al., 2007). DBT addresses core problematic behaviors (Linehan et al., 1991) and its effects continue to endure following termination (Linehan et al., 2006; Van den Bosch, Koeter, Stijnen, Verheul, & Van den Brink, 2004).

Some recent studies have provided evidence that alternative psychosocial therapies, or psychosocial therapies in conjunction with medication, may produce even better results. For example, one study compared DBT to transference-focused psychotherapy, a psychodynamic treatment, and found that transference-focused psychotherapy improved anger and impulsivity symptoms whereas DBT had no effect. However, the treatments had similar effects on other measures in this study (Clarkin, Levy, Lenzenweger, & Kernberg, 2007). Soler et al. (2005) showed that combining DBT with olanzapine, an atypical antipsychotic medication, improves treatment adherence as well as depression, anxiety, and impulsivity scores relative to DBT alone. However, this simply suggests that DBT may benefit from combination with psychopharmacological treatment and is not necessarily a weakness in DBT itself. Finally, Van den Bosch et al. (2005) showed that DBT effects, while still significant, are not as strong at 6 month post-treatment follow-up. It is therefore likely that some of the DBT effects may fade over time, and maintenance treatment may be a necessary adjunct in order to prevent relapse.

Goals and Targets of DBT

The desired outcome of DBT is a resolution of maladaptive behaviors related to impulse control and emotion regulation, especially those behaviors that may result in self-injury or death. It was originally developed to address suicidal and parasuicidal behaviors and this remains the highest priority in the hierarchy of treatment for the typical target population of BPD clients. The goals of DBT when treating BPD include a reduction or end of parasuicidal behaviors, the reduction of other associated self-injurious behaviors such as substance abuse and eating disorder traits, development of emotion regulation skills to allow clients to better process their feelings, and the development of social skills to help clients maintain healthy interpersonal relationships (Linehan et al., 1991; Linehan et al., 1994).

Progress in DBT is tracked through a variety of measures, depending on clinician preference and on the primary target behaviors for a particular client or group of clients. Self-report measures are typically used to measure progress in areas such as depression, anxiety, and suicide risk. These include the Reason for Living Scale (Linehan et al., 2006; Linehan 1991), Suicidal Behaviors Questionnaire (Linehan et al., 2006), Hamilton Anxiety Rating Scale (Soler et al., 2005), Hamilton Scale for Depression (Linehan et al., 2006; Soler et al., 2005), Beck Depression Inventory (Clarkin et al., 2007; Kroger et al., 2006, Linehan et al., 1991), Barrat Impulsiveness Scale (Clarkin et al., 2007), Social Adjustment Scale (Clarkin et al., 2007; Linehan et al., 1999; Linehan et al., 1994), DSM-IV GAF score (Clarkin et al., 2007; Kroger et al., 2006), and others. Semi-structured and structured interviews are also used to determine frequency of parasuicidal behaviors, impulsive behaviors, and substance use (Linehan et al., 2006; Kroger et al., 2006; Soler et al., 2005; Von den Bosch et al., 2005; Linehan et al., 2002; Linehan et al., 1999; Linehan et al., 1994; Linehan et al., 1991).

Supporting Evidence

Evidence supporting DBT as an efficacious treatment for BPD is substantial, with multiple replications and variations demonstrated to be successful in randomized control trials (see table I). The effectiveness of DBT for BPD has been well-established in outpatient settings (for review, see Lynch et al., 2006), expanded to include inpatient hospitalization (Kroger et al., 2006), and demonstrated to have lasting effects following treatment termination (Linehan et al., 2006; Van den Bosch et al., 2005). Studies have also addressed co-occurring disorders, which is vital for BPD research since BPD rarely occurs in isolation (Lynch, Trost, Salsman, & substance abuse (Verheul et al., 2003; Linehan et al., 2002; Linehan et al., 1999). Linehan, 2007).

In particular, it has been tested with co-occurring axis I mental illness (Kroger et al., 2006) and Marsha Linehan developed DBT and provided much of the evidence for its support. She first introduced her modified version of cognitive-behavioral therapy specifically as a method of addressing parasuicidal behavior in BPD. The first randomized control trial tested the effects of DBT versus "treatment as usual" (TAU) on 44 women aged 18 to 45, diagnosed with BPD with chronically parasuicidal behavior (Linehan et al., 1991). At the time, there was only a single published randomized-control trial for parasuicidal behavior and it did not include BPD (Liberman & Eckman, 1981). Therefore, there was not sufficient evidence in the literature for an alternative treatment that would allow it to be used as a control group. Instead, Linehan et al. compared DBT to TAU, the typical treatment that a client would receive in the community when diagnosed with BPD.

Linehan developed a year-long time-limited therapy which "emphasized the management of emotional trauma" and consisted of three components; one hour individual sessions addressing client progress and needs, 150 minute group sessions for skills training, and constant telephone access to the primary therapist by the client for emergency situations. The individual sessions addressed a hierarchy of needs that first addresses parasuicidal and life-threatening behaviors, followed by behaviors that interfere with treatment, and finally behaviors that interfere with the client's quality of life. The individual therapist assessed the client's life over the past week and would address the most pressing needs first. When a target behavior was identified, such as a suicidal act, than in response: "an exhaustive description of the moment-to-moment chain of environmental and behavioral events that preceded the suicidal behavior is elicited, alternate solutions that the individual could have used are explored, behavioral deficits as well as factors that interfere with more adaptive solutions are examined, and remedial procedures are applied as necessary" (Linehan et al., 1991, p. 1061). By addressing these personal issues, the therapist should be able to greatly reduce the client's risk of self-harm while the group simultaneously teaches them skills needed to eliminate these behaviors over the long-term. The group sessions focused on training around the four core areas of mindfulness, distress tolerance, emotion regulation, and interpersonal effectiveness, as discussed above.

Table 1

Author, Date	Sample Characteristics	Design	Treatment Protocol	Structure & Duration	Outcome	Comment *
Clarkin et al., 2007	Diagnosis of borderline personality disorder	Randomized trial: DBT group vs. transference-focused psychotherapy group vs. dynamic supportive treatment; N of 90	Manualized DBT treatment including individual and group sessions	One year of weekly individual and group sessions plus telephone contact, with assessments every 4 months and at baseline	All Tx groups had improvements in depression, anxiety, global functioning, and social adjustment. DBT and transference-focused had showed declines in suicidality, transference-focused and dynamic showed declines in anger and impulsivity.	Level A Demonstrated effectiveness of DBT, but other methods were superior on some measures
Koons et al., 2001	Women veterans diagnosed with borderline personality disorder	Randomized trial: DBT group vs. treatment as usual; N of 20	Manualized DBT treatment with shortened sessions	Six months of weekly individual and group sessions, 90 minutes each	DBT group had greater decreases in suicidality, hopelessness, depression, anger, and parasuicidal behaviors.	Level A
Kroger et al., 2006	Inpatient population seeking 3-month treatment for BPD and co-morbid Axis I disorder, mean age 30.5 years	N of 50 (44 female, 6 male)	DBT treatment adjusted for 3-month treatment, with added emphasis on group therapy	Three month inpatient treatment including a one hour individual session and three 100 minute group sessions each week, with assessments at admission (baseline), discharge, and at 15-month follow-up.	With DBT treatment this group's Beck Depression Inventory scores were reduced, symptom severity was reduced, and GAF scores were increased.	Level B Clinical evaluation, no control group or randomization
Linehan et al., 1991	Chronically parasuicidal borderline women, aged 18 to 45	Randomized trial: DBT group vs. "treatment as usual"; N of 44	Manualized DBT treatment, emphasis on management of emotional trauma	One year of weekly individual (1 hr) and group (2 ½ hr) sessions plus telephone contact, with assessments every 4 months and at baseline	Tx group had fewer parasuicide acts with lower medical risk but no fewer episodes, stayed in therapy longer, and had fewer days of hospitalization. No difference in Beck depression inventory score, number of episodes, likelihood of at 1< admissions in year	Level A
Linehan et al., 1994	Chronically suicidal borderline women, aged 18 to 45	Randomized trial: DBT group vs. "treatmentas usual"; N of 26	Manualized DBT treatment, emphasis on management of emotional trauma	One year of weekly individual (1 hr) and group (2 ½ hr) sessions plus telephone contact, with assessments every 4 months and at baseline	Tx group had reduced trait anger, reduced use of psychotropic meds, improved global adjustment. No difference in global life satisfaction.	Level A
Linehan et al., 1999	Dual diagnosis BPD and drug-dependence women,	Randomized trial: DBT group vs. "treatment as usual"; N of 28	Manualized DBT treatment, with "attachment strategies," and "dialectical abstinence" additions to address substance abuse	One year of weekly individual (1 hr) and group (2 hr) sessions plus telephone contact, with assessments every 4 months, at baseline, and at a 16 month follow-up	Tx group had reduced substance use measured by self-report and urine toxicology, improved social adjustment, global functioning at follow-up. No differences in amount and type of medical or	Level A

- Agency of Health Care Policy's Level of Evidence Coding System (Foa, Keane, & Friedman, 2000).

This initial study found no reduction in the number of parasuicidal episodes between the BPD groups but did find changes in the severity of episodes. Parasuicidal acts among the DBT group had lower medical risk and lower chances of lethality than the equivalent acts in the TAU group. While also hospitalized at a similar rate and with no fewer admissions over the course of the year, the duration of hospitalization was significantly shorter for the DBT group, with less time until recovery from the present episode. Furthermore, treatment adherence was improved by DBT, with DBT subjects staying in treatment longer than those receiving TAU.

These results demonstrating a significant effect of DBT on BPD prognosis were replicated in a subsequent study that utilized a similar procedure and population (Linehan et al., 1994). This study diverted from the concrete variables used in the prior study of number of hospitalizations and parasuicidal acts, and instead focused on global social adjustment, anger, and life satisfaction. Although no differences were found in global life satisfaction, the DBT treatment group was found to have reduced trait anger, improved social adjustment, and reduced use of psychotropic medications relative to the TAU group (Linehan et al., 1994). Additional randomized control trials by other research laboratories confirmed the reduction in suicidality, hopeless, depression, anger, and parasuicidal behaviors among clients receiving DBT relative to those receiving TAU in the community (Koons et al., 2001; Turner, 2000).

BPD with co-occurring substance abuse

Linehan's lab next focused on subjects with BPD and co-occurring substance abuse, a condition that may actually be more common than BPD alone, occurring in as much as 2/3 of those with BPD (Dulit, Fyer, Haas, Sullivan, & Frances, 1990). This study (Linehan et al., 1999) used a similar procedure to the prior two studies but included additional "attachment strategies" and "dialectical abstinence" features intended to specifically address substance abuse. They also began including counseling for the therapists themselves as a part of DBT. This reduced therapist burnout with this difficult population and helped to ensure fidelity to the treatment model. Again, the DBT group exhibited improved social adjustment and global functioning at follow-up, even 4 months after termination of treatment. For this population, these changes were accompanied by self-reported decline in substance use, which was confirmed with urine toxicology tests. Since substance abuse and BPD frequently coexist in a single client, it is advantageous to have a single treatment that simultaneously and successfully facilitates recovery from both conditions.

One shortcoming of Linehan et al. (1999) is that it compared DBT to TAU for a population with co-occurring substance use and BPD. While the TAU control group could be justified for studies focusing exclusively on BPD, it could be seen as insufficient when substance abuse is included since commonly accepted practices for treating substance abuse do exist. Their next study therefore looked at women with BPD and opium dependence, comparing DBT to an accepted opium dependence treatment known as comprehensive validation therapy plus 12-step (CVT +12). Both treatment groups also received opiate agonist therapy to treat physiological symptoms of opium dependence. This study found that both treatment groups successfully reduced their opium use with treatment. However, the CVT +12 group began to relapse after an average of 8 months, whereas progress was maintained for the DBT group. Furthermore, the DBT subjects were more accurate in self-reporting their opium usage, suggesting greater awareness or insight into the condition.

Using DBT to treat BPD in an inpatient setting

BPD also frequently co-occurs with axis I mental illness and may often be treated in an inpatient setting. It is therefore important to extend the findings of Linehan to an inpatient environment and to ensure that DBT is still effective when a client has a primary axis I diagnosis. Kroger et al. (2006) studied a group of 50 patients with BPD in an inpatient unit, the vast majority of whom also had an Axis I diagnosis. In their adjusted 3-month variation on the Linehan DBT model which included an added emphasis on the group therapy component, they found a reduction in Beck depression scores and symptom severity and an increase in Global Assessment of Functioning (GAF). Unfortunately, this experiment was a clinical evaluation with no control group or randomization, so potential interpretation of these data is limited. A study by Soler et al. (2005) considered the effect of combining DBT with an atypical antipsychotic, another likely scenario for hospitalized BPD clients. They found that both the DBT and the DBT + Olanzapine groups showed significant clinical improvement, but that the group that included medication had additional improvements in depression and anxiety scores, as well as reductions in impulsivity and aggression. Based on this study, we must continue to consider the possibility of combining DBT with medication, despite the efficacy of DBT as a psychosocial treatment on its own and despite evidence that DBT reduces a client's need for psychotropic medication (Linehan et al., 1994).

Long-term efficacy of DBT for BPD

Having established the efficacy of DBT as at treatment for BPD, the Linehan lab then attempted to demonstrate long-term effects of this time-limited therapy. They conducted a similar study as their earlier DBT work, but with an additional year of follow-up assessments. This two-year study revealed that DBT reduces suicide attempts, hospitalization for suicide ideation, overall hospitalization, medical risk for parasuicidal behavior, and increases treatment compliance. Furthermore, these effects persisted throughout the entire one-year treatment phase and the one-year follow-up phase, demonstrating a continuing effect of DBT for a substantial period following termination (Linehan et al., 2006). A set of studies by Verheul et al. (2003) and van der Bosch et al. (2005) confirmed this effect, demonstrating lasting efficacy of DBT over a 6-month post-treatment period. Their studies did exhibit a slight decline in progress, but there was no return to baseline on any measure and the follow-up prognosis was significantly better than that of the TAU group.

DBT as an evidence-based practice for BPD

Foa, Keane, & Friedman (2000) published a set of guidelines for determining the level of evidence supporting treatment for post-traumatic stress disorder. These same guidelines can be generalized to other treatments and disorders, and can be useful in concisely explaining the level of evidence supporting a particular treatment. DBT for BPD is supported by ten studies presented in this paper at a Level A degree of evidence, and in one additional study with Level B evidence. DBT has been shown to be an effective treatment for BPD and this finding has been consistently replicated in a series of randomized control trials. Based on this review, DBT can be ranked as a Level A treatment for BPD, the highest level of evidence based on this coding system.

Recent developments in DBT research

Now that DBT is established as an evidence-based practice for BPD, researchers are attempting to push the method into new directions. DBT has significantly outperformed anti-depressant medication in the reduction of depression symptoms among geriatric clients with major depression, both with (Lynch et al., 2007) and without a co-occurring personality disorder (Lynch, Morse, Mendelson, & Robins, 2003). Research into DBT as a treatment for eating disorders is expanding as well, with recent case studies providing evidence of its efficacy among adolescents with anorexia, bulimia nervosa, and binge eating disorder (Salbach-Andrae, Bohnekamp, Pfeiffer, Lehmkuhl, & Miller 2008; Safer, Lock, & Couturier, 2007). DBT had previously been shown to reduce eating disorder symptoms among BPD adolescents (Safer, Telch, & Agras, 2001; Telch, Agras, & Linehan, 2000). Another case study has produced somewhat unexpected results, showing strong effects and promise for future research in the use of DBT for the more "perfectionistic" and "risk-averse" personality disorders, considered in many ways to be the opposite of the emotion dysregulation and impulse control problems seen in BPD. Nonetheless, a client with co-morbid obsessive-compulsive personality disorder and paranoid personality disorder showed full remission from symptoms of both personality disorders as well as depression, and these effects lasted for two years after treatment termination (Lynch & Cheavens, 2008).

One final recent direction in DBT research comes from neuroscience, where researchers are now beginning to identify biological changes that result from behavioral treatments. A pilot study (BPD n = 6) demonstrated that DBT leads to reduction in activity in the limbic system, the emotional center of the brain, in response to highly valenced negative images, and that those who respond to treatment show greater reduction in the amygdala, a subcortical region implicated in the processing of emotional stimuli, especially those that are fearful or threatening. (Schnell & Herpertz, 2007). The demonstration of biological changes not only adds further evidence for the effectiveness of the treatment, but also may add legitimacy to a behavioral method in a field that is dominated by the medical and psychopharmacological model of treatment.

Implications of Research and Future Directions

Support for DBT as an evidence-based practice for BPD is substantial, far exceeding the two randomized control trials required by the American Psychological Association. With many randomized control trials, several case studies, modifications for different treatment settings and procedures, and adjustments for other related mental health and substance abuse conditions, DBT has been shown to be a consistently and broadly efficacious treatment.

DBT can address chronic reoccurring mental health problems that are not currently well handled in acute medicine-based care. Rapid shifts in mood seen with BPD can make chronically suicidal BPD clients seem recovered at the hospital, who may then relapse very soon after discharge. However, even a three-month inpatient DBT treatment can be effective, regardless of co-occurring axis I disorders (Kroger et al., 2006). Based on evidence for DBT, clinical practice can be improved by training psychologists and social workers in DBT skills. Psychiatrists can benefit from DBT training as well, although it may be more effective to educate acute care psychiatrists in hospital emergency rooms and inpatient units regarding the benefits of DBT, so that they may make appropriate referrals and not rely primarily on medication for treatment of BPD. Although this treatment modality is efficacious, it may still be difficult to engage clients and to have them initiate treatment. Programming can be improved through the development and implementation of effective intake procedures, psychoeducation for BPD clients regarding the need and efficacy of treatment, and outreach to the community providing information on how to access services. Mental health policy can benefit from DBT research as well. BPD accounts for much of mental health spending, as it may be responsible for approximately 20% of psychiatric hospitalizations in the United States (NIMH, 2001). DBT treatment for BPD may lead to widespread reductions in health care costs over the long term by training clients to better control their emotions and impulses, thereby preventing hospitalizations and emergency room visits.

Future research for DBT should focus on simultaneously addressing BPD and the frequently co-morbid conditions of Axis I disorders, eating disorder, and substance abuse. Some progress has been made in these areas, but more research is needed to ensure efficacy in these sub-populations, all of which may be as common as or more common than BPD in isolation. Initial research combining DBT with antipsychotic medication (Soler et al., 2005) and in modifying DBT to include specific substance abuse components (Linehan et al., 1999) have been successful thus far.

Another area in which DBT research is thoroughly lacking is in its applications to diverse populations. Demographic data related to race and ethnicity is lacking in many of the DBT studies. However, there have been no studies that specifically look at DBT as a multicultural treatment modality. There is especially little evidence for use of DBT with male subjects, as BPD is a very disproportionately diagnosed in females (Simmons, 1992). However, males still account for approximately 25-30% of the population diagnosed with BPD, and therefore form a significant minority that should not be excluded from evidence-based treatment (Linehan et al., 1994). Furthermore, this diagnosis may be underrepresented among males due to bias in clinicians which may lead them to give females a diagnosis of BPD and to give similarly presenting males a diagnosis of anti-social personality disorder (Simmons, 1992). Many DBT studies, including those by the Linehan lab, which developed the treatment, exclude male subjects from their subject pool (Linehan et al., 2006; Van Den Bosch et al., 2004; Koons et al., 2001; Linehan et al., 1999; Linehan et al., 1994; Linehan et al., 1991). The studies that do include subjects from both genders are still so disproportionately female that it is conceivable for them to show an effect even if all male subjects are unresponsive to treatment (Clarkin et al., 2007; Kroger et al., 2006; Soler et al., 2005). BPD presents differently to some extent in male clients and is also approached differently by clinicians with female clients (Nehls, 1998); it is therefore likely that some adaptations may be needed in DBT protocol to make it applicable to this substantial minority. Although there is now sufficient evidence to support DBT as an evidence-based practice, there has not yet been ample research towards addressing generalizing this treatment across culture and gender.

Despite the evidence and support, current challenges faced in implementing DBT are still numerous. For one, the BPD population is notoriously difficult to engage and non-adherent to treatment. Many of the studies presented above showed improved treatment adherence for the DBT group, but that still leaves us with the difficulty of initially engaging clients and beginning treatment. Even once engaged, this population is considered difficult to work with by many clinicians, and even necessitated a special counseling session for the therapists in a number of the studies presented in this paper. Compounding problems with the clients themselves are the systemic difficulties in obtaining insurance reimbursement for behavioral and psychosocial treatments, and in implementing such programs in facilities and agencies that retain a primarily medical model of mental health, such as hospitals and many community treatment centers.

Conclusion

DBT has been repeatedly shown to be a highly efficacious treatment for BPD and is likely beneficial to a substantial portion of the mental health population. However, some gaps in the research remain. DBT findings must be expanded to and multi-cultural and multi-gender population, they must be expanded to cover frequently co-morbid conditions, and ideally they should be extended into related areas of mental health, including other personality disorders and other mental illness and substance abuse conditions that involve emotion dysregulation and poor impulse control. Once these issues are sufficiently addressed, DBT can truly be considered an effective treatment for a variety of mental health conditions across a diverse and representative population.

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Multiculturalism And Mental Illness: Views of Mental Health Professionals on Mentally Ill Economic Migrants in Greece

Dr. Despina Sikelianou
Clinical Psychologist, Scientific Associate

Victoria Koutli
Post-graduate student of Social Work

Konstantina Alexandridou
Post-graduate student of Social Work
Department of Social Work, School of Health and Care Sciences, Technological and Educational Institute of Patras, Greece

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Abstract

The aim of this research was to study and investigate the views of mental health professionals on mentally ill economic migrants. The survey method was used for the implementation of this research, the aim being to achieve qualitative and statistical results. The research process lasted for a total of six (6) months (March – September 2008) and took place in two (2) Prefectures in our country (Prefecture of Achaia and Prefecture of Lesvos), where migrants reside or where a large number of migrants are accommodated in Migrant Hostels.

According to the views of mental health professionals, the results of the research have shown that: i) economic migrants present themselves at mental health services mainly for the treatment of mental illnesses such as Anxiety disorders, Mood disorders, etc., but also to be granted some kind of benefit or to seek employment, ii) there is dysfunctional cooperation between mental health professionals and migrants, whenever the latter seek help and support, iii) the ensuring of certain and qualitative provision of support services for migrants could be attained through the development or expansion of mental health services that would be addressed only to migrants and iv) the necessity for training and further education of mental health professionals on issues related to multiculturalism and sensitization towards the problems of economic migrants.

Introduction

Multiculturalism is an established doctrine embracing multiple cultures. Interculturalism, the outcome of multiculturalism, aims at the peaceful co-existence of multiple cultural groups and minorities or ethnic groups within a society with simultaneous recognition of the rights of one group by the other group and especially the minority by the majority. The dynamics of multiculturalism forces our societies to evolve, proceeding from the majority society stage to that of the society of cultures and cultural groups (Vernikos and Daskalopoulou 2000).

The phenomenon of migration has always been a very significant parameter in the history of the Greek population, while developments in recent years have led to the country changing from one of migrant outflow to one of migrant influx. This transformation emerges gently in the second half of the 1970s, continues during the 1980s and intensifies in the last decade of the 20th Century (Bagavos 2003). Special emphasis is placed on the migration flows during the 1990s due to their size, the variations observed in the characteristics of migrants and the fact that the evolution of migration was for the first time associated with the effort of establishing a migration policy based on the fact that Greece is now a recipient country for migrants (Bagavos 2003).

According to Robolis (2007), the 1990s was undoubtedly characterized by the expansion of the role of migration in the demographic changes that took place, in terms of the population size and age structure. More specifically, the influx of migrants and their stay in Greece contributed decisively to the growth of the total population size which, between 1991 and 2001, showed a rise of 704,000.

Greece, being a recipient country for a large number of migrants, has now become a European multicultural country since migrants account for more than 7% of the total population and more than 8% of its workforce.

Migrants, who number from 900,000 to 1,200,000, tend to reverse the composition of local societies, since in certain regions they constitute as much as 25% of the inhabitants (Riga 2007). The great majority of migrants are uninsured, do not receive any social security benefits or unemployment and sickness benefits, are low paid and employed in unhealthy jobs, while most of them are lodged in unacceptable conditions. They are tyrannized by the difficulties they face with regard to family reunification, while the education they receive is insufficient since their mother tongue and culture are absent (Riga 2007).

Social inclusion of migrant populations is subject to the diptych: i) the legalization of their residence in our country, ii) their integration into the official labour market (Kassimati 2003).
With regard to the migration issue in Greece, mainly during the last few years the following major issues have emerged: i) the legality of migrant residence and employment, ii) the benefit or not of their presence for the economy, iii) public safety and the crime rate and iv) the protection of human and social rights of migrants (Tsitselikis 2007).

The migrants, arriving in the recipient country, face the following: i) difficulties and restrictions in exercising their rights (e.g. family reunification), ii) the undue and uncontrollable administrative deportation procedure, iii) the scornful treatment of by the police, and by the public administration in general, iv) the acquisition of Greek nationality, which is granted through particularly restrictive conditions on the basis of 'law of blood', v) poor protection of employment rights and vi) the absence of dialogue and participation of aliens in decision making that concerns them (Psimenos 2004).

The susceptibility (or resistance) of the migrant towards psychiatric disorders may be related to the following factors: i) his ethnic origin, which concerns the frequency of psychiatric disorders in the ethnic group from which he comes, ii) the socio-demographic characteristics of the migrant (e.g. sex, age, social class), iii) the difference between the natural environment and culture in the place of origin and those in the place of migration, iv) the attitude of the native population towards migrants and vice-versa, v) the difference between the social status of a migrant in their place of origin and that in the place of destination and vi) the expectations of a migrant (Kontaxakis et al. 1994).

Madianos (2000) distinguished two psychological stages following arrival: i) The first stage, which lasts for about 2 months and is characterized by a subjective sense of 'all being well', with increased psycho-mobility, as a primitive manner of eliminating the stress and anxiety resulting from the migration and ii) The second stage, during which the migrant gradually perceives their social status and worries about communication difficulty with the natives and the differences in customs and values. The greater the difficulties, the greater the tendency of the migrant to flee the present through recollections of the past (nostalgia). During the second period, mental reactions become apparent and reach their peak approximately 6 months after the migrant's arrival. The main symptoms during this period are as follows: i) suspiciousness and paranoid trends, ii) anxiety and depression, and iii) physical complaints, such as feeling of weakness, joint and muscle pains, insomnia, anorexia, nausea, dread, peptic ulcer disease, ulcerative colitis, asthma, and a tendency to conversion disorder.

The significant factors that affect the mental state of individuals who belong to ethnic-racial minorities during the acculturation process are as follows: i) the duration of the acculturation process. The rapid acculturation of a social group, in combination with the violent dissociation from the familiar social and cultural environment, results in social disorganization and is a cause of stress, which often leads to the manifestation of a mental disorder, ii) the existence or not of strong bonds with people of the same cultural origin, iii) the existence of a cohesive family system that constitutes an additional psychoprotective factor, iv) the stereotypes and prejudices towards minorities. Stereotype thinking leads to stereotype racist behavior, thus resulting in marginalization, which in turn affects mental health, v) the non-supportive social policy, which does not protect special social groups, such as the minority-ethnic groups, who are financially underprivileged and vulnerable to morbidity, and which excludes them from having access to mental health services and vi) the classification of minority groups as belonging to lower socio-economic classes, a fact that causes the manifestation of mental disorders through the known relationship between the lowest social class and high psychiatric morbidity (Madianos 2005).

According to Patiniotis (1989), the marginalization of migrants leads to conflicts over social rules and social roles, insecurity over social status, and disorientation as well as isolation, consequences that contribute to the manifestation of psychosomatic diseases. Being uprooted from the society and culture of the homeland causes serious intrapsychic conflicts as a result of the confusion caused by their new social role and psycho-social disorientation and the overt or covert disparagement of migrants.

Research Design – Methodology

Aim of the study and research hypotheses

The aim of this study was to investigate all the views, feelings and behavior of mental health professionals towards mentally-ill economic migrants, whenever the latter seek help and support in resolving their problems.
The research hypotheses upon which this study was based are: i) there is a phenomenon of multiculturalism in our country, as the number of migrants has quintupled over the last fifteen (15) years and migrants constitute seven per cent (7%) of the total population residing in Greece (Riga 2007), ii) the Greek state is unable to adopt a social policy that will extenuate the phenomenon of social exclusion and social stigmatization of economic migrants, a fact that makes it more likely for them not to receive the treatment they need or to be offered services of lower quality, and not according to their needs (Megalooikonomou 2007), iii) there is prejudice towards mentally-ill economic migrants, which results from the lack of cultural sensitization and updating in mental health professionals themselves (Madianos 2000) and iv) the mental health services do not implement actions, and consequently mentally ill economic migrants are not informed of how and why they could approach such a service (Bilanakis 2006).

Sample

The study sample consisted of one hundred and sixty (160) mental health professionals, who worked in mental health services and health structures where psychiatric observation services were also provided. The selection of the sample was made on the basis of systematic sampling. In particular, sixteen (16) structures were selected from the two (2) Prefectures (Achaia, Lesvos), and it was from here that the number of sample subjects was gathered. Specifically, in the Prefecture of Achaia, seven (7) structures were selected: the Social Sector of the Municipality of Patras (twelve

(12) people), the Hellenic Red Cross (ten (10) people), the Mental Health Centre (thirteen (13) people), the Mental Hygiene Centre (ten (10) people), the Psychiatric Department of the Regional General University Hospital of Patras, in Rio (fifteen (15) people), and two boarding houses for chronic psychiatric patients (ten (10) and twelve (12) people, respectively). In the Municipality of Lesvos, nine (9) structures were selected: four (4) Health Centres (thirty one (31) people), the Psychiatric Department of the Hospital of Mytilene (eighteen (18) people), the Mental Hygiene Centre (thirteen (13) people), the Mobile Mental Health Unit (four (4) people), the Social Welfare Institute (eight (8) people) and one Rehabilitation Hostel for patients with chronic mental illness (five (5) people).

With regard to the sample characteristics, 120 (74.5%) were women and 40 (25.5%) were men. Their ages ranged from eighteen (18) to fifty-six (56) years old and over. 90 (56.3%) people were residents of urban centres, while 42 (26.3%) and 28 (17.5) people resided in rural and semi-urban areas respectively. 87 people (54%) were public sector employees, 34 people (21.1%) were employees with a fixed-term employment contract, 30 people (18.6%) were employees with an indefinite duration employment contract, 7 people (4.3%) were under a works contract and the remaining 3 people (1.9%) were hourly-paid employees. The specializations of the mental health professionals were as follows: five (5) psychiatrists, twenty two (22) psychologists, forty (4) social workers, ten (10) occupational therapists, forty three (43) Nurses, graduates of Technological Educational Institutes, thirty one (31) Nurses with two years of studies in Secondary Education and ten (10) health visitors. The majority of the employees (54) had work experience of 10 years and over, while approximately half of them (25) had work experience of 20 years and over. Of the remainder, 42 employees had worked from 1 to 3 years, 25 employees had worked from 3 to 6 years and 19 employees had worked from 6 to 10 years. Finally, only 12 employees had specialized (postgraduate studies), 2 of whom had obtained a PhD and 10 of whom had obtained a Master's degree. Their specialization studies were not in the discipline of multiculturalism and interculturalism

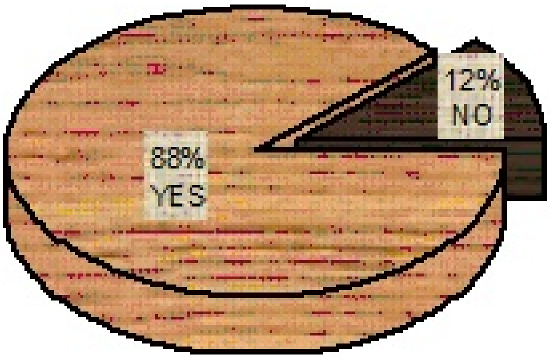
Research Method.

The survey method was used for the implementation of this study. According to the survey method, this study was divided into three (3) phases: the preliminary phase, the main phase (carrying out of research) and the statistical analysis of results phase. Specifically, the specification of the general aim of the research, the formulating of research questions and research hypotheses, the selection of the research method and identification of the population and the subjects to constitute the sample were implemented during the first (preliminary) research phase. During the second (main) phase, telephone communication with and visits to the organizations and mental health services were implemented in order to inform the officers in charge of the aims of this research, and asking them if they would agree to participate in the research process as sample subjects. The visits lasted for two (2) months (March and April 2008) and were accompanied by a formal letter also informing them in writing of the objective of the research process. Subsequently, meetings were held with those mental health professionals who agreed to participate in the research process as sample subjects, in order to inform them of the general aim of the research, the duration of the research and how the research process would be carried out. Finally, there followed the formulating of the questions in the questionnaire as a research tool, the distribution of questionnaires to the sample subjects and the collection, within a week, of completed questionnaires. During the third phase of this study, the codification and statistical analysis of research results on the basis of the Statistical Package for Social Sciences were implemented, and conclusions were drawn.

Presentation of Statistical Research Results

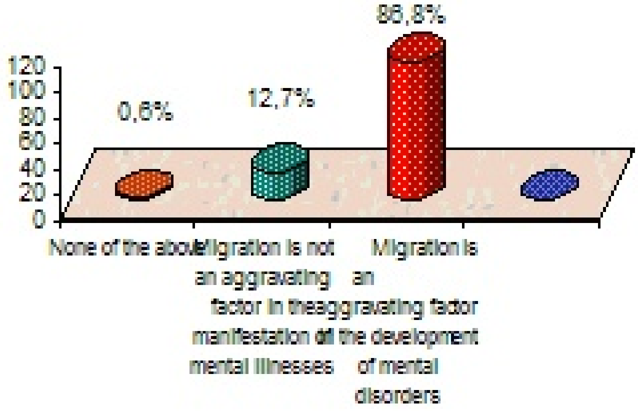
According to the results of this study it was ascertained that mental health professionals consider Greece to be a multicultural country, as 88% of professionals gave a positive answer and 12% gave a negative answer (Fig. 1).

Figure 1



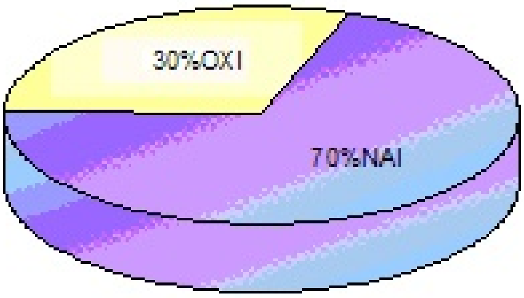
Moreover, the majority of mental health professionals (86.8%) believe that migration is an aggravating factor in the development of mental disorders, while 12.7% do not agree with this (Fig.2).

(Figure 2)



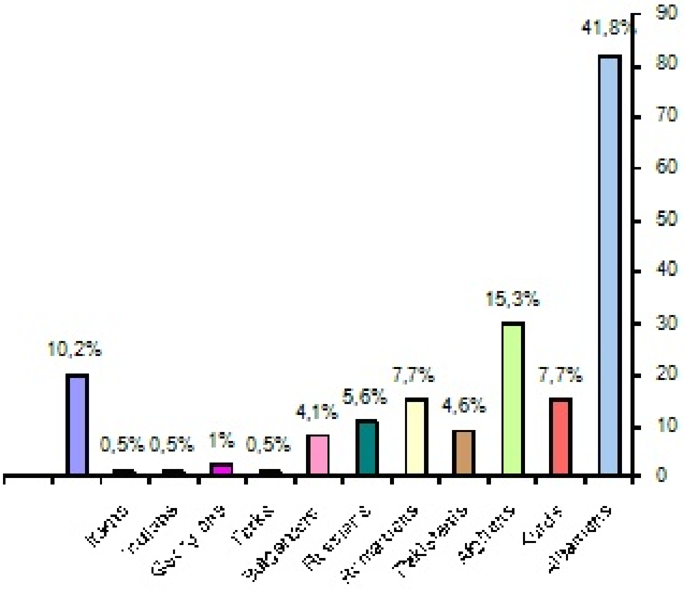
70% of mental health professionals believe that economic migrants constitute a significant part of the clinical population of mental health structures, while 30% responded negatively (Fig.3).

(Figure 3)



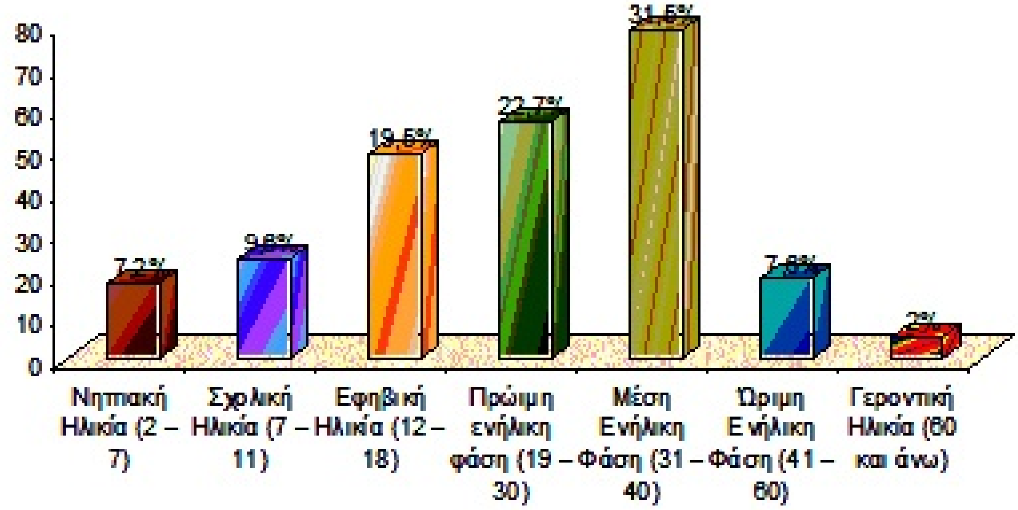
According to the responses, the migrants who approach mental health services are mainly Albanians (41.8%), followed by Afghans (15.3%), Kurds and Romanians (7.7% each), Russians (5.6%), Pakistanis (4.6%), Bulgarians (4.1%) and Georgians, Iraqis, Turks and Indians (from 0.5% to 1%) (Fig. 4).

Figure 4



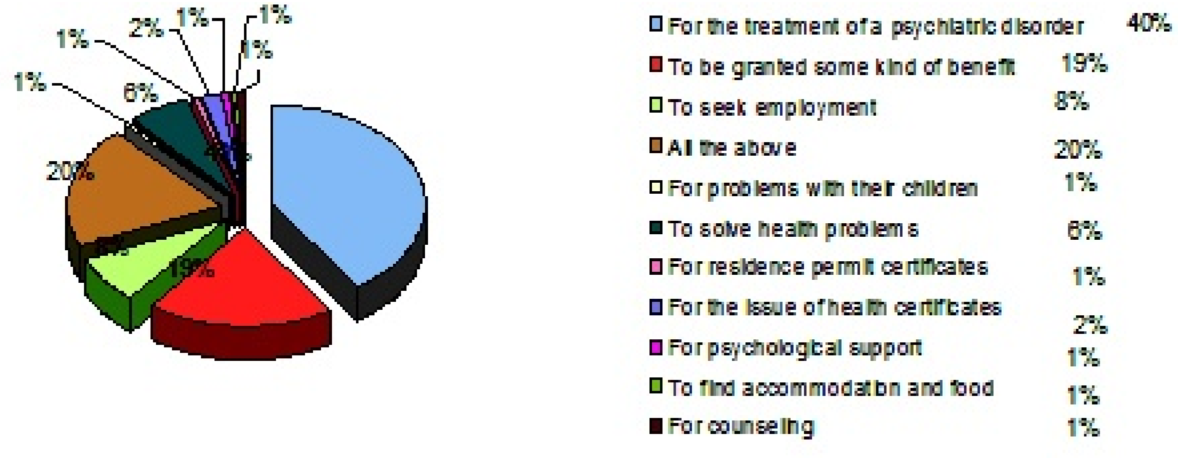
The majority of migrants (31.5%) who approach mental health services range from 31 to 40 years old (middle adulthood), 22.5% from 19 to 30 years old (young adulthood) and 19.5% from 12 to 18 years old. Migrants in the age range from 41 to 60 years old (7.6%), from 60 years old and over (2%), from 7 to 11 years old (9.6%) and from 2 to 7 years old (7.2%) are much less likely to approach mental health services (Fig. 5).

(Figure 5)



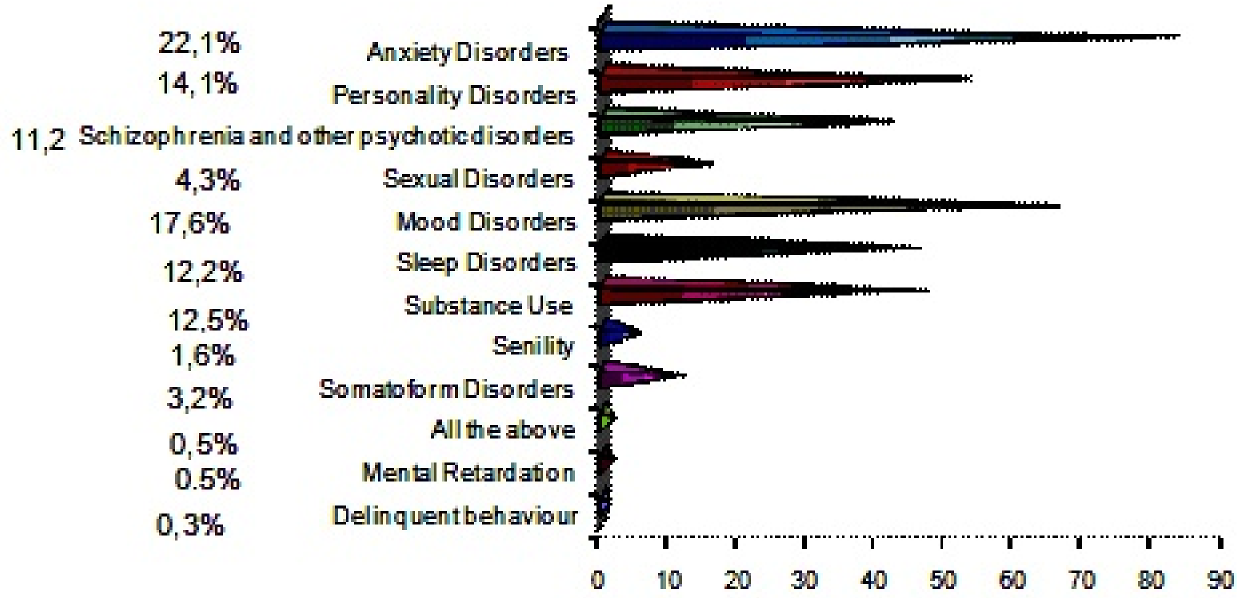
The reasons why migrants approach a mental health service are mainly for the treatment of a psychiatric disorder (40%), to be granted some kind of benefit (19%), to seek employment (8%), to solve general health problems (6%), to be granted a health certificate (2%) and much less likely for the purposes of solving problems regarding their children (1%), being granted a residence permit (1%), receiving psychological support and counseling (1%) or finding and securing accommodation and food (1%) (Fig. 6).

(Figure 6)



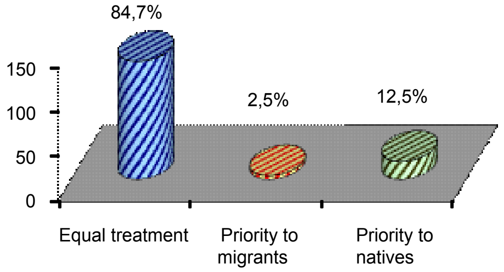
According to the responses of the mental health professionals, the disorders for which economic migrants approach Mental Health Services are as follows: Anxiety Disorders (22.1%), Mood Disorders (17.6%), Personality Disorders (14.1%), Substance use (12.5%), Sleep Disorders (12.2%), Schizophrenia and Psychotic Disorders (11.2%), Sexual Disorders (4.3%), Somatoform Disorders (3.2%), Senility (1.6%), Delinquent Behaviour (0.3%) and all the above (0.5%) (Fig. 7).

(Figure 7)



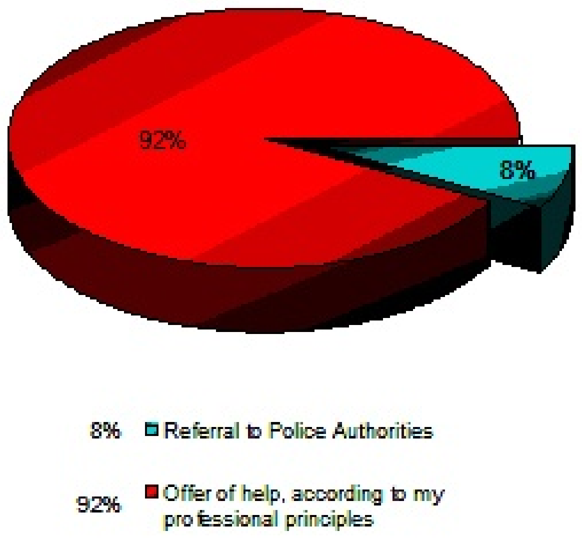
84.7% of mental health professionals maintain that they themselves treat migrants equally (as they would treat Greeks) whenever they approach mental health services to seek help, while 12.5% of them give priority to Greeks and only 2.5% of them give priority to migrants (Fig. 8).

(Figure 8)



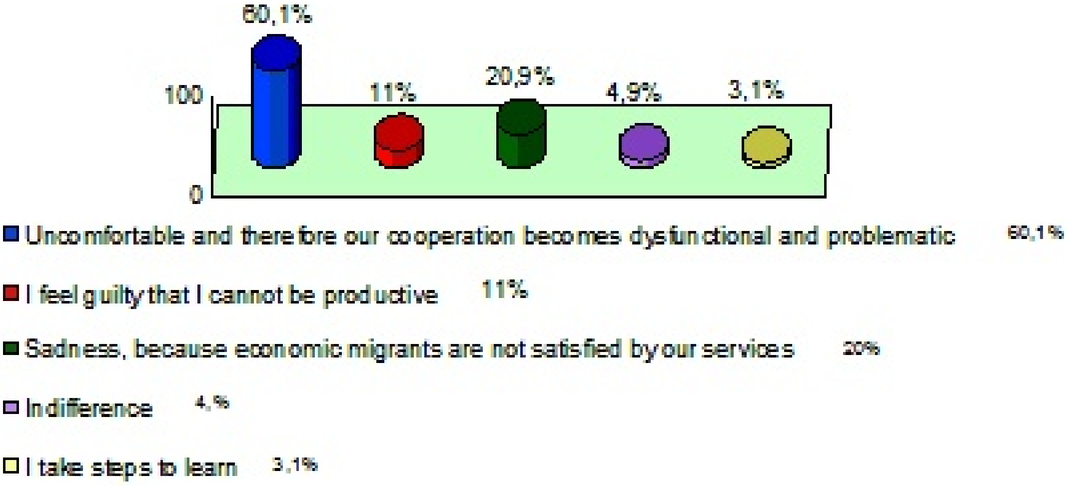
Moreover, when mental health professionals are called on to help a mentally ill migrant who does not possess the necessary legal documents, 92% of them maintain that they offer their help regardless of the existing legal problem, and 8% maintain that in such cases they refer them to Police Authorities (Fig. 9).

(Figure 9)



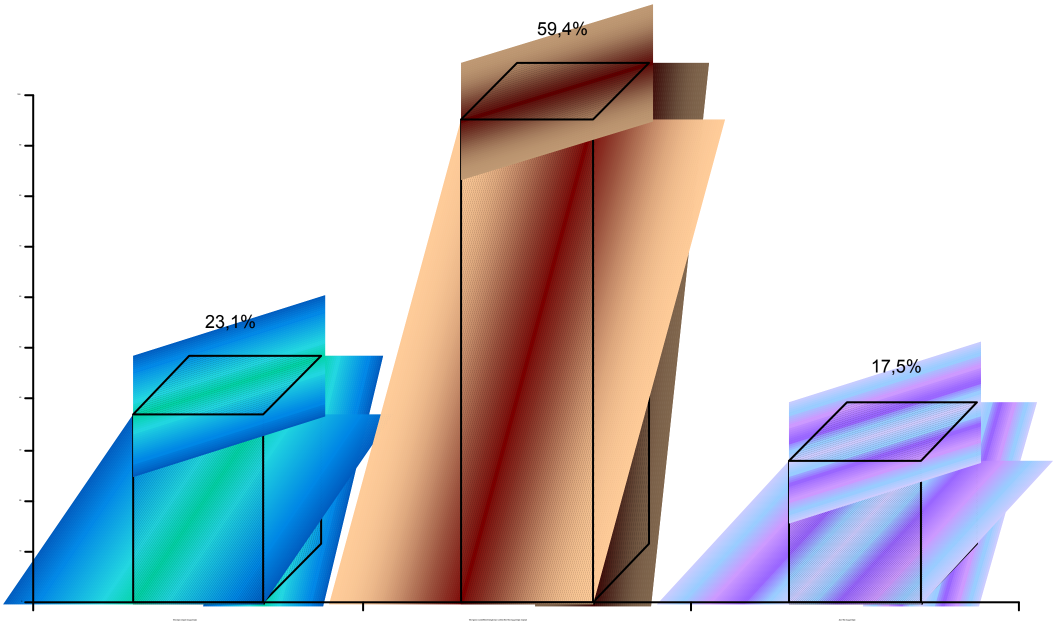
The predominant feelings of mental health professionals during their dealings with mentally ill migrants are **embarrassment**, as cooperation and communication become dysfunctional (60.1%), **sadness,** because migrants are not satisfied with the services (20.9%), **guilt** (11%) and **indifference** (4.9%) (Fig. 10).

(Figure 10)



To the question regarding the participation of mental health professionals in migrants' attempts to claim their rights, 59.4% of professionals responded that they would not actively participate, even though they are sensitized towards the problems of migrants, 23.1% responded that they would actively participate and 17.5% responded that they would not participate (Fig. 11).

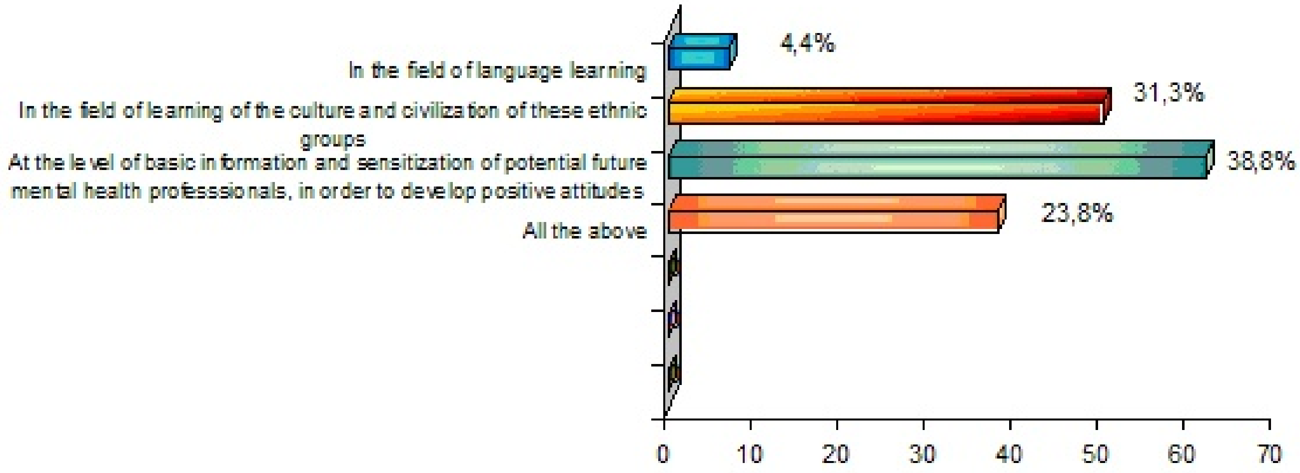
(Figure 11)



83.9% of mental health professionals believe that intercultural teaching is essential in undergraduate studies. 38.8% of them maintain that there should be actions and activities at undergraduate level to inform and sensitize potential future mental health professionals so that they might develop a more positive attitude towards migrants.

31.3% maintain that there should be undergraduate courses to facilitate learning about the different cultures and civilizations of other ethnic groups, and 4.4% believe that there should be courses in more foreign languages. Finally, 23.8% maintain that all the above should apply in the undergraduate studies of mental health professionals (Fig. 12).

(Figure 12)

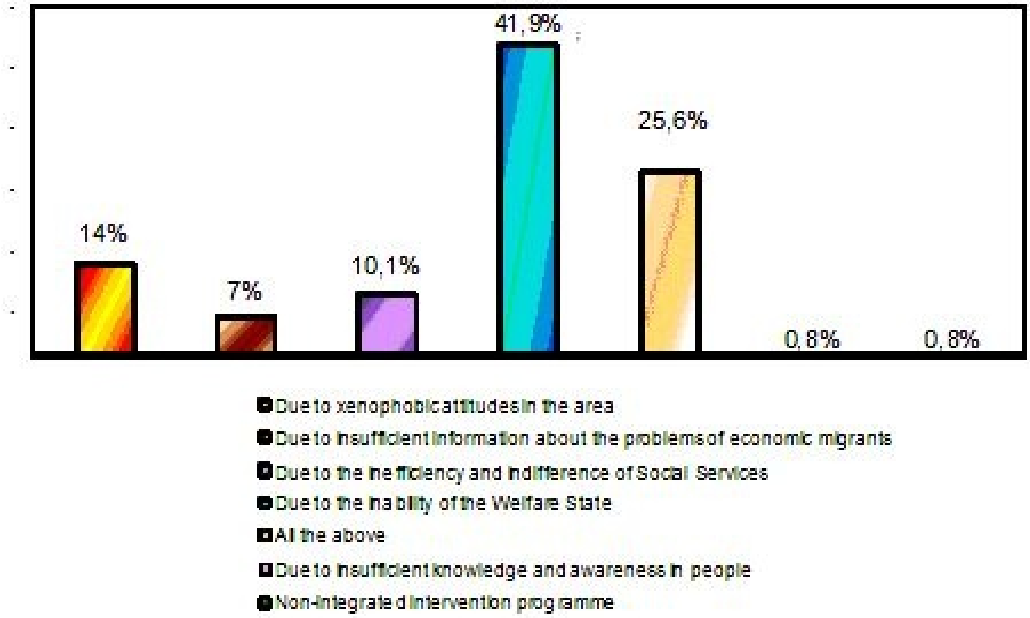


With regard to the acceptance of economic migrants by the **community** in which the mental health professionals worked, 38% answered positively, while 62% responded that economic migrants are not accepted by the community.

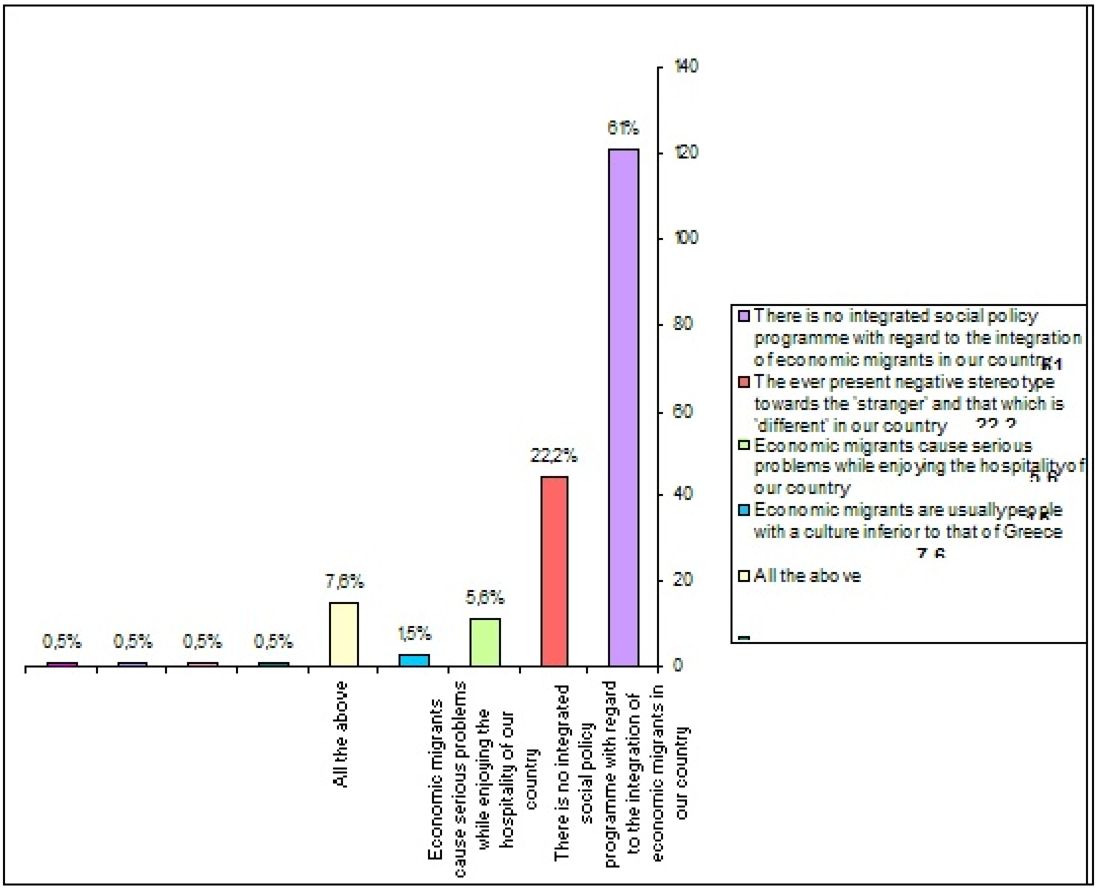
In accordance with the views of mental health professionals, **the reasons for non-acceptance of economic migrants are**: the inability of the Greek state to offer services that could ensure a better quality of life for migrants (41.9%), the xenophobia that prevails in Greek society (14%), the inefficiency and indifference of social services (10.1%), insufficient diffusion of information about the problems of economic migrants (7%), and the inadequate development of integrated intervention programmes to deal with the Social Exclusion of economic migrants (0.8%); finally, 25.6% responded that all the afore-mentioned reasons are significant reasons. (Fig. 13).

According to the views of mental health professionals, **economic migrants encounter social racism because of the following reasons:** the inadequate social policy of the Greek state with regard to the smooth integration of migrants into Greek society (61.1%), the negative stereotype and fear of the 'stranger' and that which is 'different' (22.2%), economic migrants cause serious problems while enjoying the hospitality of our country (5.6%), the cultures of migrants are inferior to that of the Greeks (1.5%) and 7.6% of responses included all the above (Fig. 14). At the same time, mental health professionals believe that it is the Greeks (63%) and not the migrants themselves (37%) who are responsible for the social stigmatization of economic migrants.

(Figure 13)

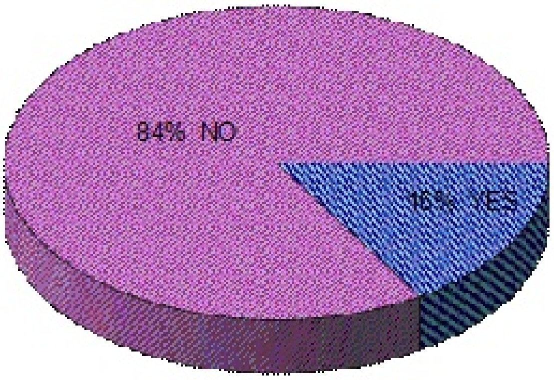

14%
7%
10,1%
41,9%
25,6%
0,8%
0,8%
Due to xenophobic attitudes in the area
Due to insufficient information about the problems of economic migrants
Due to the inefficiency and indifference of Social Services
Due to the inability of the Welfare State
All the above
Due to insufficient knowledge and awareness in people
Non-integrated intervention programme

(Figure 14)



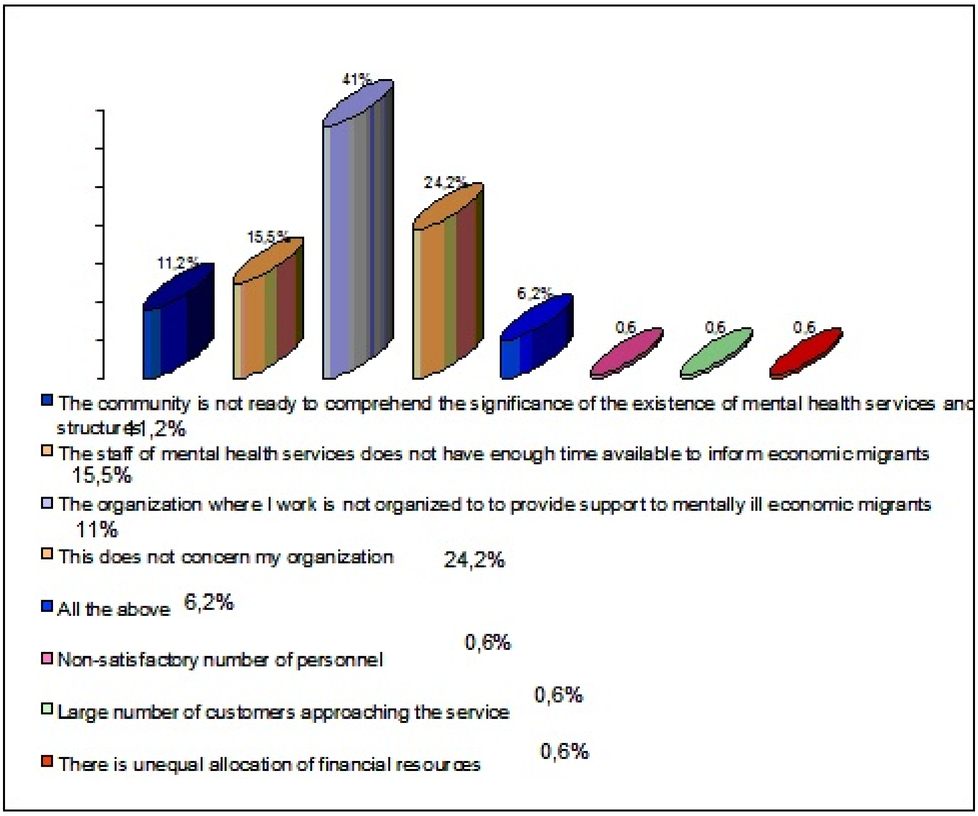
With regard to the provision of qualitative services for care and treatment of migrant mental illness by mental health services, only 16% of them responded positively, while 84% of professionals answered that no services are provided in order to meet the needs of mentally ill migrants (Fig. 15).

(Figure 15)



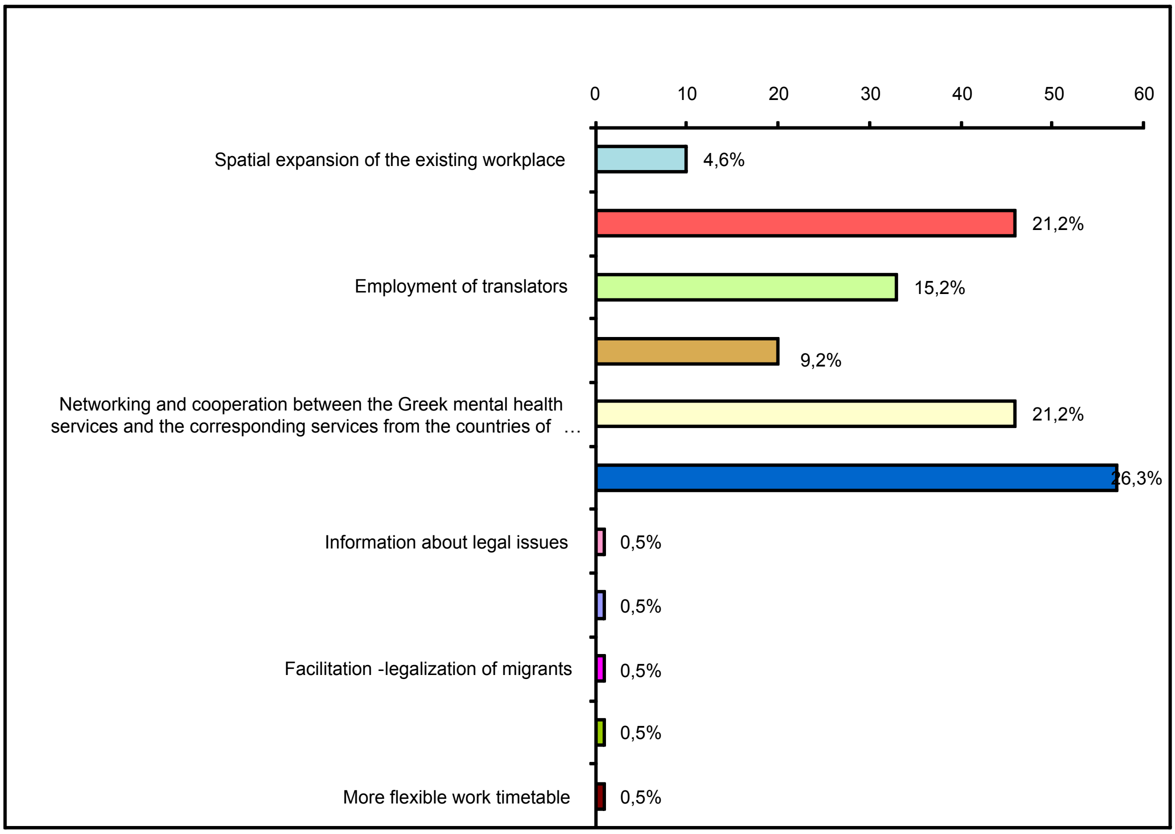
Of those professionals who do not believe that mental health services are satisfactory and qualitative, 41% maintain that the main reason why mental health services cannot meet the needs of mentally ill migrants is because they are not organized to provide support to migrants.
24.2% of professionals believe that the services have no such intention, namely also to meet the needs of migrants suffering from a mental disease, while 15.5% of them maintain that the staff in these services does not have enough time available to inform migrants through information programmes so that they can approach mental health services. 11.2% of them believe that the community is not ready in general to comprehend the significance of the existence and development of mental health services, while 0.6% of them refer to reasons such as the non-satisfactory number of personnel who staff the services, the large size of the clinical population and the unequal allocation of financial resources, respectively. Finally, 6.2% of professionals believe that all the above-mentioned constitute reasons why qualitative mental health services are not offered to mentally ill migrants (Fig.16).

(Figure 16)



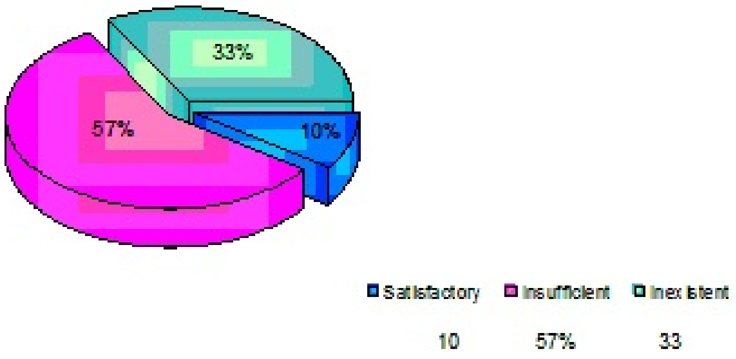
The ways in which qualitative mental health services to migrants could be facilitated are: the employment of staff specialized in community mental health and the existence of wider and qualitative networking of mental health services, through substantial action (21.2% each), the employment of translators (15.2%), the employment of mental health professionals from the same countries of origin as the migrants (9.2%), the spatial expansion of the existing workplace of professionals **(λείπει ποσοστό)**, while 26.3% of respondents included all the above. Finally, 0.5% of respondents included measures such as: informing professionals of the legal issues related to migrants, the development of more social services, the legalization of migrants, the increase in financial resources by the State and the flexible working timetable of mental health professionals, respectively (Fig. 17).

(Figure 17)



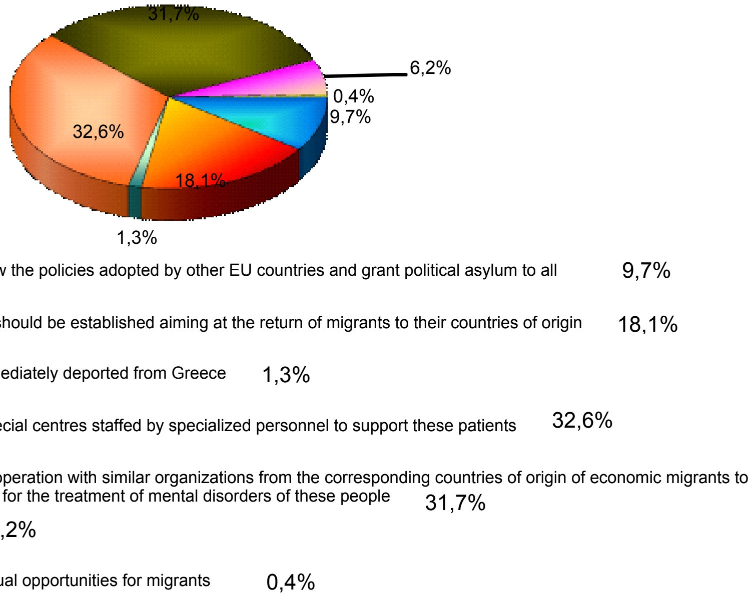
To the question regarding the effectiveness of the Greek social policy in terms of the elimination of discrimination and the social integration of migrants in our country, 57.1% of mental health professionals responded that they believe that Greek social policy is insufficient, 32.9% maintain that Greek social policy does not include an organized plan for the migrants, while only 9.9% of them believe that Greek social policy is satisfactory with regard to the social integration of migrants in our country (Fig. 18).

(Figure 18)



Finally, with regard to the support that migrants should ideally **[<u>προτείνουμε να μπει η λέξη ideally</u>]** have in Greece, 32.6% of mental health professionals maintain that there should be special centres for the rehabilitation of mentally ill migrants, staffed by specialized personnel, 31.7% maintain that there should be cooperation between the Greek mental health services and the corresponding mental health organizations from the countries of origin of the migrants, through the delegation of specialized staff to cooperate with Greek mental health professionals, 18.1% believe that temporary hostels should be established, aiming at the return of migrants to their countries, 9.7% believe that Greece should follow the EU social policy for migrants, while 1.3% believe that migrants should be deported. It is worthwhile noting here that, in response to the same question, **just 0.4%** of mental health professionals believe that migrants should have the same legal rights and equal opportunities as Greek citizens, and 6.2% believe that all the above could apply in order for migrants to be supported by the Greek state (Fig. 19).

(Figure 19)



Discussion

According to the results of this research, migration is a significant triggering factor in the manifestation of a mental disease. As Kontaxakis et al. (1994) maintain, the susceptibility of a migrant towards psychiatric disorders may be related to the following factors: i) their ethnic origin, which concerns the frequency of psychiatric disorders in the ethnic group from which they come, ii) the possibility of 'selecting' individuals susceptible (or not) to psychiatric disorders within the group of migrants, iii) the socio-demographic characteristics of the migrant (e.g. sex, age, social class), iv) the difference between the natural environment and culture in the place of origin and those in the place of migration, v) the attitude of the native population towards migrants and vice-versa, vi) the difference between the social status of a migrant in their place of origin and that in the place of destination and vii) the expectations of the migrant.

Madianos (2000) points out that the ethnic origin variable is closely associated with the phenomenon of migration. From other research studies implemented among groups of migrants, different figures regarding the prevalence of mental disorders among these groups have been ascertained, and their social status (less or more disadvantageous) certainly plays a significant role in the development of mental morbidity. The migrant's traditional culture and the degree to which **they are assimilated [μήπως εννοείτε αφομοίωση;]** by the foreign culture also play a role in the development of mental mechanisms leading to the manifestation of a mental disorder (acculturative stress). At the same time, as Madianos (2000) reports, the initial period following the arrival of a migrant has been judged crucial to the development of psychopathological conditions, since at this time they face a flood of cultural influences.

The arrival of the migrant is characterized as a period of personality crisis, and stress may cause a weakening of the migrant's Ego. According to Madianos (2000), the main symptoms during this period are suspiciousness and paranoid trends, anxiety and depression, physical complaints such as feeling of weakness, insomnia, anorexia, nausea, dread, and a tendency to **conversion disorder.** Siampos (2003) also adds to this list the intense feelings of separation and being distanced from their place of birth, parents, relatives and friends. If migrants have a family, this is crippling and migrants are loaded with two unbearable financial burdens because they have two households (one in the country of origin and one in the recipient country), increased travelling expenses, long-distance calls, visits back home, etc. If migrants bring their family or various relatives with them, they 'do not feel as if they were an uprooted tree, but rather a tree replanted in a flowerpot', as the sociologist Tsaousis characteristically remarks in his analysis of migration. Thus, emotional deprivation coexists with financial difficulties and the migrant's inner world is irreparably damaged.

The overwhelming majority of migrants who usually approach mental health services are of Albanian and Afghan descent, while the most frequent disorders they develop are mainly Anxiety Disorders, Mood Disorders and Personality Disorders. Kasimati (2003) reports that the overwhelming majority of migrants in Greece are economic migrants, while Albanians constitute the largest group of migrants within the Greek territory.

According to this study, mental health professionals feel uncomfortable and embarrassed whenever they are called on to help and support the mentally ill migrant due to their inability to communicate in the same language. Megalooikonomou et al. (2007) point out that one of the most frequent problems to arise when migrants contact a mental health service is extreme difficulty in communicating and/or complete communication failure, because neither the user nor the service officer speak each other's language and translators are not usually available.

According to this study, mental health professionals believe that intercultural teaching is essential in their undergraduate education, especially in terms of their being informed and sensitized in order to develop more positive attitudes towards economic migrants, but also in terms of their learning the culture and civilization of these nations. Megalooikonomou et al. (2007) maintain that if mental health professionals show an interest in becoming familiar with the culture of the 'foreigner' and his/her **personal [μήπως εννοείτε προσωπική γιατί δεν έχει νόημα το προσωρινή]** experience, it is possible that they may comprehend many things which otherwise would seem inexplicable and irrational.

The confidence of mental health professionals in the belief that ensuring a better quality of life for mentally ill migrants and meeting their needs would both be accomplished through the provision of support at special alternative structures of psychiatric care *addressed only to migrants*, would appear to indicate a prejudice. This prejudice seems to be characterized by two (2) prejudicial aspects: i) the first concerns the individuality of economic migrants that characterizes them as 'foreigners' and 'inferiors' in relation to the ethnic majority and Greek cultural identity (Riga, 2007) and ii) the second concerns the 'distorted image' associated with a patient with mental illness, who is believed to be violent and dangerous, unpredictable, lazy and incapable of working or making decisions about his life (Lykouras and Soldatos, 2006).

According to Anthopoulos (2000), xenophobia is mainly provoked by the Mass Media through the use of negative national stereotypes against migrants, thus creating a climate of moral panic in which racial trends and racist behaviour or practices are developed or strengthened.

With regard to the feelings of mental health professionals whenever they are called to help a mentally ill economic migrant at their service, it was ascertained that they feel uncomfortable as their cooperation with the migrants is dysfunctional and problematic.

According to this study, mental health professionals maintain that they would offer their help to migrants exactly as they would do with their fellow citizens, in accordance with their principles and professional ethics. However, they would not actively participate in migrants' attempts to secure their rights. As Zaimakis (2002) reports, the commitment of professionals to the values of racial, ethnic and cultural diversity demonstrates evidence of their ethical and professional conduct. Within the framework of a society which is inhabited and characterized by the coexistence of population groups with discrete collective identities, what is being sought is the formation of a multicultural environment, a structure that enhances interaction between different populations, mutual recognition, mutual acceptance and social incorporation of various cultural realities.

According to the views of mental health professionals with regard to the sufficiency of mental health services offered in Greece, it was ascertained that the insufficiency of mental health services is due to the lack of an integrated social policy programme with regard to the integration of economic migrants in our country.

Megalooikonomou et al. (2007) point out that, although migrants and refugees constitute 10% of the population in the territory of Greece, the provision of health services and specifically mental health services in order to meet their needs has been totally ignored. According to Kasimati (2003), it is widely accepted that current migration policy has failed since it lacks social justification.

Bagavos and Papadopoulou (2006) maintain that the process of legalization of migrants in Greece has turned out to be inefficient and the biggest hindrance to social incorporation and integration of migrants.

According to Tsitselikis (2007), under pressure from the concerned bodies, Law 3386/2005 was passed, according to which the third phase for legalization of migrants was set. At the same time, the Greek Nationality Code was cleaned up, especially on a technical level, without, however, spectacular improvements in its content, and migration policy in Greece has remained devoid of a fixed target and orientation.

With regard to the migration issue in Greece, mainly during the last few years the following major issues have emerged: i) the legality of migrants' residence and employment and the benefit or not of their presence for the economy, ii) public safety and the crime rate and iii) the protection of human and social rights of migrants (Tsitselikis 2007).

Conclusions

According to the results of this study, certain conclusions were drawn; these are, however, indicative as they represent the views of only a part of the whole of mental health professionals who work in Mental Health Services in our country.

Mental health professionals maintain that migration is an aggravating factor in the development of mental illness, as a large number of economic migrants approach Mental Health Services to deal with and solve their psychological or psychiatric problems, **even though actions and programmes to inform migrants of the objectives of the Greek Mental Health Services are neither organized nor implemented**. A possible explanation that may justify this contradictory situation is the implementation and organization of actions to inform migrants by mainly **voluntary medical and social organizations in Greece** which aim to fill the wide gap in primary psychiatric care and nursing in Greece, and specifically in terms of prevention.

The reasons why economic migrants approach a mental health service are mainly for the treatment of a mental illness and to be granted some kind of benefit, but only of course when economic migrants have managed to obtain the documents for their legalization.

The disorders from which migrants suffer and consequently cause them to approach the relevant services are mainly Anxiety Disorders, Mood Disorders, Personality Disorders, Substance Use Disorders and Sleep Disorders.

The predominant feeling of mental health professionals in their communication with the migrants is one of **embarrassment**. The main reason for this is their inability to communicate with the migrants and therefore communication becomes dysfunctional as the necessary means and ways are not available to facilitate the provision of their therapeutic work.

Mental health professionals maintain that Mental Health Services do not offer quality services to migrants for the following reasons:

i) The initial aim of the establishment of these Services was to meet the psychiatric needs of beneficiaries of Greek descent. The sheltering and continued arrival of economic migrants in our country found the Greek State unprepared and with no organized plan for meeting the psychiatric needs of migrants.
ii) The inability of Greek society to comprehend the significance of the existence of Community Mental Health Services, since it continues to 'stigmatize' the mentally ill and even more so the mentally ill economic migrant.
iii) The difficulty that professionals encounter in finding and dedicating more time within the framework of their work timetable to implement actions that could be beneficial for migrants in terms of informing them of issues related to the prevention and treatment of mental illness.

Despite all the afore-mentioned impediments, mental health professionals maintain that they endeavour to offer their services to migrants **without discrimination, even when migrants do not possess legal documentation for residence and shelter in Greece. It is worth mentioning that they would not actively participate in whatsoever action or activity necessary to claim the legal rights of migrants.**

With regard to this allegation, a probable prejudice towards the 'stranger' and that which is 'different' is revealed, arising from the wider value system of mental health professionals which has its roots in the very community in which these professionals live and work. Besides, mental health professionals constitute part of the community and hold the views and values of the community for which they are called to offer their services.

According to mental health professionals, migrants are not accepted by the Greek society mainly for three (3) reasons which are divided into three (3) levels: i) the Greek State, ii) the Mental Health and Social Care Services and iii) the community. Consequently, on the one hand, we have the inability of the Greek State to develop or expand actions or services aiming at the social integration of migrants into Greek society, the inability or indifference of Mental Health Services to develop actions related to the social integration of migrants and the negative stereotype within the community towards the 'stranger' and that which is 'different'.

The suggestions made by the mental health professionals with regard to the provision of qualitative mental health services to migrants, which could also contribute to their social integration, are:

i) the existence of more professionals engaged in the provision of social care to citizens, and also offering supplementary services to those of the Mental Health Services, such as the direct issuing of legal documentation for residence in our country, the granting of benefits, the direct finding of accommodation, etc.
ii) the cooperation between the Greek Mental Health Services and the mental health professionals from the corresponding countries of origin of the migrants, also helping with translation during communication with the migrants
iii) the wider networking and mutual supplementation of Mental Health Services
iv) the development of special rehabilitation centres, the services of which are to address only migrants
v) the cooperation with the Mental Health Services of the corresponding countries of origin of the migrants
vi) the development of more shelters for migrants and their return to their homelands.

SUGGESTIONS

- The granting of equal civil, employment and democratic rights to both natives and migrants.
- The financial boosting or expansion of mental health services with the aim of improving the services provided and which will coincide with the needs and rights of mentally ill patients and migrants, and acceptance of the appropriate number of patients
- The coexistence of mentally ill migrants and natives in common structures (boarding houses) to eliminate social stigma, aiming at commitment to treatment and improvement of health standards.
- Action by mental health services and organizations to attract mentally ill migrants, through either information leaflets or special seminars or even provision of a helpline.
- The enhancement of programmes for prevention, information and sensitization of the phenomenon of migration and mental health-illness by both the professionals themselves and the community.
- The introduction of courses on Intercultural Education and Interculturalism at all levels of education, but especially at Tertiary level, emphasizing respect for personality, free will, acceptance of individuality, the fight for each human's rights and the elimination of prejudice and inequality.
- Lifelong learning for mental health professionals in the sector of interculturalism.
- The co-organization of educational seminars for mental health professionals from different countries, aiming at broadening their knowledge and putting it into practice.
- The development of mental health professionals' abilities to work with mentally ill patients of different cultural, ethnic, linguistic and religious origin, through the application of Counseling, mainly in Tertiary Education.
- The provision of counseling support in regions accessible to migrants by specialized staff and translators, in the form of either an organized counseling centre or streetwork. This form of service presupposes a carefully selected team of social workers with well-rounded knowledge and great flexibility. Specifically, this involves searching for employment, organization of self-help groups, counseling on health issues, facilitation of communication with welfare authorities and the Social Security Institute, etc. Social workers will offer material, therapeutic and cultural support.
- The role of social workers, which should be more active in terms of informing, sensitizing and mobilizing the community with regard to multiculturalism.
- Greece following the migration policies adopted by the Scandinavian countries (Sweden, Norway and Finland) and Canada, and granting political asylum to all, bearing in mind the fact that there are those for whom migration to another country is a one-way street, sometimes a matter of survival and other times a quest for a better quality of life.

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Stress, Immunity, and Health: Research Findings and Implications

Dilwar Hussain

Thapar University, Patiala
Assistant Professor, School of Management & Social Sciences, Thapar University, Patiala, Punjab-147004, INDIA.
e-mail: dhussain81@gmail.com

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Abstract

A wealth of research indicates that psychological stress suppresses various parameters of immune functions and consequently can cause diseases. Various studies suggests that the nature of stressor (acute or chronic) may have differential impact upon the immune functioning, with brief acute stress enhancing some parameters of immunity whereas chronic stress adversely affecting almost all parameters of immune functions. Stress and immune functions are mediated by the hypothalamic-pituitary-adrenal (HPA) axis and the autonomic (sympathetic and parasympathetic) nervous system. In addition, there is a possibility of behavioral pathways (such as alcohol intake, sleep disturbances) through which stress affects immune functions. This paper is an attempt to review various research linking stress, immunity and health. Major theoretical models explaining the conceptual link between stress and immunity are introduced. Further, the pathways through which stress impacts upon immune system and ultimately health are addressed. Finally, implications of stress and immunity research for therapeutic interventions are discussed.

Key Words: Stress, Immunity, Health, Psychoneuroimmunology, meta-analysis, review

Introduction:

The interest in the study of relationship between emotional states and disease has a long history. In the second century A.D, Galen popularized the concept of emotions causing illness which he termed "passions or perturbations of the soul". He made a distinction between diseases caused by organic reasons and emotional reasons. However, it is only recently, this field has received increased attention from researchers. A relatively new branch of interdisciplinary science called "psychoneuroimmunology" looks into the interactions among psychological states, neurological system and immune functions. The term psychoneuroimmunology was coined by Robert Ader, who accidentally found that immune system could be classically conditioned. In an experiment of classical conditioning of rats, Ader and Cohen (1975) fed rats with saccharin while injecting a drug that caused stomach upset. As a result, mice learned to avoid the saccharin. An additional side effect of the drug was that it suppressed immune system. When the experiment was repeated without the injection of drug to reverse the aversion, they found high proportion of the rats died when receiving saccharin alone. This led them to hypothesize that, by classical conditioning saccharin alone suppressed the immune system enough to kill the rats. This experiment indicated that signals from nervous system can affect immune system. A growing body of research has found that negative psychological states such as stressful experiences and depression may influence health and disease by altering immune system (Glaser et al. 1987; Kiecolt-Glaser & Glaser 1994). Evidences indicate that stress suppresses immune functions and consequently impairs resistance to infectious diseases (Glaser & Kiecolt-Glaser, 2005) and lends support to the idea that stress related immune changes mediates the relationship between stressors and various diseases.

Human Immune System

Immune system consists of a network of cells, tissues and organs that defend body against foreign harmful invaders or antigens (such as bacteria and virus). The network of immune system is spread throughout the body. Key player of immune system is white blood cells also called lymphocytes. Lymphocytes can travel throughout the body using blood vessels. There are mainly two types of lymphocytes: B and T cells. B cells secrete antibodies into the body fluids to destroy antigens. Each B cells produce a specific antibody when triggered by an antigen. Unlike B cells, T cells do not recognize free floating antigens. The surfaces of T cells contains specialized antibody like receptors that see fragments of antigens on the surfaces of infected or cancerous cells. T cells are of two types: helper and killer T cells. Helper T cells (also known as CD4 cells) coordinate immune responses by communicating with other cells. Killer T cells (also called cytotoxic T lymphocytes or CD8 cells) directly attack other cells carrying certain foreign or abnormal molecules on their surfaces. Other major components include natural killer cells (NK), phagocytes, and cytokines. NK cells are component of innate immunity which can attack several kinds of cancerous and virus infected cells without any prior sensitization and identifying specific antigens. Phagocytes are a group of immune cells that are specialized in finding and swallowing microbes and dead or injured body cells. Cytokines are chemical messengers by which various components of immune system communicate with each other. Cytokines include interleukin (IL-1, IL-6), and tumor necrosis factor alpha (TNFα). Important organs which are store house of immune cells include bone marrow (soft tissue in the hollow centers of bones), thymus (lies behind breastbone) and spleen (flattened organ at the upper left of the abdomen).

Pathways Linking Stress and Immunity

Relationship between stress and immune function is very complex and many mechanisms are yet to be discovered. However, some major pathways are well established. It has been found that stress affects immune system through the mediation of brain and endocrine system (Ader, Felten, & Cohen, 1990). After the perception of a stressor by the brain, hypothalamus releases corticotrophin releasing hormone (CRH). In turn, CRH stimulates the pituitary gland to secrete adrenocorticotropic hormone (ACTH), which in turn stimulates the adrenal cortex to secrete glucocorticoids. In humans, the primary glucocorticoid is cortisol. The hypothalamus also increases the activity of sympathetic nervous system, which in turn stimulates adrenal medulla to secrete hormones called epinephrine and norepinephrine. These stress hormones may make us more resistant to stressors but are generally found to impair immune systems (Boneau et al. 1993). For example, cortisol has been found to inhibit the production as well as activity of white blood cells. Cortisol also suppresses white blood cells to produce chemical messenger, so that different varieties of immune cells become unable to communicate with each other. Cortisol can also signal many immune cells to shut and stop working (Talbott & Kreamer, 2007).

It also merits mention that behavioral component could be an important pathway linking stress and immune response. It is possible that coping with stressful experience may lead individuals to engage in activities such as alcohol use, which ultimately influence immune processes (Kiecolt-Glaser & Glaser, 1988). High alcohol intake has detrimental effect on immunity (Diaz et al., 2002). Stress and immune function may also be mediated by exercise. Individuals reporting high stress are less likely to exercise than low stress (Stetson, Rahn, Dubbert, Wilner, & Mercury, 1997) and exercise may have protective effect on immunity (Venjatraman & Fernandes, 1997). Further, stress may promote sleep difficulties (Rosch, 1996) which in turn may lower various immune cells and their activities (such as suppressor T cells, natural killer cells) (Savard et al., 1999; Irwin et al., 1994; Savard, Laroche, Simard, Ivers, & Morin, 2003).

Stress and Immunity: Theoretical Models

Various models have been propounded to explain the relationship between stress and immune system. One of the first proponents to study the relationship between stress and disease was Hans Selye. Selye (1975) suggested that stress globally suppresses the immune system and provided first model relating stress and immune response. He described three stages of general adaptation syndrome in response to stress. Stages include alarm, resistance and exhaustion phases. “Alarm stage” is the first stage where body prepares for fight-or-flight in response to a threat. If the stressful situation persists, second stage of “resistance” comes into play. In the stage of resistance, body channelizes all its resources by secreting further hormones and blood sugar to sustain energy to fight. Third stage called “exhaustion” phase kick off when the stressor remains for a long time. In this stage, body has run out of its reserve energy and immunity. At this juncture, due to heavy depletion of body resources, one may fall ill or die. Many early studies have supported this model by reporting association of chronic stress with decrease in natural killer cell, suppression of lymphocyte responses (Herbert & Cohen, 1993). Although this global immunosuppressant model continues to be influential, newer models have emerged recently. Dhabhar and McEwen (1997, 2001) proposed a biphasic model which takes account of type of stress (acute or chronic) and their affect on immune response. This model states that acute stress enhances while chronic stress suppresses the immune response. Acute stress helps in the redistribution of immune cells in the body and as a result increases the efficiency to fight against invaders. However, chronic stress depletes resources and weakens immune responses. This conclusion was derived from a series of experiments conducted on rats by Dhabhar and McEwen (1997). They found that acute stress caused T cells to redistribute into skin, where they improved immune response. On the contrary, chronic stress caused T cells to move away from the skin, thereby decreasing immune response.

Stress and Immunity: Empirical Evidences

Several studies have reported associations between stress and immune functions. Impairments in the immune system such as fewer immune cells and increased susceptibility to common cold have been reported among healthy individuals during the periods of stress (Herbert & Cohen, 1993; Cohen et al., 1998). Reduction in the numbers and functions of the natural killer cells (NK) were reported for students undergoing examination stress (Kiecolt-Glaser et al. 1984; Glaser et al. 1986). Poorer immune functions among divorced or separated men and women as compared to their married counterparts were reported (Kiecolt-Glaser et al. 1987, 1988). Similarly, fewer T-cells, B-cells, and NK cells were reported among individuals experiencing posttraumatic stress disorder than unaffected individuals (Davidson & Baum 1986). Research also reported lower percentage of T cells among the female caregivers of handicapped relatives (Pariante et al. 1997) and caregivers of Alzheimer’s patients (Kiecolt-Glaser et al., 1987; Kiecolt-Glaser, 1999). Apart from that, evidences of association between perceived stress and immune functions are also available. An inverse correlation between natural killer cell activity and psychological distress and anxiety (Locke et al., 1984; Cohen et al., 2002) were reported. Similarly, higher perception of stress was found to be associated with poorer response to vaccines (Miller et al., 2004; Jabaaij et al., 1993). The experience of high depression and anxiety symptoms prior to surgery was associated with lower numbers of lymphocytes, B cells, and T helper cells in a sample of women (Tjemsland et al., 1997). Women scoring high on trait anxiety showed decrease in the NK cell activity during chemotherapy treatment as compared to women scoring lower on trait anxiety (Fredrikson, Furst, Lekander, & Blomgren, 1993).

Herbert and Cohen (1993) conducted a meta-analysis of 38 studies relating stressor and immune functions. They included three types of stressors-(a) acute laboratory stressors (such as speaking before audience), (b) short-term naturalistic stressors (such as examinations), and (c) long term naturalistic stressors (such as unemployment, bereavement). They reported that stress is associated with higher numbers of circulating white blood cells and lower numbers of circulating B cells, T cells, helper and suppressor/cytotoxic T cells, and large granular lymphocytes. They also reported significant association of stress with decrease in the percentage of T cells, helper T cells, and suppressor/cytotoxic T cells. Further, they reported that immune function change was greater for objective events as compared to self reported stress. Stressor duration had distinctive outcomes on immune functions. Acute laboratory stressors were associated with the increase in the number of circulating suppressor/cytotoxic T cells, but long-term naturalistic stressors decreased their numbers. In terms of natural killer (NK) cell function, both short and long term naturalistic stressors decreased NK functions whereas a laboratory study showed increase in NK functions in response to acute stressor. This inconsistent result could be a function of the short term enhancement of immune function due to the acute secretion of the stress hormones (Herbert & Cohen, 1993).

Segerstrom and Miller (2004) also conducted an extensive meta-analysis on 293 independent studies reported from 1960 to 2001 (N=18,941). Analysis of the results confirmed that stress alters immune functions. The most distinctive finding was that the short term stress may enhance immune function as an adaptive response, but chronic stress suppresses immune response as a result of too much depletion of body resources. Further, older and sick people are more vulnerable to stress related immune change. Authors also assessed how different types of immune response correlated with different types of stress. Some stressor categories and their immune responses are as follows-

Acute time limited stressor: This category included experimental manipulations of stressful life experiences such as public speaking and mental arithmetic. These types of stressors enhanced natural immunity (provides defense against non-specific different kinds of foreign invaders in a relatively short span of time) as reflected by increase in the number of natural killer cells in peripheral blood. However, some aspects of specific immunity (attacks specific invaders and characterized by less speed) were suppressed.

Stressful event sequences: This category included a focal event such as natural disaster or loss of spouse. This category of stressors was not strongly associated with immune changes when taken as a whole. However, upon the consideration of the category of stressors some evidence emerged. After the loss of a spouse, decline in natural immune responses was observed. A non significant increase in natural and specific immune responses following exposure to natural disaster and no immune alterations with breast biopsy was observed.

Chronic stressors: This category included long term stressors without any clear end point such as living with a handicap, dementia care giving, and unemployment. Chronic stressors have negative effects on almost all functional measures of the immune system (both natural and specific immunity) irrespective of demographic variables such as gender and age.

Conclusion and Implications

Majority of the research on stress and immunity revealed a negative impact of stress on immune responses. This review indicates that both objective as well as perceived stress may negatively influence immune functions. The nature of stressor (acute or chronic) may have significant impact on the immune functioning. Brief acute stressors appear to enhance some parameters of immunity whereas chronic stress consistently showed detrimental effect on almost all parameters of immune functions. Research also elucidate that there is a possibility of behavioral pathways through which stress affects immune functions. Stressful experiences may lead individuals to engage in certain behaviors such as high alcohol intake, reduction in sleep and exercise which may have detrimental effect on immune functions. Pathways through which stress influences immune functions are complex and yet not fully understood. However, research show that stress and immune functions are mediated by the hypothalamic-pituitary-adrenal (HPA) axis and the autonomic (sympathetic and parasympathetic) nervous system.

The detrimental effect of stress on immune function has far reaching implications. One important corollary that can be derived is that the interventions aiming at stress reduction may have immune enhancing effect. Some research evidences are emerging in this direction too. Alexander et al. (1989) reported dramatic reduction in mortality rate by the use of meditation techniques. They found 0% mortality among elderly nursing home patient who practiced meditation daily over a period of 3 years while 40% mortality in control group. In another series of studies, Fawzy and colleagues (1990a, 1990b, 1993) found significantly higher immune cell activity for a group of people who underwent 6-week intensive group psychotherapy (focused on coping strategies for stress management). They reported that this higher immune activity persisted even 6 months after the intervention. Witek-Janusek et al. (2008) reported that therapeutic interventions such as mindfulness based stress reduction prevents decline in NK cell activity and increases cytokines (IL-10 and IL-4) among newly diagnosed breast cancer patients. Similarly, McCain et al. (2008) reported that 10 week cognitive-behavioral relaxation training (such as tai chi, spiritual growth groups) enhanced lymphocyte proliferative responses in a group of HIV patients. However, at present, research on the effectiveness of psychotherapeutic interventions on immune functions is sparse and difficult to make generalizations due to the varieties of immune measures and intervention techniques used. Future research in this direction may provide useful insights for theory as well as therapeutic interventions.

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Building a Bridge from Hospital to Community: One Patient's Experience

Peter J. O'Brien, MSW, RSW,

Clinical Consultant

Shared Mental Health Care, Alberta Health Services,

Christine Hewitt, BScOT,

Occupational Therapist

Community Mental Health Rehabilitation Team, Alberta Health Services

Shahid I. Hosain, MD, FRCPC

Consulting Child and Adolescent Psychiatrist

Foothills Medical Centre, Calgary, Alberta

Mary Elizabeth Lauzon, RN

Staff Nurse, Department of Psychiatry,

Foothills Medical Centre, Calgary, Alberta

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Correspondence should be sent to: Peter J. O'Brien, Shared Mental Health Care,
Sheldon M. Chumir Health Centre, 1213 – 4th Street S.W., Calgary, AB, T2R 0X7

or sent to: peter.obrien@albertahealthservices.ca

Note: The four authors worked together as part of the staff complement of the
Young Adult Program, Foothills Medical Centre, when this "patient experience" occurred.

Abstract

This article describes a unique and comprehensive rehabilitation plan that was created between staff of a hospital psychiatric unit, personnel from two community agencies, high school staff and the family of a patient admitted to hospital with a complex illness, in order to integrate a treatment plan that would lead to successful discharge home. The steps taken to augment the care on an acute psychiatric unit, as well as to create a collaborative rehabilitation plan that involved the integration of hospital, community and school staff to develop an effective continuum of care for the patient and family will be described. Tensions and challenges addressed throughout the process, as well as the success in achieving genuine community collaboration will be highlighted. The spontaneous and informal creation of a collaborative enterprise with the patient, family and community of care will hopefully prompt others to share similar stories.

Terms: rehabilitation, collaboration, community, hospital.

Introduction:

The admission of a seventeen year old student to an acute adolescent psychiatric program offered a unique opportunity to develop a comprehensive rehabilitation program to support this severely ill patient in transitioning home. This involved addressing administrative and acute care staff concerns about the capability of a psychiatric unit to provide an extended rehabilitation plan in the care of the patient and family.

While providing medical and psychiatric care to this adolescent it was necessary to negotiate a comprehensive rehabilitation plan and to recruit the involvement, during the young man's admission to hospital, of community agency personnel already contracted to offer services to the patient and his family.

The steps toward realizing the goal of transition back to home and school will be chronicled and discussed herein.

Admission Crisis

Upon attendance at the Emergency Department, the young man was reported to have experienced two days of sudden decline in functioning with the onset of severe anxiety, delusions, hallucinations and catatonic symptoms. According to his parents this was a profound vegetative shift. On admission, the patient did not respond either verbally or physically and required one-to-one assistance with all activities of daily living (ADL's). The symptomatic presentation impressed as organic in nature, and therefore, full medical investigations were completed. The results of virtually all of the investigations were normal, apart from a positive parvo virus serology, which is usually self-limiting, as is the case with most viruses.

Early on in the admission, the patient was started on anti-psychotic medication, Olanzapine, and after approximately one month started to respond quite well to the medication. After about one month of complete silence he gradually became verbal and it became evident that he was suffering from a number of obsessive thoughts. For example, these included the worry that some fictional character would come to the hospital unit to do harm to him. Accordingly, the patient was started on the SSRI, Sertraline, in order to treat these obsessive thoughts. (Sertraline had been prescribed when the patient was at a much younger age, with reported efficacy).

Cognitive testing by the unit psychologist and a full functional assessment with the occupational therapist (O.T.) suggested that the patient was significantly compromised in terms of cognitive and functional capacity. This adolescent already had several diagnoses over the course of a few years, including Pervasive Developmental Disorder with secondary psychotic symptoms, speculation of Asperger's Disorder based on previous symptomatic presentations and Obsessive-Compulsive Disorder. A further diagnosis of a primary psychotic process was also being considered as a result of the admitting symptoms.

Over the course of the three month, three week admission there was a slow, steady improvement in the patient's functioning and in his ability to interact with family and staff. However, one-to-one care and constant supervision in the hospital environment was required through almost the entire admission, and as transition to community was contemplated.

Setting

The patient was assessed in the Emergency Department of a major teaching hospital, affiliated with the university and serving a city population of almost one million. The acute deterioration of physical condition, functioning and communication prompted admission to an inpatient adolescent psychiatric unit. The admission was for three months and nineteen days in total.

The eleven bed adolescent inpatient unit serves teens ages thirteen to eighteen years with mental health concerns. The adolescent unit is staffed by psychiatrists, nurses, a psychologist, recreational and occupational therapists, family therapists, a pastoral services representative and a Board of Education teacher and behavioural specialist in the on-site classroom. The patient and family had access to the full complement of these services throughout the admission.

Initial Steps in Hospital

As noted, this young man was seriously compromised in literally all facets of daily functioning at admission to hospital. Within a few days concerns were articulated across the staff complement as to how this patient could possibly be cared for long-term on this unit. The adolescent psychiatric unit was simply not staffed to provide such acute, twenty-four hour nursing care for an unforeseen period. A debate arose over organic vs. psychiatric causes of his illness. The puzzling nature of the illness, its sudden, inexplicable onset and inability of all professional staff to predict its course or duration, alarmed staff of the adolescent unit and the family. In addition to requiring constant nursing care and being immobilized in bed, he was initially unable to benefit from any of the multi-disciplinary assessments or treatment, or the milieu therapies that were intended for residents of the adolescent unit program.

The initial nursing care plan addressed both physical and psychological deficits manifested on admission. Nursing staff dealt with the patient's self-care deficits including feeding, hygiene, dressing grooming and toileting. The patient was suffering total incontinence, hyperthermia, risk of fluid volume deficit, altered nutrition, risk for self injury, sleep disturbance as well as altered thought content, sleep disturbance, decreased insight, reality impairment, anxiety, fear and impaired verbal communication. For example, the patient's father related to staff that the patient appeared to be terrified of both contamination and of disinfectants. Nurses began planning and implementing specific techniques dealing with all aspects of this patient's care.

The parents were perplexed and alarmed by the rapid and severe onset of the symptoms. Their concern included wondering if the staff of a psychiatric unit could or would meet the complex medical needs of their son. Unit treatment staff met with the parents and began to 'map out' a course of action that would provide basic nursing care and also incorporate the parent's ability to supplement the daily care alongside intense psychiatric observation.

It was clear to all concerned that this situation could not be sustained with the current unit resources. A critical turning point arose early in the admission when a small subgroup from the staff of the adolescent inpatient unit, comprised of the admitting psychiatrist, a few of the nursing staff, the occupational therapist, psychologist and social worker formed an informal and impromptu treatment team committed to fashioning a rehabilitation treatment plan in support of this young man and his family.

This subgroup took a special interest in the evolving rehabilitation plan, above and beyond the demanding daily schedule of a psychiatric unit.
A commitment to working collaboratively with one another, the family and community partners to successfully facilitate the eventual discharge home and return to school were realized as a result of this plan.

Community Partner Recruitment
From the initial family meeting on the adolescent unit, staff was aware that this patient had an open file with a provincial agency mandated to offer funding support to children qualifying for handicapped children's services. Over a series of preliminary discussions with the assigned caseworker from Children's Services it was learned that the case worker had considerable leeway to augment the care being provided in hospital. However, affecting the kind of program created required front-line staff and supervisors within the respective community agencies to respond with a reciprocal intention of being truly collaborative.

An initial Case Conference was held on the adolescent unit to explore with Children's Services their willingness to support a hospital rehabilitation program on an acute unit. Members of the hospital unit, the case worker from Children's Services and the parents of the patient participated in this meeting. The teen was not yet well enough to attend the Case Conference. Assessment findings, treatment recommendations and an outline of a treatment protocol with time lines were discussed at this meeting.

The major thrust of the Case Conference was to consolidate resources between hospital staff, the family and a funded community agency, to share the care plan while the patient remained on the adolescent unit. The parents had been augmenting the daily care plan from admission, particularly at the supper hour, in the early evening and on weekends. The more innovative idea was to enlist the support of a community agency that offered daily living support in the community to further augment the care being provided on the unit. In particular, the request from hospital staff was that caregivers/aides be available to support the patient and hospital staff in the morning, when breakfast and basic hygiene care was required, thereby exacting a heavy toll, as this was not normally required of staff on a psychiatric unit.

The next significant step was for the case worker to return to Children's Services to review the proposal for collaboration between hospital, family and community with their supervisor and secure authorization and funding support for the unfolding innovative plan. Following agreement to the proposal with the Children's Services supervisor, the case worker was in contact with a community resource agency that was mandated to provide activities of daily living support to clients of Children's Services. The request was that two staff of the community resource agency would be contracted to attend at the adolescent psychiatric unit to initially provide daily living assistance to the patient, and subsequently to be involved in the more comprehensive rehabilitation program that was evolving.

The case worker from Children's Services was instrumental in recruiting aides to attend at hospital to augment nursing care for up to five hours per day in the morning, seven days per week. Implementation of the daily schedule involved a further meeting with the members of the community of care team. Once this program was established it remained in place through the entire course of the hospitalization, through the transition phase to community and beyond discharge into the teen's return home and resumption of school studies.

Hereafter, all people involved in the rehabilitation plan, including the subgroup from the hospital unit, the family members and community agency personnel will be referred to as the community of care team.

The Rehabilitation Program
The first involvement of the occupational therapist (O.T.) was to complete an assessment of the patient's ADL functioning. The purpose of the assessment was to create a structured daily routine that all staff involved could follow to ensure the same routine and the same cueing was used to assist the patient. This patient functioned better with a

structured routine and appeared to decompensate when his routines were altered so this was an important principle in his recovery plan. The team also believed that a visual aide that encompassed the ADL routine may help cue both staff and eventually the patient to the routine. The O.T. created a wall poster for the patient's room of the daily ADL routine with feedback from unit staff.

The most important and critical component of this ADL routine was the cooperation and use by all staff involved in this patient's care. The wall poster, structured routine, and cueing strategies were discussed in detail at a meeting of the community of care team. These team members had knowledge of what already worked for this patient and what the issues were. With this feedback and brainstorming session the team was able to create a viable structured daily routine. Added to this plan was a checklist of ADL's that staff would use to track the patient's activities and increasing level of independence.

A recommendation was to maintain consistent staffing with this patient instead of continuously introducing new staff to the treatment plan. The result was that the patient was assigned three primary nurses who would work with him on different shifts to provide continuity of care.

As the patient began his slow recovery and started ambulating it was important to use other means of cueing to assist patient to engage in these self-care activities and create opportunity for the patient to relearn skills, a routine and gain independence. These cueing strategies included: hand-on-hand with verbal, partial hand-on-hand with verbal, demonstrative, just verbal and eventually cueing to wall poster for next step.

A second purpose of the O.T. assessment was to look for adaptations that could be made to equipment and environment to assist this patient in gaining independence in his ADL's. Suggestions included having his parents bring in easy-to-don clothing such as elasticized waist pants and t-shirts and slip on shoes. Other examples of equipment recommended were: pump top shampoo bottles, large grip brush instead of small handled comb, bathroom bars for safety in transfers, larger grip cutlery, grips for writing utensils, and beginner level reading books.

The patient had reduced function in both gross motor and fine motor abilities due to the slow recovery from his initial catatonic state. It was important to use the patient's leisure interests in combination with participation in gross and fine motor activities to improve function. The patient was interviewed regarding his leisure interests and staff and family also brainstormed ideas on activities the patient showed interest in. Activities were made readily available on the unit for the patient. A list of recommended activities for patient was charted and discussed with all staff at one of the regular rehabilitation meetings regarding the patient. Some activities included were: playing catch with a ball, kicking a ball, coloring, reading, puzzles, tic tac toe wall game, crafts, board games, and regular walks outside. This was time consuming for staff but by sharing this task between multiple staff it created a variety of interactions and activities that created intense rehab program for the patient to enable him to improve his skills.

Keys to success of this patient's recovery included:

1.) Small graduated steps towards increasing independence
2.) Structured daily routine
3.) Slow integration back to community and home with lots of support

But the most important component that enabled these first three points to be possible was:
Team work and regular, clear communication and cooperation between all involved as part of the community of care team.
The tasks for the aides during the five hour morning shift were determined in consultation with the community of care team to incorporate the patient's 'high demand' early morning care requirements. The parents' schedule allowed them to be most available at the supper hour and during early evening visiting hours.

The original daily schedule was basic and included much verbal direction and cuing for the client in terms of relearning to wash appropriately in the shower and after toileting, dressing, using utensils for meals, brushing his teeth

and combing his hair. Over the course of several weeks and the repetition of daily routine the care staff shifted their focus to cuing the patient as he became more independent and capable with his ADL's.
In the early rehabilitative phase the patient was only able to tolerate brief walking excursions on the unit. He expressed considerable fear about using the elevators in order to connect to any other area of the hospital. He also continued to express paranoid ideas about evil apparitions that might attend at the hospital to harm him.

The process of basic rehabilitation was exceedingly slow in the first few weeks, but with the daily chart of successfully achieved self-care activities being tracked by the aides, nursing staff and parents each day, it was possible to confirm incremental gains from week to week. At approximately the mid-way point in his hospitalization the patient began to verbalize much more freely, finally indicating his comprehension of his situation. His improvement in overall functioning and weekly gains also began to accelerate at this point.

The role of the classroom teacher, classroom behavioural specialist and the psychologist became more significant as the patient increased his basic skills, began to communicate more directly verbally and showed an inclination to return to the structure and familiarity of the classroom. On a number of occasions the treatment team introduced more elaborate rehabilitative steps, based on the progress being noted, often in the service of monitoring the length of stay issue. Invariably, there would be a significant regression in the patient's overall functioning when changes to the daily rehabilitation regimen were introduced. The rehabilitation team learned to introduce alterations to the program in the most modest fashion, resulting in progress becoming more uniform over time.

The introduction of the classroom component was a significant feature of the rehabilitation program and served as an effective barometer of the patient's readiness to embark on more ambitious steps, including forays out of hospital with family initially, and eventually consideration of a return to school as a key goal of the discharge plan. The ability to tolerate participation in the classroom, initially for only brief periods in the morning in the company of the aide who would assist with reading, led to a gradual increase in time spent in the classroom milieu, and the introduction of independent academic activities.

The fact that the patient had advanced through the school system prior to illness, made the classroom setting a place of familiarity and success. He was motivated to be in the classroom and this served as an effective way to interrupt his isolation from other residents of the hospital unit. Social interactions that were gradually introduced in the classroom led to interactions with peers in the common area of the adolescent unit and at the meal table. Observation and information gathered from these interactions was documented by the rehabilitation team and served as additional evaluative data to confirm that an effective course of treatment was unfolding. During this phase of participation in the classroom, it was noted that the psychotic symptoms gradually resolved.

Transition to Community School

The next phase of the rehabilitation plan, initiated after a couple of months in hospital, involved consulting with education staff from the community school. A similar process to the one entered into with Children's Services, of open communication, accenting collaboration and a sharing of resources unfolded. A Case Conference now involved the patient and his community of care team, which now expanded to include the school guidance counsellor and the patient's classroom teacher.

Similarly to the initial Case Conference discussion in hospital, considerable trepidation and doubt was articulated about the capacity of the school to contend with such a compromised and disabled student. An added dilemma was that the school administration would have difficulty obtaining approval for aides who were not employees of the school system to attend in the classroom to assist the student, as had been happening so effectively in hospital with the aides from the community resource agency. This dilemma was resolved by the school reallocating their internal resources to provide a classroom aide for the student during school hours, which initially involved only one or two classes, then increased to the entire morning at school and ultimately to the full school day.

The ability of these major institutions to be flexible and innovative in fashioning the treatment plan, rather than being wedded to policy and protocol that inhibits creative problem solving was critical to the successful outcome of the process.

The aides from the community resource agency took responsibility for assisting the patient to get ready for school, accompanied him to the school, and then met him for the return to hospital at the end of his morning. The resource agency and aides continued to adapt to the increased school hours and adjusted their support to still be available to accompany the student to and from school each day. As the rehabilitation program expanded to introduce home visits and eventual discharge from hospital, the aides adjusted their schedules further, to accommodate time at home as well as hospital. The commitment of the aides was tied to the patient and family, regardless of setting.

When home visits were added to the rehabilitation plan, they initially involved day passes home on the weekends, when the parents could be most readily available, and incorporated the participation of the aides from the resource agency. Gradually, overnight passes home on the weekends were added, and as these were successfully incorporated a full weekend pass was introduced. Finally, dinner passes through the week, and evening passes during the week were added to increase the time that the patient spent at home and in the community, thereby decreasing the reliance on hospital.

All parties involved in the rehabilitation plan were aware that the prolonged hospitalization had left the patient secure with the routines and relative comfort of the institution, even while protesting about the desire to be back at home. Lessons learned in the early phase of treatment, related to increasing autonomy in a carefully graduated manner, as opposed to abrupt changes in the expectations for enhanced independence, supported the slow but steady progress through the transition period.

The introduction of the school community component occurred while the patient was in hospital. This step supported the rehabilitation team on the adolescent unit in continuing to monitor progress toward readiness for independence and discharge. Consultation with the community of care team was frequent during this phase.

Discharge Plan

The circumstances surrounding discharge involved a continuing dialogue among the community of care team. In the last few weeks of his admission to hospital, the patient was increasingly impatient with remaining in hospital, though there was a shared apprehension among all concerned about his readiness to be at home full-time. The parents alternately expressed exasperation with the prolonged transition out of hospital and anxiety about being able to cope completely without the support of the hospital unit.

The school staff remained ambivalent about their capacity to continue increasing their care and instruction to allow the student's return to a full academic program, especially as the one-to-one aide being allocated in the classroom was proving to be onerous in a system already taxed by several years of cutbacks and resource reductions.

The ambivalence of school personnel was juxtaposed by increasing concern and pressure from the administration of the adolescent unit about the patient's extended length of stay in hospital. In spite of the creative and effective approach of all involved in addressing this complex admission, the institutional pressures continued to build.

This confluence of pressures led to a decision to discharge the patient after three months and three weeks in hospital, though there remained several unresolved matters. For example, how to structure the remainder of the patient's day after his partial academic program was completed at noon hour and he left the school for home was unresolved. An additional concern arose as to the community resource agency's ability to indefinitely maintain their high level of involvement, at five hours of direct one-to-one aide time per day, seven days a week.

Subsequent to his discharge from hospital and in the couple of months that followed, the patient was described as increasingly responsive in returning to his former level of functioning. In fact, before the end of the school year this young man had resumed his former level of full-time school attendance. Just seven months after being discharged from hospital with a tentative prognosis, he successfully completed his final requirements to graduate from high school. Such an outcome attests to the resiliency of the patient, the faith and dedication of his parents, and the quality of the rehabilitation plan, which included the collaboration of hospital, school and community staff with the young man and his family.

No re-admissions to hospital were required.

Discussion

A main interest for the authors in reviewing this course of illness and rehabilitation is to highlight the ability of mainstream systems to adapt and offer high quality care, bringing to life ideas of meaningful collaboration between traditional institutions of the community and the patient/family. The inexplicable and dire circumstances of the admission, and the successful outcome arising from the determination of all concerned parties to create a collaborative rehabilitation program, deserve elaboration.

These efforts were maintained from the outset of the admission and through the lengthy rehabilitation course, even while contending with a high degree of emotional turmoil and even some resentment generated in the health care and educational systems, in particular, about the propriety of being responsible for the comprehensive treatment plan that evolved. In addition, myths about the inability of an acute care hospital unit to offer effective long-term rehabilitation, and about the inviolability of financial and logistical barriers between the main hospital institution, Children's Services and the contracted community resource agency in creating a comprehensive and collaborative rehabilitation program, were successfully addressed.

Length of Stay

Concerns about the length of stay in hospital and the capability of the school to support an incrementally increasing school program over a number of months arose and persisted despite considerable and consistent success in the overall treatment plan. This young man was successfully rehabilitated from an acute, inpatient adolescent psychiatric unit and then graduated from high school barely 10 months after becoming incapacitated and catatonic in the Emergency Department of the hospital.

Several important issues are raised in situations such as this one. In a health care climate of fiscal restraint and cutbacks (McGrath & Tempier, 2003) length of stay may become a principal measure of the efficacy of a treatment approach or program (Parsons, 2006; Murphy & Noetscher, 1999). It is possible that individuals with more complicated circumstances are screened-out, as there is an understanding that they will tax limited resources and do not allow for a speedy resolution. However, decisions related to treating the mentally unwell individual in hospital or not will also be influenced by the social climate of the community and the availability of alternatives (Gordon, 1997)

Although not necessarily articulated directly, when an acute unit of a hospital is faced with such a complex circumstance as evidenced with the admission of this young man, pressure can build quickly to transfer elsewhere. The combination of uncertainty about diagnosis and prognosis, as well as acute care staff not being proficient in organizing a modified rehabilitation plan, and pressure to demonstrate efficiency via meeting administrative targets related to length of stay, can conspire to shift a focus from client/family needs to those of the hospital unit.

Ability to Provide Care

From the outset, there was apprehension among the staff of the unit as to their capability in providing care for this. The demands placed on the nursing staff, in particular, in the first several weeks of the admission, prompted much questioning of the merits of having such an ill teen on the unit. As well, many staff of the hospital program were unfamiliar with a long-term rehabilitation orientation. "While programs may refer to themselves as rehabilitation programs, and systems may consider themselves rehabilitation oriented, if the personnel are not trained and experienced in rehabilitation, then rehabilitation will not be practiced." (Anthony, 1992, p.167). However, there is a growing awareness that the quality of care can be improved as rehabilitation-oriented services are introduced onto hospital units (Birkman, et al, 2005), and this was certainly the experience on the unit in this situation.

Perceived Hardship for Staff

Even the introduction of the community resource agency aides on a daily basis, providing the bulk of the direct and labour-intensive care of getting the patient up and ready for his daily routines did not divert some staff and administration from the lament that the patient needed to be placed elsewhere than a psychiatric unit with limited resources. With the family being in attendance on the adolescent unit over most supper hours and each evening, thereby providing further care for the high-demand bed-time routines, there was actually considerable relief being provided for the acute care staff.

In fact, it was the community of care team who were addressing the most significant care demands, and these tended to be in the domain of fine-tuning the rehabilitation plan. The family bore the principal emotional burden and the Children's Services agency accepted the financial burden of supplying aides via the community resource agency. Once the patient was able to transition back to school, the Board of Education and the host school found the funding support to provide the additional classroom aide.

In this context the concerns being expressed by many staff were striking. Anecdotal feedback suggests that the concerns reflect the stress/distress being experienced by many staff in 'doing more with less' and facing ever-increasing acuity overall. It suggests that an opportunity to think and practice innovatively remains a challenge. The immediate response to the suggestion of an impromptu and informal long-term rehabilitation team within the acute care psychiatric setting can be sharp and pessimistic. And, even with each successful step forward in securing additional support to relieve the demands on the unit staff, it can be difficult to alter an entrenched and pessimistic mind-set.

Competing Goals at Admission

Decisions about resource allocation often occur via administrative processes in which the complex needs of the patient with a challenging mental illness are not adequately represented (Rosenheck, et al, 1998). Impatience with acute and chronic illnesses, coupled with the extraordinary pressure on current health systems, risks that poor decisions will be made. The quality of care cannot always be measured in dramatic results (McGrath & Tempier, 2003). An unclear focus on specific goals, or unresolved concern about the goals of the admission, also risks disregarding the excellent work being done in the management and rehabilitation of the most severely mentally ill.

Such a situation calls for an examination of the mission of the program or unit, as well as familiarity with current and relevant concepts such as recovery (Anthony, 1991; Anthony, 1993; Mental Health Commission Canada, 2009). It is not enough for health care staff to know about the existence of standards of good practice. It is essential that staff are prepared to participate in discussions about their role, construction, adequacy and acceptability of these standards (Cribb & Duncan, 2002).

The tenets of the Canadian health care system, including universality and equal access (Canada Health Act, 1985) can provide an alternate focus at admission which will not necessarily be in sync with an administrative focus on admission goals. One could also argue that there is an obligation to treat the least well off (Rosenheck et al, 1998), not to arbitrarily discharge them to units in other cities with no discussion with family about the implications.

At the very least, a discussion among the treatment staff and with the patient and family is imperative, if appropriate goals of the admission and a complex rehabilitation plan are to be undertaken. Constructive discussion involving all of the concerned parties will hopefully allow for realistic and clear treatment goals to be set (Rudnick, 2002). Such an approach would also allow all parties to move forward with a clear understanding of roles. In keeping with these ideas, the host of supportive relationships that developed among members of the community of care team were key factors in the recovery process (Mancini, Hardiman & Lawson, 2005).

Implications for Family

There was administrative concern expressed throughout the admission, and on occasion a resolve to relocate the teen to a long-term care institution some 200 miles away, as a way to address the acute unit's lack of long-term rehabilitation capability and the ongoing length of stay worry. Although this idea of transfer was raised internally to the adolescent unit on a few occasions, it was not raised with the family.

The discussion about length of stay pressures being resolved by transfer to a long-term care setting were muted in the context of the implications of such a transfer for the family. Budget constraints and pressure to provide care for high-needs patients with reduced staffing in recent years are legitimate concerns to address. However, the disadvantage and hardship of hospitalization, or transfer to a chronic-care setting in another city, thereby separating the child from the family and their community also merits consideration (Steinhauer, 1996, p.16).

Steps Contributing to a Successful Plan

A key feature of moving forward ideally includes administrative support for the unfolding plan. In addition, the support and involvement of the admitting physician is critical in a hospital environment. The formation of an impromptu rehabilitation team on the acute care unit was also essential to create the unfolding treatment plan. Especially where there is not whole-hearted support for creating a long-term rehabilitation plan for an acute-care patient, the cohesion of the smaller staff group involved in the rehabilitation plan is essential. The quality of hope shared among the members of this smaller staff group can extend to the client and family to create an essential climate of hope (Spaniol, 2008) that will sustain all involved through the long process of rehabilitation.

Clear communication via periodic formal Case Conferences, and frequent informal communication was essential. Role delineation was important, with at least one member of the rehabilitation group being responsible for the overall coordination and management of the treatment plan on the unit, and facilitating meetings with the patient, family and community agencies.

Importantly, an ethos of optimism and collaboration, informed by actions that underlined these words, was evidenced and encouraged on a daily basis. Starting with the small rehabilitation team formed within the adolescent unit, this attitude extended to the family and to the few community agencies and numerous individuals who became part of the community of care team. Rather than a focus on territory or who might delegate to whom, there was an evolving spirit of camaraderie in sharing a common goal.

Much is written about the value of "team" and collaboration between institutions and agencies, and including a community of caregivers, and most importantly with a client and family. In this instance, these ideas became a lived experience on a daily basis and thereby contributed significantly to the outcome.

Collaboration with Community

As well, the approach delineated in this situation follows protocols of collaboration and collegiality among the three major social systems that are charged with responsibility for the care of children and families in need in this society – health care, children's services and education. The Steinhauer report (Steinhauer, 1996, p.31) speaks to the need for true collaboration among those very major social systems in order to provide effective care. In seemingly spontaneous fashion, the various individuals engaged in fashioning this community of care demonstrated what is referred to as deliberate and purposeful ways of relating that are simultaneously flexible and responsive to others (London, et al., 2009). The importance of well-planned transition from hospital to community (Watt & el-Guebaly, 1981) and the goal of interactions to support greater continuity of care, a central feature in the provision of mental health servcies (Joyce et al, 2004) were also demonstrated in the team effort.

The individuals that made up the community of care team were all in uncharted territory in terms of creating this collaborative plan. Each of the main community agencies contributed to the effort to maintain a regular dialogue with one another and with the family. Especially in the early stages of this evolving rehabilitation plan, this practice was critical.

While each of the respective agencies was familiar with planning and negotiating with clients and family members, none had experience with such a comprehensive plan for inter-agency/family collaboration. Given that at the outset this patient was uncommunicative and in an adolescent psychiatric unit bed, with an uncertain prognosis, the circumstances were even more troubling. Despite these uncertainties, or perhaps as a result of a collective willingness to tolerate them, the staff that made up the community of care team sat together to create a plan that addressed the patient's acute needs. This involved hospital staff, non-hospital staff and family members working closely together on the hospital unit, major budgeting requirements and the development of a rehabilitation plan that would unfold gradually over about fifteen weeks.

Each time a new concern or a new opportunity arose in the treatment course, the community of care team gathered, and with input eventually from the patient as well, the concerns and opportunities were addressed, an appropriate adjustment in the treatment plan was made, and the entire community of care moved forward with the patient and his family. An ethos of believing in possibilities and maintaining a focus on the resourcefulness of all involved contributed to this approach and has elsewhere been described as an organizing framework for collaborative practice and family-centered services (Madsen, 2009).

In retrospect, a number of salient traits adopted by the entire community of care team also reflected key narrative principles and practices in community work (Freedman & Combs, 2009). These included the determination to proceed at a pace that worked for the patient more so than for the hospital, remaining cognizant that we were all part of a team that was making significant contributions to the eventual outcome and that it was important to honour each of the "little steps" that were being taken from week to week.

Conclusion

It is our hope that in telling the story of this unique approach to a genuinely puzzling and unusual admission conundrum, others will be inspired to share similar stories of their success in fashioning authentic community collaboration. The whole process was fraught with challenges and occasional tensions, including those caused by the pressures on the hospital and school systems to produce efficient and cost-effective measures.

The comprehensive planning and the determination of all involved, to commitments in the service of a shared goal, over the course of a more than three month admission to hospital, was innovative and effective. The community of care team developed a meaningful and ultimately successful treatment plan.
What goes without saying, is that no one individual, not one discipline, could have forged the result for this patient and family that was collectively reached. The power inherent in the team, evolving as a collaborative and coordinated entity, offered the energy that was shared by each member, and accounted for the salutary outcome that was achieved.

This spirit of collaboration, which arose spontaneously and informally in the adolescent unit, was extended first to the patient and family, and then to the community. This attitude was met with a matching spirit from the key partners that were forged in the community. A simple equation, to be sure, but one easily missed in the relentless and competing demands and pressures that inform health care in the current climate.

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European Union's Lifelong Learning Policy and the EMILIA Mental Health Project: Including the Excluded

Dr. Christopher A. Griffiths, BSc, PhD
Project development and researcher
Middlesex University
Department of Mental Health and Social Work
Holborn Union Building (F Block)
Archway Campus
2-10 Highgate Hill
London
N19 5LW
Email: c.griffiths@mdx.ac.uk

Dr. James Ogunleye, BA, MSc, PhD
Researcher
Middlesex University

Dr. Tim Greacen, PhD
Director of Research
Université de Paris

Professor Peter Ryan, DProf, MSc, DipSW
Professor of Mental Health
Middlesex University

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Abstract

EMILIA (Empowerment of Mental Illness Service Users: Lifelong Learning, Integration and Action) used a five step process embedded in European lifelong learning policy to set up learning courses, developed with mental health service users. There were two strands to the research. One was an organisational strand which assessed the learning organisations based in eight European countries. The second focused on mental health service user participants. The main result and conclusion is that promoting and facilitating lifelong learning and employment opportunities for an excluded group can have a positive effect social inclusion of that group and produces benefits for organisations involved, including making them more open to mental health service user involvement.

Key words: Lifelong learning, social inclusion, mental health, service users, empowerment, and employment.

Introduction:

Lifelong learning, social inclusion and mental health have been found to be interlinked (Griffiths & Ryan, 2008). The Treaty of Lisbon (2009) refers to mental health in Articles 151-161 (Social Policy); Article 165 (Education); Articles 174-178 (Economic, Social and Territorial Cohesion), Articles 179-190 (Research) and Article 168 which states: "European Union action, which shall complement national policies, shall be directed towards improving public health, preventing physical and mental illness and diseases, and obviating sources of danger to physical and mental health. Such action shall cover the fight against the major health scourges, by promoting research into their causes, their transmission and their prevention, as well as health information and education..."

The Lisbon strategy (COM, 2000) set a clear and ambitious goal: to make the European Union region the most innovative, competitive and dynamic knowledge-driven economy by 2010. An important element of the Lisbon strategy is lifelong learning (CEC, 2002) which has become a major tool for fostering community cohesion/citizenship and social inclusion. European policy on lifelong learning has five linked operational elements, corresponding to the stages involved in developing lifelong learning, all of which are key to achieving coherent and comprehensive national strategies for lifelong learning (COM, 2001a; COM, 2001b; COM, 2003). These elements are:

1) Building up partnership or partnership working
2) Insight into the demand for learning
3) Adequate resourcing
4) Facilitating access to learning opportunities/Creating a learning culture
5) Striving for excellence

The EMILIA project sought to evaluate this policy with regard to people with serious and enduring mental illness by the implementation and evaluation of each of these five elements. The main theme of the paper is to link lifelong learning policy to the operational research strategy and results of the EMILIA project and to evaluate whether the lifelong learning process can be a mechanism for facilitating the social inclusion of socially disadvantaged groups such as mental health service users.

EMILIA was a research project which sought to facilitate social inclusion and empowerment through providing formal lifelong learning and employment opportunities for mental health service users. It commenced in September 2005 and was completed in February 2010 (54 months).

To achieve this, a radical new approach to education and training for this population was called for. The EMILIA project employed innovative pedagogical strategies beginning with a shift in emphasis away from knowledge acquisition to competence and capability development, building on expertise acquired as patients and users of health and social care systems, and necessarily implying new roles for teachers and learners. The EMILIA strategy for lifelong learning was founded on a partnership approach; EMILIA sought to encompass the learning needs of the individual learner, of organisations, communities and the labour market itself. It also sought to increase learning opportunities, raise participation levels and stimulate demand for learning whist striving for excellence on an ongoing basis. EMILIA collaborated with a European-wide mental health network of local level partnerships of learning communities and learning organisations with the aim of organically linking education and training to the mental health workplace, so as to optimise the quality of the working environment both for service users and for the clinical and management staff of mental health services. It encouraged mental health services to maximise mental health service user involvement in the training for, and delivery of, new and innovative services, thus opening up new employment routes for mental health service users.

A major goal of the EMILIA project was to make a contribution in the area of mental health to the European Union’s ambitious objective to become: “the most competitive and dynamic knowledge-based economy in the world, capable of sustained economic growth with more and better jobs and greater social inclusion” (COM, 2000). The EMILIA project thus set out to link European policies on both lifelong learning and social exclusion; given that people living with long term mental illness are one of European society’s most disadvantaged groups. EMILIA adopted the concept of social innovation (OECD, 2000) with its four main characteristics: social inclusion, social cohesion, cooperation, and mobilisation of resources.

Social innovation seeks new answers to social problems by, on the one hand identifying and delivering new services that improve the quality of life of individuals and communities and, on the other, identifying and implementing new labour market integration processes, new competencies, new jobs and new forms of participation. The EMILIA project can thus be seen as part of the existing social agenda, as described in the Renewed Social Agenda: Opportunities Access and Solidarity in the 21st Century (COM, 2008), by focussing on: “empowering and enabling individuals to realise their potential while at the same time helping those who are unable to do so” (COM, 2008, p. 3). The EMILIA project links to the Social Agenda in that both were built around creating opportunities (for learning and employment), providing access (to actively participate and integrate in society) and demonstrating solidarity (fighting poverty and social exclusion and enabling adaptation to change). The main purpose of the paper is to link lifelong learning policy to the operational research strategy and to evaluate the EMILIA Project in relation to this.

Innovatory nature of the EMILIA project

-Engaged a socially excluded and multiply disadvantaged group – mental health service users.

-Consulted with service users on lifelong learning subjects resulting in training that was more meaningful for their lives.

-Developed a series of twelve lifelong learning training programmes designed in conjunction with mental health service users and housed on a free-to-access public website.

-Developed innovatory new roles for service users such as lifelong learning trainers, personal medicine coaches and assistant researchers.

-Developed a lifelong learning organisational implementation tool which identifies obstacles and solutions so as to enable organisations to become effective deliverers of lifelong learning to disadvantaged and socially excluded groups.

-Enabled universities and health care centres to realise the value of the experience and knowledge of mental health service users and to employ mental health service users to positively contribute to health care management and education.

Methods

Design

EMILIA consisted of 8 separate case studies with a 20 month follow-up within groups research design. Data collection took place on individual (strand 1) and organisational (strand 2) levels. The data were collected in eight demonstration sites: Paris, France; Tusla, Bosnia-Herzegovina; Sjalland, Denmark; London, UK; Athens, Greece; Warsaw, Poland; Barcelona, Spain; and Bodø, Norway at baseline (T0) and 20 month (T20) follow up point. These demonstration sites delivered the EMILIA intervention to participants.

Participants

Strand 1 of the research included a total of 212 mental health service users with a history of long-term mental illness, aged 18-64. The diagnostic inclusion criterion for the EMILIA participants was a diagnosis of schizophrenia F20 (ICD-10), schizoaffective disorder F25 (ICD-10) or bipolar disorder F30-F31 (ICD-10) and at least three years of using mental health services. The EMILIA intervention did not include people with a diagnosis of learning disabilities or dementia.
The participants of strand 2 of the research were the eight EMILIA European demonstration site learning organisations.

Intervention

The EMILIA project intervention consisted primarily of participation in learning modules specifically designed for the project. In addition to these modules, participants were provided with optional opportunities to have paid or voluntary employment.

Research Measures

The five stages of the operational research strategy were directly linked to the five operational elements of EU lifelong learning policy (COM, 2001c). These were measured using information collected through the Client Social-demographic and Service Receipt Inventory (CSSRI), the quality of life instrument SF-36-v2 and self reports and interviews from participants in strand 1 and with audits of the demonstration sites in strand 2.

Table 1. Five stages of the operational research strategy

Stage	Description	Implementation Indicator	Research measure / question
1	Partnership working across the learning spectrum	Number, frequency and quality of communication and teaching links between European team of mental health learning organisations	Audit: Quantity and quality of communications between the project's demonstration sites.
		Participation rate in work-based education and training	Audit: What courses are provided (internally/externally) to the staff?

		Proportion of work-based education offering open access	Audit: What training opportunities (excluding EMILIA training packages) were available in the past six months that were accessible to people with serious mental illness?
		Proportion of working week spent by mental health service staff on work-based learning	Audit: On average how many hours per week do staffs of the learning organisation spend in training?
2	Insight into demand for learning	Mental health service user questionnaire response	Self-report and key user interview: What do you want to achieve in the coming year?
3	Analysis, generation and development of adequate financial and learning resources for the task	Innovations in occupational role task analysis	Audit: Describe innovations in occupational role
4	Facilitating user access to learning and work opportunities	Problems and success factors in implementation survey	What were the problems, solutions employed and successes in implementing the project?
5	Striving for excellence through service improvement	Level of participation of service users in educational design and delivery	Audit
		Level of participation of service users in mental health service delivery system	Audit
		Service user income level pre and post project intervention	CSSRI
		Service user employment level pre and post project intervention	CSSRI
		Health related quality of life	SF-36-v2

The SF-36-v2 (Ware & Sherbourn, 1992) is the most widely used health related quality of life measure. The SF-36-v2 is a 36 question generic self-report measure of functional health and well-being, psychometrically-based physical and mental health, and preference-based mental and physical health (Ware, 2006). The SF-36-v2 is well established and has proven reliability and validity (Jenkinson, Stewart-Brown, Petersen, & Paice, 1999; Ware et al., 2000; Ware, 2006).

The Client Social-demographic and Service Receipt Inventory – EU version (Chisholm et al., 2000), which itself is an adaptation of the CSSRI (Beecham & Knapp, 1992), was developed as an instrument for international research.

Self reports and key user interviews: both the self-report and key informant service user interviews consisted of a series of ten open-ended questions. The answers to one of these questions: ‘What do you want to achieve over the coming year?’ will be examined in the present paper.
Audit: through a series of questions the audit aimed to monitor the implementation of the five stages of the European lifelong learning strategy in the eight EMILIA demonstration sites.
The ‘problems and successes factors in implementation survey’ consisted of seven consecutive surveys addressed to researchers, users and care professsionals at all sites in different phases of implementation with the aim of discovering descriptions of obstacles encountered in the implementation process and sharing information across sites on facilitators and solutions

Procedure

Representatives from the case study demonstration sites and participants taking part in the EMILIA intervention completed the strand 1 research measures before the intervention at baseline and at the 20 month follow-up point, when the intervention was completed.

Results

Stage 1 - Partnership working across the learning spectrum approach

Across all sites there was a reported increase in the quantity of communication between European teams of mental health learning organisations (phone calls, emails, and chatroom meetings). At both baseline and follow-up, communication was generally described as useful, helpful and productive. Qualitativement statements from demonstration sites provided detail on the usefulness, helpfulness and productive nature of the various forms of communication.

Influence of project on work-based education and training:
Continuous professional development was available for staff at all demonstration sites at baseline. Course topics included mental health promotion, legal aspects relating to mental health issues and fighting stigma. At follow-up, all sites except Bosnia reported additional courses directly related to the EMILIA intervention and henceforth integrated into the continuous development training programme.

Work-based education offering open access to service users:
At baseline three demonstration sites (Spain, Norway and Bosnia) stated that they did not provide training opportunities that were accessible to people with serious mental illness. However, at follow-up, all demonstration sites except Bosnia stated that they provided training opportunities that were accessible to people with serious mental illness.

Proportion of working week spent by mental health service staff on work-based learning:
Although the training offered had changed during the time span of EMILIA, no significant changes were observed in the number of hours spent in training between baseline and follow-up.

Stage 2 - Insight into Demand for Learning

EMILIA participant self-report and key user interview data:
The qualitative data collection from participants of the lifelong learning intervention consisted of service user self reports (baseline=165, T20=86) and key user interviews (baseline=27, T20=23). The percentage who mentioned learning in answer to the open-ended question: ‘What do you want to achieve in the coming year?’ increased from 20.7% at baseline to 24.4% at 20 month follow-up. Although this difference was not statistically significant, it must be underlined that the question asked was an open question: it purposefully did not specifically ask the user if he or she wanted to take part in formal learning in the coming year. So the figures do not reflect the plans of all of those who had the ambition to take part in formal learning, but instead record freely expressed learning ambitions. The desire to achieve learning-related goals came second only to the desire to achieve employment related goals.

The percentage of key users who mentioned learning in answer to the open-ended question: ‘What do you want to achieve in the coming year?’ was 48.3% at baseline and 39.1% at follow-up. However, there was a significant shift amongst key users towards the ambition of getting and holding employment: 27.6% at baseline to 43.5% at 20 month follow-up, raising the hypothesis that for certain users goals related to learning had been transferred to goals related to employment. This may have been because EMILIA had fulfilled some of their learning ambitions allowing them to shift their focus towards to ambitions related to obtaining work.

Innovations in occupational role task analysis:
All eight sites reported that new roles, jobs and activities had been created for mental health service users since the beginning of the EMILIA Project. See table 2 below.

Table 2: New roles, jobs and activities created for mental health service users since the beginning of the EMILIA Project

Demonstration site	**New roles, jobs and activities**
Bosnia	Trainers, driver, accountant, secretary
Denmark	Personal Medicine Coaches employed to provide advice and support to mental health service users
France	Administrative staff, assistant researchers, trainers
Greece	Assistant researchers
Norway	Two service user representatives are in a project group establishing an Assertive Community Treatment team. A user who is also a parent has been employed half-time to focus on the importance of children as relatives
Poland	Providing peer support
Spain	Experts Through Experience are employed to give help and support to newly hospitalized patients and their families using their own experience as mental health service users as the key tool to their work
UK	Teaching and assessment roles on the social work and nursing degrees

Innovations in occupational role task analysis:
Five out of the eight sites (Spain, UK, Bosnia, Greece, and France) listed new roles, jobs or activities created for mental health service users outside the learning organisation during the project. For example, in France, employment in a state vocational centre and, in Greece, voluntary roles on a geriatric hospital ward, in the hospital library and in running a hospital radio station.

Stage 4 - Facilitating user access to learning and work opportunities

Problems and Success Factors in Implementation Survey:
Seven surveys were conducted recording the implementation of stage 4 and these identified problems, solutions and success factors in implementing the project. The main result of this was the development of the 'Obstacles and Facilitators Checklist' tool for use in project implementation.

Stage 5 - Striving for excellence through service improvement

Demonstration sites were asked to rate how the EMILIA project had changed the level of participation of service users in design and delivery of training programmes, on a scale of 1 (unsatisfactory) to 7 (satisfactory). Results ranged from 3 (Poland) through to 7 (Bosnia, Spain, UK) see Table 3.

Table 3: EMILIA project and changes the level of participation of service users in educational design and delivery

Demonstration site	**How the implementation of the EMILIA project has changed the level of participation of service users in educational design and delivery on a scale of 1 (unsatisfactory) to 7 (satisfactory)**
Poland	3
Denmark	5
Norway	5
Spain	7
France	6
UK	7
Bosnia	7
Greece	4
Average for EMILIA demonstration sites	5.5

Demonstration sites were then asked what they would suggest for the improvement of the level of participation of service users in future educational actions. Sites systematically underlined the importance of integrating users into the decision-making process but also into training delivery from the very start.

Table 4: Recommendations for improving user participation in future educational actions

Poland
Promote education for service users in mental health services, make it as regular action
Implement this as part of mental health service staff programme of education
Collaborate with user associations
Denmark
Involve service users in high level administrative and political processes. For example, user-representatives should be present at all meetings regarding staff, finances and organisational issues.
Norway
Involve the users from the first minute in all work.
Spain
Get the users on board from the very start.

France
Train more users to do EMILIA training
Train users in a greater variety of skills appropriate for different training themes
Get management on board in a more systematic way
UK
Involve service users as early as possible in any new educational projects, i.e. from planning stage onwards
Involve service users at all levels of any educational project: planning, design, accreditation, teaching, assessment, student feedback, student support, etc.
Engage with all parties early on to resolve issues related to payments, income, tax and benefits
Greece
Engage service users as trainers
Being able to pay user trainers
Train users on empowerment methods
Bosnia
Provide users with the opportunity to be actively involved in planning and delivery of education
Develop a strong level of cooperation with inpatient services
Transfer valuable knowledge gained through EMILIA to service user groups across Europe

Service user income level before and after the EMILIA intervention:

A total of 72 participants provided data on their net income at baseline and 20 month follow-up. T-test results revealed a significant increase in income from baseline (M=€760.64, SD=509.63) to the 20 month follow-up point (M=€865.03, SD=575.82), t(71)=-2.42, p=.018 (two-tailed). The mean increase in income scores was €104.39 with a 95% confidence interval ranging from -190.43 to -18.35. The eta squared statistic (.08) indicated a moderate effect size. The average increase in net income from baseline to 20 months was 19%. The total Euro Zone inflation for the 2008-2009 period was 3.51%, indicating a real-world increase of over 15% in net income.

Self-perceived health and quality of life status:

Information was available from 97 participants at both baseline and 20 month follow-up concerning mental and physical health-related quality of life. SF-36-v2 mental health related quality of life scores rose by .65 (with a 95% confidence interval ranging from -2.74 to 1.44) from baseline (M=33.93, SD=7.39) to the 20 month follow-up point (M=34.58, SD=8.1), but this difference was not statistically significant: t(96)=-.61, p=.54 (two-tailed T-test). Concerning SF-36-v2 physical health related quality of life, T-test results revealed that there was a very small non-significant decrease from baseline (M=48.81, SD=10.82) to the 20 month follow-up point (M=48.41, SD=11.54), t(96)=-.42, p=.68 (two-tailed). The mean decrease in SF-36-v2 physical health related quality of life was .4 with a 95% confidence interval ranging from -1.49 to 2.29.

Service user employment level pre and post project intervention:

Sixty-nine participants provided data on employment status at baseline and 20 month follow-up, 6 (7.1%) reported being in competitive paid employment at baseline and 12 (14.3%) at 20 month follow-up. This increase in the numbers in competitive paid employment was not significant (p=.51) using the McNemar test.

Discussion

The results indicate possible positive effects of the project at both an individual and organisation level. At an individual level participants experienced an increase in factors related to social inclusion and at an organisational level the organisations involved demonstrated an increase in open access to training and employment, and innovations in employment roles.

An important element of the European Union's lifelong learning strategy is concerned with the building and working of partnerships. This study's findings show that the EMILIA project may have made a contribution to partnership working across a wide range of the project's operational activities and, by extension, to this strategic element of the European Union's lifelong learning policy agenda. The use of information and communication technologies involving mental health academics, practitioners and mental health service users has helped to build and develop cohesion and cross-cultural understanding, and to foster professional relationships within and outside the EMILIA consortium. This outcome has contributed to the European Union wider vision of developing social inclusion (see, for example: COM, 2008).

In connection with partnership working, results show that at baseline only three of the sites provided open access for work-based education, whilst all sites did so at the follow up point. A implication for lifelong learning policy here would be that services or institutions working with disenfranchised groups such as people with long term mental health difficulties should consider opening up their staff continuous development training programmes to their client population.

The results also show that a contribution may have been made to the second critical bedrock for lifelong learning: Insight into the demand for learning. The EMILIA project's lifelong learning training intervention was demand-led: it was explored, designed and developed with the active involvement of the mental health service users themselves, the primary target group. Service users were co-trainers and were involved in delivering the training modules. Such an innovative, demand-led and needs-addressed approach has brought a new set of learners to lifelong learning and has contributed to the European Union agenda on widening access and participation in education and training (see COM, 2003). This success is in all likelihood largely due to the collaborative, participatory process through which the learning needs agenda was co-developed through a partnership approach with the service users themselves. The training received by the participants has led to a demand for new learning as evidenced by a high proportion of service users who expressed a desire to achieve learning related goals at follow-up.

The findings may also contribute to the third strategic element in the policy framework of lifelong learning – Adequate resourcing and judicious deployment, use and allocation of human and financial resources. The indicator here did not refer to the lifelong learning programmes themselves, but to the consequences of these in terms of more meaningful and socially inclusive roles and tasks for the participants. It is clear that the demonstration sites were successful in developing, either inside or outside of their own organisational systems, a variety of innovatory new roles, both paid and voluntary. For example, UK users were employed in a variety of teaching roles within a university department of Mental Health and Social Work. In both London and Paris, users participated in research projects and audits of local services. Many also undertook additional voluntary work in local user groups.

Stage 4: Facilitating user access to learning and work opportunities, involved cross-European analysis on four levels: individual, microsocial, institutional and macrosocial and this analysis revealed problems, solutions and success factors. One of the fruitful outcomes was the development of the EMILIA Obstacles and Facilitators Checklist. This tool, initially conceived of as a simple checklist to be used by learning organisations as sites begin implementation, was considerably extended throughout implementation to include obstacles and facilitators encountered by individual sites during projects, thus allowing sharing of solutions and facilitating success across all sites.

Stage 5: Striving for excellence, is concerned with establishing and embedding credible quality assurance mechanisms in lifelong learning provision. In the EMILIA project, measures were used to examine the quality and effectiveness of the training outcome. The results indicate, for example, greater numbers of service users in open, competitive employment; although this increase was not statistically significant. Also, the findings indicate an increase in disposable income. Although there was virtually no change in health-related quality of life this is a somewhat positive result, as health-related quality of life would be expected to decline over time in this participant group. The results provide some support for findings in early studies that demonstrate a link between recovery and lifelong learning (Lanham et al, 1997; Griffiths & Ryan, 2008). Of more strategic importance, the findings show that EMILIA may have contributed to the broader economic and social dimensions of the Lisbon strategy.

The future social policy agenda can be further improved by taking into account the findings of the EMILIA project. There will continue to be a need for creation of opportunities for employment and social inclusion for socially excluded groups. There is also a need to ensure and facilitate potential individual progression in these opportunities and onto other opportunities – linking to individual and societal goals and competiveness. There will continue to be a need for provision of access. When individuals have gained access, consideration should to be given to the needs of these individuals in order to support them to make the most of their opportunities.

The EMILIA project demonstrated ways to encourage access and to support disadvantaged individuals once access is gained so that they can realise their full potential through lifelong learning. In reference to the Social Agenda (COM, 2008) ‘demonstrating solidarity,’ there will continue to be a need to fight poverty and social exclusion and enable adaptation to change. EMILIA has shown that it may be possible to do this by facilitating a sense of social cohesion through developing lifelong learning collaborations and networks amongst lifelong learning students and supportive organisations. Lifelong learning programmes facilitate and encourage the development of the strengths of individuals and this can benefit the future social agenda through the application of these individual strengths within society.

The EMILIA project represented a major attempt to systematically review each of the five stages of the European lifelong learning policy (COM, 2001a). The policy as stated made no suggestions as to how its implementation might be measured, or what indicators might be particularly appropriate. The development of such indicators in the EMILIA project is in itself innovatory and represents the first attempt to monitor European lifelong learning policy using this methodology. Inevitably, some indicators worked better than others and future projects can hopefully learn from the EMILIA project experience in their improvement.

Conclusion and recommendations

The wide range of research and intervention themes covered in the EMILIA project has underlined the role of lifelong learning as a driver for the economic dimension of the Lisbon strategy, and as key to achieving its social dimension in terms of enhancing the social inclusion of disadvantaged groups such as people experiencing long term mental health illness. These findings give rise to a number of recommendations which are particularly important as the European Union devises a new strategy for sustainable growth and employment for the period beyond 2010 – known as the EU 2020 Strategy. Main recommendations from this project include:

-Promoting lifelong learning and employment opportunities for service users to facilitate social inclusion.

-Support at the European and national level the adaptation of currently existing lifelong learning policies and strategies to ensure that on a permanent basis they take on board the specific strategies necessary to engage with the variety of socially excluded groups in the EU.

-Support the need for a universal assumption of a return, following illness, to full participation in society, defined on an individual basis, including participation in learning and employment.

-Actively promoting the employment of mental health service users through appropriate awareness and skills training.

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End of Volume 1

IJPR Volume 15, Number 2

July 2010 - June 2011

Feature Articles

Page

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IJPR Feature Articles

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Family Burden and Rehabilitation Need of beneficiaries of a Rural Mental Health Camp in a Southern state of India

Prafulla S
Research Assistant, Dept. of Psychiatry, National Institute of Mental Health & Neuro Sciences, Bangalore

Suman K Murthy
Reader & HOD, Dept. of Studies in Social Work, Pooja Bhagavat Memorial Mahajana PostGraduate Center, Mysore

Dharitri Ramaprasad
Professor, The Richmond Fellowship Postgraduate College for Psychosocial Rehabilitation, Bangalore

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Correspondence
Dharitri Ramaprasad
The Richmond Fellowship Post Graduate College for Psychosocial Rehabilitation
"Chetana", #40-1/4, 6th Cross, Vjpeyam Garden,
Ashoknagar, Banashankari I stage,
Bangalore-560 050
E-mail: dharitri_r@yahoo.co.in

Abstract

Family care is the predominant type of care in India. The concern of the parents and significant family members led to their involvement in rehabilitation of the affected persons. Chronic mentally ill population is a diverse group comprising of the patients with different problems of varying degree of disability and different levels and types of needs. Assessing the rehabilitation needs and the burden of care faced by the families is an important component constituent of planning effective mental health services. The present study aims at assessing the burden faced by the families and the needs for rehabilitation among the beneficiaries of a rural mental health camp in South India. Using the Interview Schedule for the Assessment of Family Burden and Rehabilitation Needs Assessment Schedule, 50 care givers were interviewed. The results indicated mild to moderate objective burden experienced by the families. All respondents had some need or the other pertaining to the rehabilitation of the ill family member.

Key Words: Rehabilitation Need, Family Burden, Chronic Mental Illness, Psychosocial Rehabilitation.

Introduction:

Community mental health movement in India began about two decades ago, especially the rural programs. Involving the community in the developmental activities, especially in the health sectors was given prime importance. This gave impetus to various rural mental health programs. More than 70 percent of the 960 million people in India live in rural areas. There are more than half a million villages of differing population sizes. Majority of these villages have problems of communication and have limited regular access to basic needs like sanitation and water supply (Reddy, et al, 1986). One of the studies in a rural area reports that 90% of the persons with schizophrenia and epilepsy were ill for more than one year at the point of contact (Murthy, R S, 1986).

Similar findings have been reported from the rural areas of other states in India (Wig et al, 1981; Kapur, et al, 1978). Almost all of them had sought help from locally available traditional healers (Murthy, 1987, Kapur, et al, 1975) and a few had contacted modern medical services. Later systematic studies of mentally ill in the rural areas show that problems of transport, cost of treatment, lack of awareness of the available help and wrong beliefs in supernatural causation had been the main reasons for the large majority of the mentally ill persons to “suffer in silence” (Murthy, 1987).

Based on the results of experiments in integrating mental health care with general health care system the National Mental Health Program was formulated. This program has stimulated initiatives for mental health care among professionals, nongovernmental organizations, and citizens using a variety of community based care programs (Murthy, 1998).

Despite the best intentions and governmental programs, it has to be noted with concern that majority of Indian population still do not have access to mental health care. The responsibility for providing care lies with the families. The families as caregivers take the burden of care. Therefore, they have to be provided with effective rehabilitation services for the ill person, which would ease the burden faced by the families and help the patient lead a more productive life.

Burden refers to the presence of problems, difficulties or adverse events which affect the lives of individuals who are primary care givers. The shift from hospital based care to community based care has resulted in emotional and financial burden and this affects the lives of other members in the family.

In India 80% of the mentally ill live with their families, and only 5 to 10 percent receive professional psychiatric care. As majority of India’s population lives in remote rural areas, about 75 percent of families who care for their mentally ill kin have little or no access to medical facilities. Families in this situation live under constant stress of societal stigma and the challenge of providing high cost 24 hours care (Murthy, 1980).

In one of the studies Nautiyal (1993) found 65% of the study sample reported mild to moderate degree of objective burden and 60% reported severe subjective distress. Negative orientation towards outcome of mental illness was associated with objective burden. In her study financial difficulties were perceived as most burdensome.

Although families have traditionally been the caregivers for mentally ill persons, this situation is changing, creating a need for more structured interventions with families. The concern of the parents and significant other family members has led to their involvement in rehabilitation of the affected persons. The rehabilitation processes have to be flexible and contingent upon the changing needs of the patient over a period of time. This makes it necessary to carefully study the needs of the patients and plan the interventions based on these needs. Nagaswamy., et al (1985) found varied needs expressed by the families in their study of subjective rehabilitation needs. The needs were in the area of employment, vocational training, accommodation, help for family and leisure time activities. Other studies (Padmavathi., et al, 1998; Banerjee and Roy., 1998; Naik., et al, 1996) have reported strong need for public education and awareness programs for developing awareness about the nature of mental illnesses and their treatment. This would facilitate seeking early treatment and reduce chronicity.

This highlights the importance of understanding the needs of the families and the burden faced by them to plan effective Mental Health Programs as well as psychosocial rehabilitation services.

Objectives

1. To assess the burden faced by the families of the beneficiaries of the rural mental health camp.
2. To assess the need for rehabilitation of the beneficiaries of the rural mental health camp.

Methodology

It is an explorative and a descriptive study. The sample was drawn from the beneficiaries of rural mental health camp conducted by 'Pragati', RFS(I) Sidlaghatta branch, in a rural area of Karnataka. 50 respondents were selected using systematic random sampling technique from the list of beneficiaries of the camp. Persons with mental retardation, epilepsy, minor mental illness and major physical illness were excluded from the study.

Tools used

1. Socio-demographic data sheet.
2. The Interview Schedule for the Assessment of Family Burden by Pai and kapur (1981). This interview schedule has 26 items to assess burden in seven categories of Objective Burden and 1 item on Subjective Burden. The seven categories of objective burden are; Financial burden, Disruption of routine family activities, Disruption of family leisure, Disruption of family interaction, Effect on physical health of others, Effect on mental health of others, Other burden.
3. Rehabilitation Needs Assessment Schedule by Nagaswami., et al (1985). This assessment schedule is designed to collect purely qualitative information on the subjective rehabilitation needs. The questions are open ended and cover the following areas: Employment, Vocational training/guidance, Accommodation, Leisure time activities, psychological attitude modification, Skills training, Any help needed by the family, Any other area.

Caregivers in the families were interviewed using the above mentioned tools.

Results and Discussion

The present study aimed at assessing the burden faced by families of chronic mentally ill persons and their need for rehabilitation in a rural mental health camp.

Family Burden

Most of the caregivers (60%) were in the age range of 45 yrs. to 65 yrs. Others (40%) were in the age range of 25 yrs. to 45 yrs. Majority of the caregivers of the patients were parents (44%). 50% of the caregivers were illiterates. 60% of the caregivers were women and 40% were men. Female patients were deserted by the spouses and had to be taken care by the parents, whereas married men who had the illness were looked after by their wives. 72% of the patients had a diagnosis of schizophrenia, 16% were diagnosed as having bipolar affective disorder and 12% had psychosis.

The scores on burden scale show that the families faced mild to moderate burden in taking care of their mentally ill family member. The mean score of subjective burden score was 1.2 which shows moderate burden. The highest burden was experienced due to disruption of family activities. The ill member not attending to their routine activities like work, school/college and also not helping in the household chores but needing to be helped had caused disruption of the normal activities. Caregivers had to spend considerable amount of time attending to the ill member at the cost of their essential routine work/duties. This also results in neglect of the needs of other family members.

Table 1. Scores on the Family Burden Scale

Domain	**N**	**Mean**	**S D**
Financial Burden	50	1.2	0.50
Disruption of family activities	50	1.4	0.51
Disruption of family leisure	50	1.0	0.04
Disruption of family interaction	50	1.1	0.52
Effect on physical health of others	50	1.0	0.67
Effect on mental health of others	50	1.0	0.72
Subjective Burden	50	1.2	0.50

Another study comparing family burden among rural and urban population (Rao, 1988) reports that urban families experienced greater burden than rural families due to disruption of family activities in the sample of their study. Caregiver burden was found to increase when the ill person's disability was more.

Financial Burden was the second most highly reported burden faced by the families. The experienced financial burden was due to varied reasons. Significant of these were loss of ill member's income as a result of loss of job due to illness, loss of income of other member of the family (family member had to stop working in order to stay at home with the ill member) and the cost of treatment including cost of transportation to the treatment center. This was compounded by the expenditure made on transport, faith healing, visiting temples etc. There were some who reported that they had borrowed money for the treatment purpose. Most of the families in the study lived a lower middle class life. Gautham and Nijhawan (1984) reported similar results specifying that families of persons suffering from schizophrenia face more financial burden.

All other domain scores, i.e. Disruption of family interaction, disruption of family leisure, effect on physical health of others and mental health of others showed a mean score of 1.1 and 1.0 which indicates moderate burden. Though all these areas did affect the daily activities of the family, they did not perceive it as severe burden.

Rehabilitation Needs

Needs were expressed in almost all the rehabilitation domains (Table 2). Most of the families expressed needs in the areas of 'Help for the family' (78%), 'Employment and Occupation' (76%), Psychosocial attitude modification' (68%), 'Skills training' (66%). Nagaswami, et al, (1985) in their study on an Indian population from a different state, report similar results.

Table 2. Scores on Rehabilitation Needs Domains

Need Domains	**N**	**%**
Occupation and Employment	38	76
Accommodation	7	14
Attitude modification	37	68
Leisure activity	17	34
Skills training	33	66
Help for family	39	78
Other area of help for ill persons	33	66

Families expressed need for financial support, help in finding employment for other members in the family, educating younger members in the family and access to treatment services, medical as well as psychiatric treatment. This is in keeping with the burden experienced by the families.

There is a dire need for help in finding occupation and employment. In the present study 26% of the families wanted vocational guidance and help in finding an employment for the ill person in recovery. 26% of them preferred part time open employment options and only 12% expressed need for full time employment. 24% of them were particular about sheltered employment options either full time or part time, as suitable. Hansson et al (1995) assessed the needs on psychiatric patients using the Camberwell Assessment of Needs (CAN) tool. They found duration of illness being associated with the pattern of needs. Participants with longer duration of illness (>4 years) more often had need in the area of employment, daily activity and accommodation.

Family members were concerned about the attitude of relatives, friends and neighbours towards the ill person and the family. They reduced socializing with the ill person as well as the family since the onset of the illness. The families felt stigmatized as others in the community and society harboured negative attitude towards them. In the present study 68% of the families expressed the need to change/modify people's attitude towards mental illness and those suffering from mental illness. The rural population has little knowledge regarding mental illness which needs to be addressed. Negative attitude towards mental illness has been reported in many studies (Raguram et al, 1996; Thara and Srinivasan, 2000; Raguram et al, 2004; Thara et al, 2003a,b).

Another domain of felt need was Skills training (66%). The training required was in the area of activities of daily living and personal care, social skills (communication and interpersonal relations), and problem solving skills. The Skills training is an important component of psychosocial rehabilitation program. Many studies (MacCarthy., et al, 1989; Murray., et al, 1996; Ralston., et al, 1998; Ochao., et al, 2003) have reported need for Skills training in areas of personal and domestic tasks like personal care, housekeeping, budgeting, communication and social interaction and relationship.

As for the need to have a structured leisure time activity very few of the families felt the need for any specific help. Most of them were satisfied with the way leisure time was spent i.e. listening to radio, and watching television except 14% of them who expressed specific need to be addressed. Types of leisure activities desired were physical exercise and outdoor games, indoor games, and organized group activities. Gandotra., et al. (2004) studied the rehabilitation needs of in-patients and outpatients with schizophrenia. They found majority of the outpatients had some need in the area of leisure time activities.

It was interesting to note that accommodation was not seen as a major need by most of the families. Most of the families were happy about the existing living arrangement. Only 14% of them expressed accommodation as a need to be looked into. The need was in terms of alternative arrangement like hospitals, institution or a residential facility in the community. Nagaswami., et al (1985) also found only 6.8% of the ill members and families indicating need for accommodation. This is unlike other countries where accommodation is a major concern (Winefield and Hearvey,, 1994; Hansson., et al, 1995). These studies also report that patients, whom the caregivers preferred that they live in supervised accommodation, were described as less skilled in self-care and communication and more turbulent, while those whom the caregivers preferred that they live with them were more responsible.

Conclusions

The present study aimed at understanding the burden of care and the rehabilitation needs of families of persons with chronic mental illness in a rural population. Majority of the respondents expressed mild to moderate burden in various domains. Highest burden was perceived in the domain ‘disruption of family activities’ followed by ‘Financial burden’. As for the rehabilitation needs, all the respondents expressed needs in one area or the other. Majority of the respondents felt a need for some help for the family which included easy access to treatment, financial support, and other basic facility for other members. Other major need expressed was employment, occupation and attitude change.

These findings bring attention to the immediate urgent need to develop comprehensive mental health programs for the rural population. This should include both public education activities as well as organizing treatment facilities which are easily accessible, and cost effective in the rural areas of India.

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Met and Unmet Needs of Persons with Severe Mental Illness in a Half Way Home

Kamlesh Kumar Sahu, M.A, M.Phil. PSW
Programme Coordinator
Paripurnata (centre for Psychosocial Rehabilitation)
Former Lecturer, RFPG College for PSR, Bangalore, India
1912, Panchasayar Road
P.O Panchasayar, Kolkata – 700094 (India)
Web: www.paripurnata.org

Sophia C. A., M.A, M.Phil. M&SP
Former Lecturer, RFPG College for PSR, Bangalore, India

Dharitri R., M.A., D M&SP, Ph.D
Professor, RFPG College for PSR, Bangalore, India

Kalyanasundaram S., M.D.
Professor of Psychiatry & Principal, RFPG College for PSR, Bangalore, India
Richmond Fellowship PG College for Psychosocial Rehabilitation
'Chetana' No. 40 – 1/4, 6th Cross, Vajpeyam Gardens
Ashoknagar, Banashankari, 1st Stage, Bangalore – 560050 (India)
Web: www.rfpgcol.com

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Correspondence:
Kamlesh Kumar Sahu
265/4/1 Gopal Lal Tagore Road,
Baranagore Kolkata – 700036 (India)
Email: withkamlesh@gmail.com

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Abstract

Assessment of needs of persons with mental illness is an essential task of the mental health professionals in order to plan, develop and evaluate mental health services. This in turn will help to achieve, maintain or restore an acceptable or optimal level of social independence or quality of life. The persons with severe mental illness constitute an incredibly diverse population, numbering in millions, shares needs unique to themselves in the areas of clinical intervention, environmental support and rehabilitation. The accurate assessment of the individual's needs has been the focus of increasing discussion in mental health service delivery and evaluation (Issakidis C, Teesson M. 1999). The present study was undertaken with the objective to identify the met and unmet needs of persons with severe mental illness in a half way home. Thirty persons with severe mental illness from "Asha" Half Way Home run by Richmond Fellowship Society, Bangalore, India were assessed cross-sectionally by using the 'Camberwell Assessment of Need'. Results: The unmet needs were less than the met needs of residents of half way home which indicates residential setting like half way home has very important role in fulfilling the needs of the persons with severe mental illness.

Key words: Met and Unmet Needs, Mental Illness, Need Assessments

Introduction:

Assessment of needs of persons with mental illness is an essential task of the mental health professionals (Issakidis C, Teesson M. 1999) in order to plan, develop and evaluate mental health services. It is essential to understand this in order to enable them to achieve, maintain or restore an acceptable or optimal level of social independence or quality of life. The persons with severe mental illness constitute an incredibly diverse population, numbering in millions, shares needs unique to themselves in the areas of treatment, rehabilitation and environmental support. In recent years these areas of the mental health system are given more importance in order to give proper care to the patients by assessing their needs.

The needs of all humans include basic survival needs (food, clothing, housing, transportation, financial resources, and personal safety); health care needs (mental health care, physical health care including dental care); and social-connectedness needs (friends, a group to belong to, a role in life, and a meaning or purpose in life). Needs are cantilevered rather than hierarchical with each need supporting all other needs. One unmet need that adversely affects all needs is the ability to adapt to stressors, and achievement of well-being (Hansell, 1976). According to Abraham Maslow (1985), the individuals' whole life – perceptions, values, strivings and goals, is focused on the satisfaction of a set of four needs, which are arranged in a hierarchy. They are physiological needs for food, water, sex and sleep in the lower level. One step above these are safety needs for feeling safe and secure in ones life. In next level, these are social needs for love and belongingness, appreciation to fit in to a network of social relationship. Above all these needs, there are the esteem needs to develop self- respect, gain the approval of others and achieve success. At top of the hierarchy are self- actualization needs to become concerned not only concerning one's selfish interest but also with issues that affect the well - being of others. He points out that, the higher level needs cannot be activated, until lower level needs have been satisfied.

Harry Stack Sullivan (1985) defines 'needs' as 'needs for satisfaction' and 'needs for security'. The need for satisfaction includes physical needs- air, water, food, warmth. Emotional needs to be secured include needs for human contact and

expressing ones talents and capacities. Here, interpersonal relationships are of central concern, which leads to tender responses to human needs. According to him failure to meet these needs result in loneliness and anxiety.
Although the concept of need is used internationally, there is no consensus about the precise meaning of the term. Psychological theories have employed concepts of need as a basis for understanding action, such as Maslow's hierarchy of needs (Maslow, 1985). Psychiatrists; by contrast, use measurement of need to inform service provision.

In Britain the Inspectorate and community Care Act (1990) defines needs as "the requirements of individuals to enable them to achieve, maintain, or restore an acceptable level of social independence or quality of life" (Department of Health social services Inspectorate, 1991). This definition equates need with level of social functioning. Thus need arises as a result of social disablement, which occurs when a person experiences lowered psychological, social and physical functioning in comparison with the norms of society (Wing, 1986).

An objective of need assessment is to help those persons with mental illness to communicate clearly about their difficulties. The mental health professionals are concerned with assessing the persons' unmet needs that are sufficiently serious to merit interventions by service. For care- givers, assessment is an opportunity both to act as advocates for the mentally ill people and to help them access support and respite services themselves. The other purpose of assessment of needs is to make various social and political concerns aware of the plight of the mentally ill people and initiate them to take the necessary steps to improve their quality of life.

Several studies have been done with the aim of assessing the needs of the persons with mental illness. Assessment of 'felt needs' forms an important constituent in the planning of mental health services (Wig & Srinivasamurthy, 1981). This would suggest that the first step towards programme planning and delivery of after-care services would be the proper evaluation of subjective needs. Assessment helps persons with mental illness to communicate clearly about their difficulties. The mental health professionals are concerned with assessing the person's unmet needs that are sufficiently serious to merit interventions by service. For the care-givers, the assessment is an opportunity both to act as advocates for the persons with mental illness and to help them access support and services, themselves. The other purpose of assessment of rehabilitation needs is to make various social and political concerns aware of about needs of the persons with mental illness and encourage them to take necessary steps to improve their quality of life. Needs assessment may strengthen the therapeutic alliance, improve our understanding of priority needs and aid in service development. There are few attempts in India to assess the needs in severe mental disorder. Work is required to ensure that care is targeted explicitly towards unmet need.

Objectives

The present study is intended with the objectives to identify the presence of needs of persons with mental illness living in a Half Way Home setting within a range of domains addressing the following; basic, health, social, functioning and service issues; and to assess the informal and formal help currently being given and to assess the formal help needed.

Materials and Methods Used

This study was conducted in 'Asha' Half Way Home run by Richmond Fellowship Society, Bangalore, India. Every consecutive resident (persons with mental illness) with above 18 years of age from either sex were approached to participate in the study. Those who had not given consent, or presented with sensory/neurological disorders or with any chronic physical illness were excluded. Sample consists of 30 consecutive persons (residents) with Severe Mental Disorder (schizophrenia or bipolar affective disorder) according to International Classification of Diseases – 10 (ICD-10; WHO, 1992). Relevant socio-demographic and clinical data collected through the specially designed data sheet. To rule out the psychiatric morbidity, General Health Questionnaire-5 (Shamsundar et al, 1986) was administered on staffs (who were identified as a Key Support Provider (KSP) for the respective resident), and those who scored 1 or more on GHQ-5 was excluded. Met and unmet needs of the residents were cross sectionally assessed with help of KSP using 'The Camberwell Assessment of Need – Research' (CAN-R; Phelan and Slade, 1995). CAN-R is intended for research use which assess needs in 22 health and social domains: accommodation, food, looking after the home, self care, daytime activities, physical health, psychotic symptoms, information, psychological distress, safety to self, safety to others, alcohol, drugs, company, intimate relationships, sexual expression, childcare, basic education, telephone, transport, money and benefits. The last domain benefit was not used for this study since it was found not appropriate for this study. For each domain, the goal was to identify whether the service user has any difficulties, and if they do then to establish what level of help they needed and how much they were actually getting it, and whether they are getting the right type of help. All were items coded in the same way. First, the KSP interviewed whether a particular need is present for a particular resident, and if present whether it is met (resulting in a score of 1) or unmet (score of 2). If there is no need (score of 0), the interviewer proceeds to the next item. If there is a need, the respondent is asked for information on the levels of help received from family and friends, help received from formal services and help needed from formal services (help levels are each rated as 0, no help; 1, low level of help; 2, medium level of help; 3, high level of help).

Results and Discussion

Data collected was analyzed using statistical package for social sciences (SPSS) for windows version 10.0. Descriptive statistics were used and the frequency tables were made, results can be discussed under the following headings:-

Socio-demographic Characteristics of the Residents:
The mean age of residents was 36.50 ± 8.11. Males 19 (63.3%) were comparatively more than females 11 (36.7%). Mean years of education was 13.87 ± 2.21. Majority of the residents were Hindus (76.7%), in comparison to Christians (13.3%) and Muslims (3.3%). All residents belong to general category. Majority of the residents (70%) were unmarried 13.3%, were married and 16.7% were widow/widower. With regard to area of residence, 80% were from urban background, 16.7% from semi-urban and 3.3% were from rural areas. Majority of the residents (60%) were unemployed, 13.3% were students, home makers, and business persons each 3.3%, and 20% other category. Al most all (96.7%) of the residents were having monthly family income above Rs.10000 except one resident (3.3%) having less then Rs. 10000 monthly. Majority (93.3%) of the residents belonged to nuclear family and only 6.7% belonged to joint family.

Clinical Profile of the Residents:

Majority (76.7%) of the residents were diagnosed as suffering from with schizophrenia and 23.3% were with other disorders. Mean age of onset of illness of residents was 22.07 ± 6.50 years. Residents having mean duration of illness (in years) were 14.93 ± 7.06. Number of hospitalization (in last one year) was 00.73 ± .94. Mean duration of treatment was same as illness duration and it shows that these persons with mental illness received treatment since the onset of illness. It could be due to the influence of their back ground most of them from upper or upper middle urban families with good educational background.

Met and unmet Needs of the Residents:

From Table 1 Findings reveals that there was moderate or better agreement for met needs in all 21 domains of needs assessed. The range of unmet needs (12.54%) identified in important need-domains were less than met needs (29.37%). The areas in which highest proportion of met needs were basic needs (61.1%); which includes; accommodation (70%), food (66.7%), and daytime activities (46.7%) followed by service needs (38.89 %) which includes; telephone (56.7%), information (43.3 %) and transport (16.7%). Besides meeting any person's basic needs such as adequate family support, socialization, work, housing and nutrition; providing psychiatric and medical care are also indispensable for better functioning and minimal quality of life of the severely mentally ill (Issakidis C, Teesson M. 1999).

Table 1. Met and unmet Needs of the residents {frequency (%)}

Different Domains of Needs	Met	Unmet	No Need	Unknown
Basic	55 (61.1)	10 (11.1)	25 (27.8)	00

1. Accommodation	21 (70.0)	03 (10.0)	06 (20.0)	00
2. Food	20 (66.7)	01 (03.3)	09 (30.0)	00
3. Daytime activities	14 (46.7)	06 (20.0)	10 (10.30)	00
Health	41 (19.5)	23 (11.0)	146 (69.5)	00
4. Physical health	04 (13.3)	02 (06.7)	24 (80.0)	00
5. Psychotic symptoms	13 (43.3)	12 (40.0)	05 (16.7)	00
6. Psychological distress	14 (46.7)	07 (23.3)	09 (30.0)	00
7. Safety to others	04 (13.3)	01 (03.3)	25 (83.3)	00
8. Safety to self	05 (16.7)	01 (03.3)	24 (80.0)	00
9. Alcohol	00	00	30 (100.0)	00
10. Drugs	01(03.3)	00	29 (96.7)	00
Social	24 (26.6)	22 (24.5)	22 (24.5)	22 (24.5)
11. Company	12 (40.0)	11 (36.7)	07 (23.3)	00
12. Intimate relationships	09 (30.0)	09 (30.0)	09 (30.0)	03 (10.0)
13. Sexual expression	03 (10.0)	02 (06.7)	06 (20.0)	19 (63.3)
Functioning	30 (20.0)	14 (9.3)	105 (70.0)	01 (0.7)
14. Looking after the home	17 (56.7)	06 (20.0)	07 (23.3)	00
15. Self care	10 (33.3)	04 (13.3)	15 (50.0)	01 (3.3)
16. Childcare	00	01 (3.3)	29 (96.7)	00
17. Basic education	00	01 (3.3)	29 (96.7)	00
18. Money	3 (10)	2 (6.7)	25 (83.3)	00
Service	35 (38.89)	10 (11.11)	43 (47.78)	02 (2.224)
19. Information	13 (43.3)	4 (13.3)	13 (43.3)	00
20. Telephone	17 (56.7)	1 (3.3)	12 (40.0)	00
21. Transport	5 (16.7)	5 (16.7)	18 (60.0)	02 (6.7)
Total (%)	185 (29.37)	79 (12.54)	340 (53.97)	25 (3.96)

The residents' most frequently identified four unmet needs were ‘psychotic symptoms’ (40%), ‘company’ (36%), ‘intimate relationships’ (30%), ‘psychological distress’ (23.3%) and ‘day time activities’& ‘looking after the home’ (20%).The staff generally had a good knowledge concerning the residents' need for care but they not know about the sexual expression/problem of 63.3% of residents or it could be because the residents do not disclosed it. Most of the residents were unmarried (70%) and (16.7%) were widow/widower and even married people are living separately; and as a result of this they perhaps had some unmet sexual needs. However the socio-cultural background from where they come from might be one of the important factors which made them unable to express about sexual needs/problems.

Informal or Formal Care Receipt and Formal Care Needs of the Residents:

From (Table 4) The findings indicate that the residents’ required high help from formal care services in the areas of basic needs such as accommodation and food (70%) followed by the service need in areas of information (45%). They need high formal care in social needs like company (40%) and intimate relationships (40%). Health needs like psychological distress (40%) and psychotic symptoms (30%) of the residents were also found high. In functioning needs such as looking after the home (50%), self care 35% and 30% residents' needs high help from formal care services.

Table 4 Informal or Formal Care Receipt and Formal Care Needs of the Residents {frequency (%)}

Needs domains	Informal Care Receipt				Formal Care Receipt				Formal Care Need			
	No	Low	Moderate	High	No	Low	Moderate	High	No	Low	Moderate	High
Basic												
Accommodation	14 (46.3)	5 (16.7)	5 (16.3)	0	0	0	12 (40.0)	12 (40.0)	0	1 (3.3)	7 (23.3)	16 (53.3)
Food	13 (43.3)	5 (16.7)	3 (10.0)	0	0	0	5 (16.7)	16 (53.3)	0	1 (3.3)	5 (16.7)	15 (50.0)
Daytime activities	7 (23.3)	6 (20)	5 (16.7)	2 (6.7)	0	1 (3.3)	5 (16.7)	14 (46.3)	0	1 (3.3)	7 (23.3)	12 (40.0)
Health					0				0			
Physical health	3 (10.0)	2 (6.7)	1(3.3)	0	0	1 (3.3)	4 (13.3)	1 (3.3)	0	1 (3.3)	2 (6.7)	3 (10.0)
Psychotic symptoms	4 (13.3)	6 (20.0)	14 (46.3)	1 (3.3)	1(3.3)	3 (10)	8 (26.7)	13 (43.3	0	0	14 (46.3	11 (36.7)
Psychological distress	5 (16.7)	3 (10.0)	10 (33.3)	3 (10.)	0	1 (3.3)	13 (43.3)	7 (23.3)	0	0	15 (50.0)	6 (20)
Safety to others	0	1 (3.3)	3 (10.0)	1 (3.3)	0	0	3(10.0)	2 (6.7)	0	3 (10.0)	2 (6.7)	0
Safety to self	1 (3.3)	0	5 (16.7)	0	0	0	4 (13.3)	2 (6.7)	0	0	4 (13.3)	2 (6.7)
Alcohol	0	0	0	0	0	0	0	0	0	0	0	0
Drugs	0	0	1(3.3)	0	0	0	0	1 (3.3)	0	0	0	1 (3.3)
Social												
Company	4 (13.3)	8 (26.7)	10 (33.3)	1 (3.3)	0	1 (3..3)	6 (20)	16 (53.3)	0	2 (6.7)	5 (16.7)	16 (53.3)
Intimate relationships	3 (10.0)	9 (30.0)	4 (13.3)	2 (6.7)	0	2 (6.7)	9 (30)	7 (23..3)	0	1 (3.3)	5 (16.7)	12 (40.0)
Sexual expression	3 (10.0)	0	2 (6.7)	0	1(3.3)	1 (3..3)	3(10)	0	0	1 (3.3)	3 (10)	1 (3.3)
Functioning												
Looking after the home	12 (40.0)	4 (13.3)	5 (16.7)	2 (6.7)	0	2 (6.7)	10 (33.3)	10 (33.3)	0	2 (6.7)	6 (20)	15 (50.0)
Self care	9 (30.0)	2 (6.7)	3 (10.0)	1 (3.3)	0	1 (3.3)	4 (13.3)	9 (30.0)	0	1 (3.3)	3 (10)	10 (33.3)
Childcare	0	0	0	1 (3.3)	1(3.3)	0	0	0	1 (3.3)	0	0	0
Basic education	0	0	1 (3.3)	0	0	0	1(3..3)	0	0	0	1 (3.3)	0
Money	1 (3.3)	4 (13.3)	0	0	0	2 (6.7)	3(10.0)	0	0	1 (3.3)	2 (6.7)	2 (6.7)
Service												
Information	7 (23.3)	5 (16.7)	5 (16.7)	0	0	3 (10)	8 (26.7)	5(16.7)	0	0	4 (13.3)	12(40.0)
Telephone	10 (33.3)	5 (16.7)	3 (10.0)	0	0	7 (23.3)	2 (6.7)	9 (30.0)	0	2 (6.7)	10 (33.3)	2 (6.7)
Transport	2 (6.7)	3 (10.0)	3 (10.0)	1 (3.3)	1 (3.3)	1 (3.3)	8 (26.7)	8 (26.7)	0	1 (3.3)	6 (20)	3(10.0)

Regarding the amount of help residents were getting from the formal care services was also found to be high, particularly in the areas of food (70%), accommodation (55%), for management of psychotic symptoms and loneliness (40%). Residents were getting help from formal care services for better functioning, 30% residents are getting help for maintaining their living space and 25% to maintain their personal hygiene. They were also getting moderate help in almost all areas of need from the formal care services. Major part of the formal care was provided by the half way home, where residents were living. People with mental health problems have complex needs. Care should be provided according to need (Xenitidis K, 2000). Formal care providers or mental health professional have better understanding of the needs of the persons with severe mental illness, so they are able to fulfill their unmet needs.

Informal care provider such as family or friends were providing mild to moderate help to fulfil their needs, 40% residents were getting moderate help to manage their psychiatric symptoms, in terms of taking them for psychiatric consultation and helping them to avail the other formal care services. 25% were moderately helped by informal care providers for the management of there psychological distress. They used to visit them, share their feeling and emotions which helped residents, similarly its help to resolve loneliness (15%). Occasionally family or friends would take them to their home and providing opportunities to participate in different social and family events which helped them to fulfil their various needs. Inadequate knowledge of needs of persons with severe mental illness would be the major reason involved to provide inadequate care from informal care providers such as family and friends. Social attitudes towards persons with severe mental illness cause more distress to the persons and his/her near and dear ones, than the illness itself. The major psychosocial issues related to persons with severe mental illness are: knowledge about illness and its managements, quality of medical management, rejection, overprotection, education, employment, marriage and pregnancy. Informal care provider, such as family or friends has vital roles to play in order to address them.

Residents were Getting Right Type of Service or not:

Professional staff felt that residents were getting the right type of help for almost all needs except for the sexual expression (40%) and psychiatric symptoms (20.8%), and expressed the view that they are not getting right type of service.

Conclusions and Implications

The unmet needs were less than the met needs since residents were getting help from formal service providers followed by informal care givers. Major part of the formal care was provided by the half way home, where residents were living. The results indicated the need for further emphasis on interventions towards the management of psychotic symptoms and psychological distress as well as to focus on interventions concerning the social relations of persons with severe mental illness. Most of the residents had no outside friends or they were unable to maintain intimate relationships with relatives. Some more structured occupational therapy could address the unmet needs in the areas of day time activities and looking after the home. Assessment of different needs of persons with severe mental illness is an essential task of the mental health professionals, and the assessment should be as rigorous and comprehensive as possible focusing both on the individual with mental illness and caregivers and at the community levels (Issakidis C, Teesson M. 1999). Results suggest that fully integrated care, formal and informal is essential to meet the needs of persons with severe mental illness. Residential setting like half way home has a very important role in fulfilling the needs of the persons with severe mental illness.

Small sample size and one way perspectives of assessment for needs are the major limitations of this study since residents and staff may show different perceptions of needs for care therefore multiple perspectives should be taken into account for planning and providing effective needs led psychosocial rehabilitation services and comprehensive mental health care.

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Social Disability and Symptomatic Outcome in Schizophrenia

-Where are the Unmet Needs of Schizophrenia Patients?

Rebecca Schennach-Wolff 1

Markus Jäger 1

Florian Seemüller 1

Michael Obermeier 1

Hans-Jürgen Möller 1

Max Schmauss 2

Gerd Laux 3

Herbert Pfeiffer 4

Dieter Naber 5

Lutz G. Schmidt 6

Wolfgang Gaebel 7

Joachim Klosterkötter 8

Isabella Heuser 9

Wolfgang Maier 10

Matthias R. Lemke 11

Eckart Rüther 12

Stefan Klingberg 13

Markus Gastpar 14

Michael Riedel 15

Affiliations:
1Department of Psychiatry and Psychotherapy, Ludwig-Maximilians-University, Munich, Germany;
2Psychiatric Clinic, District Hospital Augsburg, Germany;
3Psychiatric Clinic, Inn-Salzach Hospital Wasserburg/Inn, Germany;
4Psychiatric Clinic, Isar-Amper Hospital, Munich-Haar,, Germany;
5Department of Psychiatry and Psychotherapy, University of Hamburg, Germany;
6Department of Psychiatry and Psychotherapy, University of Mainz, Germany;
7Department of Psychiatry and Psychotherapy, Medical Faculty, Heinrich-Heine-University, Düsseldorf, Germany;
8Department of Psychiatry and Psychotherapy and Psychotherapy, University of Cologne, Germany;
9Department of Psychiatry and Psychotherapy, Charite Berlin, Campus Benjamin Franklin, Germany;
10Department of Psychiatry and Psychotherapy, University of Bonn, Germany;
11Department of Psychiatry, Alsterdorf Hospital, Hamburg, Germany
12Department of Psychiatry and Psychotherapy, University of Göttingen, Germany;
13Department of Psychiatry and Psychotherapy, University of Tübingen, Germany and
14Department of Psychiatry and Psychotherapy, University of Essen, Germany.
15 Psychiatric Clinic, Vinzenz-Von-Paul-Hospital, Rottweil, Germany

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Corresponding author:
Rebecca Schennach-Wolff, MD

Department of Psychiatry
Ludwig-Maximilians-University Munich
Nussbaumstr. 7, 80336 München, Germany
E-mail: Rebecca.Schennach-Wolff@med.uni-muenchen.de

Abstract

Purpose
Aim of the study was to assess social disability and its influencing factors in acutely ill schizophrenia inpatients and to evaluate its predictive validity of subsequent symptomatic outcome in order to evaluate the unmet needs of schizophrenia patients.

Methods
107 inpatients suffering from schizophrenia spectrum disorders were examined within a multicenter trial by the German Research Network on Schizophrenia with biweekly PANSS ratings. Social disability was assessed using the WHO's Disability Assessment Schedule (DAS) at baseline. Early response was defined as a 20% PANSS total score reduction within the first two treatment weeks, response as a 50% PANSS total score reduction from baseline to discharge and remission according to the Andreasen consensus criteria. Regression analyses and CART-analyses were performed to evaluate the predictive validity of social disability regarding symptomatic outcome at discharge.

Results
The global evaluation of the DAS in 107 patients with schizophrenia at admission revealed 21 patients (20%) to have no social disability, 50 patients (47%) to have some disability and 36 patients (33%) to suffer from severe social disability. Patients without social disability achieved early response significantly more often (p=0.0292) and scored significantly lower on the PANSS general psychopathology subscore (p=0.0102) at admission. The DAS item "interests and information" was found to be a significant predictor of symptomatic outcome by both statistical methods.

Conclusions
The prevalence of social disability in acutely ill patients with schizophrenia is emphasized concurrently identifying targets for improving psychosocial rehabilitation.

Key words: Schizophrenia, social functioning and adjustment, symptomatic remission, predictive validity

Introduction:

Remarkable attempts have been made to identify predictors of treatment outcome in schizophrenia in the past decades. For reliable predictors would bear considerable benefits in the treatment of schizophrenic patients by avoiding unnecessary continuation with ineffective treatment before attempting alternative strategies [1]. Additionally, poor treatment responders could be identified timely resulting in early treatment adjustments in turn reducing the risk of accruing morbidity, the level of care required and the overall costs incurred. Amongst others, the duration of untreated psychosis [2], negative symptoms [3] as well as the development of parkinsonism during antipsychotic treatment [4] have been identified to predict poorer treatment outcome.

Other researchers have focused on the assessment of social functioning as an influencing factor of treatment outcome especially after its importance was recognized with the introduction of social functioning into the Diagnostic and Statistical Manual of Mental Health, 3rd edition in 1980 [5]. Consistently, social dysfunction was found to predict an unfavorable course and impaired outcome in patients with schizophrenia [6] underlining primarily the prognostic importance of this dimension in addition to psychopathological or anamnestic variables. Secondly, the importance of adequately treating and supporting the patient's handicaps in this field was emphasized [7].

Different rating scales to assess this dimension have been developed since then. For example, in 1988 the World Health Organization (WHO) proposed a semi-structured interview, the Disability Assessment Schedule (DAS), designed for the comprehensive evaluation of social functioning of patients with mental and, in particular, psychiatric disorders [8]. The DAS was tested and used in the WHO Collaborative Study on the Assessment and Reduction of Psychiatric Disability and found to be a reliable and valid tool for the assessment and cross-cultural comparison of psychiatric disability [9]. The DAS examines several areas of functioning such as self-care, social activities, partnership as well as work and general interests [10]. Also, as a semi-structured interview the DAS provides advantages of both an observer- as well as a self-rating instrument. The patient himself can describe his behavior and experiences on the one hand, on the other hand the professionally trained observer decides how much weight is put on the information the patient gives during the interview [11]. This reduces the scope for inaccurate assessment resulting from difficulties in the patients' perception of themselves.

Interestingly, despite the proven importance of social functioning for treatment outcome its influence and predictive validity have not been evaluated yet applying the recently proposed remission criteria [12].

Therefore, we evaluated social functioning at baseline in acutely ill inpatients with schizophrenia applying the DAS and analyzed the predictive validity in respect of symptomatic treatment outcome.
Aims of the study were to:
1) assess social functioning at baseline in acutely ill patients suffering from schizophrenia and to
2) identify influencing variables of social disability and to
3) evaluate the predictive validity of social functioning for early response, response and remission.

Methods

Subjects

Data were collected in a multicenter follow-up programme (German Research Network on Schizophrenia) [13] at eleven psychiatric university hospitals and three psychiatric district hospitals in the region surrounding Munich. From all patients who were admitted between January 2001 and December 2004 to one of the above mentioned hospitals patients with the diagnosis of schizophrenia (paranoid, disorganized, catatonic or undifferentiated subtype), schizophreniform disorder, delusional disorder and schizoaffective disorder according to DSM-IV criteria were randomly selected to be eligible for inclusion. The patient selection resulted from a randomisation software. Subjects were aged between 18 and 65 years. Exclusion criteria were a head injury, a history of major medical illness and alcohol or drug dependency. An informed written consent had to be provided to participate in the study. The study protocol was approved by the local ethics committees [14].

Assessments

DSM-IV diagnoses were established by clinical researchers on the basis of the German version of the Structured Clinical Interview for DSM-IV [15]. Using a standardized documentation system [16] during interviews with patients, relatives and care providers sociodemographic variables (partnership, employment status) and course-related variables such as age at onset, age at first hospitalization or episodes of illness were collected.

Symptom severity was assessed using the Positive and Negative Syndrome Scale for Schizophrenia (PANSS) [17]. Depressive symptoms were evaluated via the Hamilton Depression Rating Scale [18]. The Subjective Well-being Under Neuroleptic Treatment Scale, short version (SWN-K) was used to assess subjective well-being. [19].

Social disability was assessed using the Disability Assessment Schedule (DAS) [20]. The WHO-DAS is a semi-structured interview with an informant and with the patient to elicit responses to a number of questions on several areas of functioning: self-care, social withdrawal, participation in the household, relationship with

spouse or partner, occupational role and general interests [20]. Guiding questions and descriptions of anchor points for the assessment lead to the rating of a dysfunction on a six points scale : 0, no dysfunction; 1, minimum dysfunction; 2, obvious dysfunction; 3±5, serious to maximum dysfunction. At the end of the interview an overall judgement of total functioning is required for a Global Evaluation on a six-point scale (0, excellent adjustment to 5, severe maladjustment). The global evaluation can also be categorized according to the following classification: no disability (0) ; some disability (1±2); and, severe disability (3±5) [21].
PANSS ratings were performed within the first three days after admission, biweekly as well as at discharge. The DAS was rated within the first three days after admission. All raters had been trained using the applied observer scales. A high inter-rater reliability was achieved (ANOVA-ICC > 0.8).

Statistical analysis

Outcome definitions:

1) Early response: Early response was defined as a 20% PANSS total score improvement within the first two treatment weeks [22].

2) Response: Response was defined as a 50% PANSS total score reduction from baseline to discharge [23].

3) Remission: Symptomatic remission was defined using the symptom-severity component of the standardized remission criteria [24] as a PANSS score of three or less of the following items: delusions (P1), unusual thought contents (G9), hallucinatory behavior (P3), conceptual disorganization (P2), mannerism/posturing (G5), blunted affect (N1), social withdrawal (N4) and lack of spontaneity (N6). Discharge was chosen as the final endpoint because we implied that clinicians would judge the mental state at the time point as stable. Due to the study design the time component of the remission criteria could not be considered.

For descriptive analysis of singular variables mean scores and standard deviation were used as well as the median and interquartils range. Furthermore, the non-parametric Wilcoxon test or, in case of assumed normality, the t-test was used. A forward-backward selection based on the Akaike Information Criterion (AIC) was used to identify the relevant predictors of early response, response and remission in a linear logistic model. All single DAS items and the categorized DAS total were regarded as possible predictors. To adjust for the influence of the patients' baseline psychopathology the PANSS total score was considered in the prediction models. Predictive value, sensitivity and specificity levels depend on the cut-off point of the model. The discriminative ability of the regression model was also evaluated using a receiver-operating characteristic (ROC) curve. The area under the curve (AUC) is a measure of the overall discriminative power. A value of 0.5 for the AUC does not represent discriminative ability, whereas a value of 1.0 indicates a perfect power. A value of 0.7-0.8 is considered as a reasonable value and a value greater than 0.8 as a good discriminative capacity. Additionally, Classification and Regression Trees (CART) were used to confirm the results of the regression model.
All statistical analyses were performed using the statistical software environment R (25).

Results

Patients

The entire multicenter study comprised 474 patients. Forty-six patients dropped out for different reasons (e.g. retrospective violation of inclusion criteria, withdrawal of informed consent, incomplete information). 28 patients were furthermore excluded because they were discharged from the hospital within 7 days after admission. 293 patients did not complete the semi-structured DAS-interview.

Therefore, the sample available for analyses enrolled 107 patients (60 male/47 female) with a mean age of 27.47 years (±9.76). The mean age at first treatment was 27.75 years (±9.41). The mean duration of illness was 5.14 years (±9.15) and the mean number of clinical treatments 3.62 (±5.50). The duration of current episode was ≤12 months for 61 patients (57%) and >12 months for 46 patients (43%). The mean duration of current hospital stay was 64.19 days (±46.44). 23 patients (21%) lived within a partnership, 84 patients (79%) did not. 59 patients (55%) had a job, 28 patients (26%) were jobless and 20 patients (19%) were retired.

Patients were treated under naturalistic conditions as follows: 39% of the patients received first-generation antipsychotics, 75% second-generation antipsychotics and 30% first- as well as second-generation antipsychotics. 62% of the patients were treated with tranquilizers and 11% with mood stabilizers. 25% of the patients also received antidepressants. DSM-IV diagnosis are listed in Table 1.

Table 1: DSM-IV diagnoses

Patients' diagnoses
schizophrenia: § disorganized type (295.1): 5 § paranoid type (295.3): 48 § catatonic type (295.2): 1 § residual type (295.6): 2 § undifferentiated type (295.9): 6
schizophreniform disorder (295.4): 20
schizoaffective disorder (295.7): 17
delusional disorder (297.1): 1
brief psychotic disorder (298.8): 7

Assessments

Patients with and without DAS ratings

Complete data were available from 107 patients, 293 patients did not complete the semi-structured interview of the DAS. Comparing patients with/without a completed DAS rating we found patients with a DAS rating to have significantly more insight into their illness (p=0.0015), to be significantly more depressed (0.0239), to have significantly worse subjective well-being (p=0.0401) and to have significantly more often a duration of current episode of < 12 months (p<0.01) (Table 2).

Table 2: Comparing patients with/without DAS scale

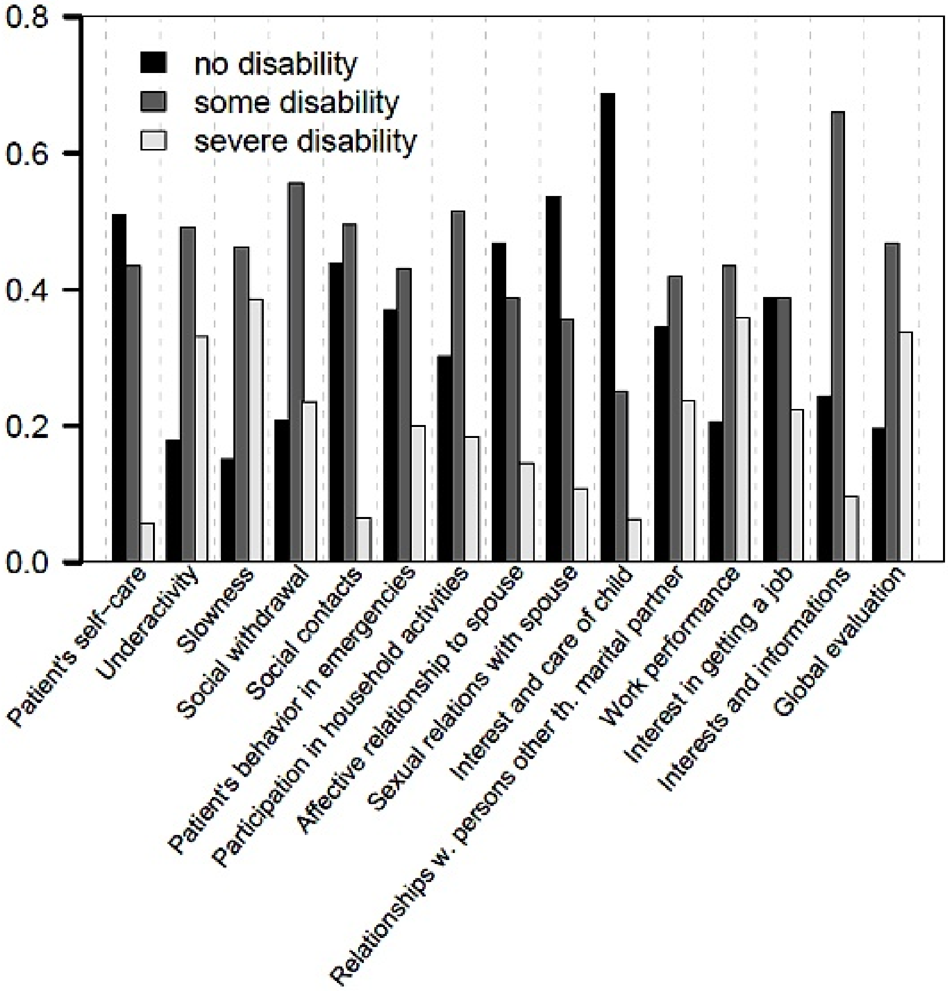
	Patients with DAS scale ***(27% of the patients)***	***Patients without DAS scale*** ***(73% of the patients)***	***p-value***
	Mean (SD)	Mean (SD)	
Age	27.47 (±9.76)	27.85 (±9.3)	0.7305
PANSS total score	70.98 (±17.6)	71.24 (±19.7)	0.899
PANSS positive subscore	18.36 (±5.75)	19.3 (±6.56)	0.1631
PANSS negative subscore	17.42 (±7.52)	17.58 (±7.3)	0.85
PANSS general psychopathology subscore	35.21 (±9.81)	34.36 (±10.21)	0.4522
HAMD 21 total score	**16.77 (±7.96)**	**14.64 (±8.2)**	**0.0239**
SWN total score	**77.3 (±18.52)**	**82.32 (±18.15)**	**0.0401**
	N	N	
Male	60	166	1
Female	47	127	
Duration of current episode < 12 months	**65**	**248**	**<0.001**
Duration of current episode ≥ 12 months	**42**	**45**	

Suicidal	89	230	0.3974
Non suicidal	18	63	
	Median (IQR)	Median (IQR)	
PANSS insight item G 12	**3 (3)**	**3 (4)**	**0.0015**
Duration of illness	2 (7)	4 (13)	0.1093

Social disability at admission

The global evaluation of the DAS in 107 patients with schizophrenia at admission revealed 21 patients (20%) to have no social disability, 50 patients (47%) to have some disability and 36 patients (33%) to suffer from severe social disability. Figure 1 shows the 15 single items of the DAS scale at admission. Patients with severe disability performed very poorly in the item "underactivity" examining the time during the day spent in what the society considers to be doing nothing, the item "slowness" evaluating the overall speed of movement and agility in carrying daily activities, and the item "work performance" examining whether the patient goes to work regularly and also the quality of performance as well as output.

Figure 1: Social disability in acutely ill patients with schizophrenia



Comparing patients with/without social disability

To identify influencing variables of social disability patients were grouped according to their global evaluation of the DAS: patients with some and severe disability were grouped into the subgroup "patients with disability" and compared to patients without social disability, the subgroup "patients without disability". Table 3 shows the results of univariate tests between these two patient subgroups. Patients without social disability achieved early response significantly more often (p=0.0292) and scored significantly lower on the PANSS general psychopathology subscore at admission (p=0.0102).

Table 3: Comparing patients with/without social disability

	Patients without social disability **(20%)**	**Patients with some and severe social disability** **(80%)**	**p-value**
	Mean (SD)	Mean (SD)	
Age	36.62 (±12.25)	32.52 (±10.89)	0.1714
PANSS total score at admission	65.76 (±15.59)	72.26 (±17.91)	0.1061
PANSS positive subscore at admission	17.95 (±4.99)	18.45 (±5.95)	0.6943
PANSS negative subscore at admission	16.9 (±8.09)	17.55 (±7.42)	0.7429
PANSS general psychopathology subscore at admission	**30.9 (±7.6)**	**36.26 (±10.04)**	**0.0102**
HAMD 21 total score at admission	14.06 (±6.35)	17.36 (±8.18)	0.0676
	N	N	
Male	10	37	0.8076
Female	11	49	
Current episode < 1 year	18	47	0.2016
Current episode > 1 year	6	36	
First episode of illness	12	55	0.619
Multiple illness episode	9	31	
Suicidal at admission	1	17	0.1887
Non suicidal at admission	21	68	
With partner at admission	5	22	0.5541
Without partner at admission	12	68	
In job at admission	16	44	0.2552
Jobless at admission	10	19	
Retired at admission	2	16	
Early response at week 2	**15**	**43**	**0.0292**
No early response at week 2	**6**	**43**	
Response at discharge	15	46	0.7669
Non response at discharge	6	40	
Remission at discharge	11	53	0.6541
Non remission at discharge	7	24	
	Median (IQR)	Median (IQR)	
PANSS insight item (G12) at admission	2 (3)	3 (3)	0.7299
Duration of illness	1 (6.25)	2 (8)	0.1136
Number of previous hospitalizations	0 (1)	0 (1)	0.4103

Social disability and symptomatic outcome

Social disability and its predictive validity for early response

54% of the patients achieved early response with 26% of them not suffering from social disability, 48% featuring some disability and 26% featuring severe disability. In comparison, 46% of the assessed patients did not achieve early response at week 2 with 12% of them not suffering from social disability, 45% featuring some disability and 43% featuring severe disability.

Comparing patients with/without early response regarding the DAS single items we found patients with early response to perform significantly better in terms of interest and care of child, relationships with persons other than marital partner, interests and information and the global evaluation of social disability (Table 4).

Table 4: Comparing patients with/without early response regarding social disability at admission, higher scores indicating higher impairment

	Early responder ***(54%)***	***Non early responder*** ***(46%)***	***p-value***
	Median (IQR)	Median (IQR)	
Patient's self-care	**0 (1)**	**1 (2)**	**0.01**
Underactivity	2 (1)	2 (2)	0.05
Slowness	2 (2)	2 (2)	0.55
Social withdrawal	2 (1)	2 (2)	0.19
Social contacts	1 (2)	1 (2)	0.52
Patient's behavior in emergencies	1 (2)	2 (2)	0.05
Participation in household activities	**1 (2)**	**2 (3)**	**0.04**
Affective relationship to spouse	1 (2)	1.5 (2)	0.30
Sexual relations with spouse	0 (1.25)	0.5 (2)	0.52
Interest and care of child	**0 (0)**	**0 (2)**	**0.01**
Relationships with persons other than marital partner	**1 (2)**	**2 (2.75)**	**0.01**
Work performance	2 (2)	2 (1)	0.11
Interest in getting a job	1 (2)	2 (3)	0.06
Interests and information	**1 (2)**	**2 (1)**	**<0.001**
Global evaluation	**2 (1)**	**2 (2.5)**	**0.01**

Logistic regression analysis revealed the DAS item "interests and information" to be significantly predictive of early response with moderate predictive power (AUC=0.686), see Table 7. The regression model reached statistical significance (p=0.005). The additionally performed CART-analysis also revealed the item "interests and information" to be significantly predictive for early response as well as the items "interest and care of child", "relationships with persons other than the marital partner", "work performance", "patient's behavior in emergencies" and the PANSS total score.

Social disability and its predictive validity for response

57% of the patients were treatment responder at discharge with 25% of them having no social disability, 39% with moderate disability and 36% with severe disability. In comparison, 43% did not achieve the response criterion. Of these, 13% were rated to have no social disability, 57% to have moderate disability and 30% to have severe disability.

Comparing patients with/without response no significant differences in ratings of the DAS single items could be observed (Table 5). Performing logistic regression analysis the DAS items "slowness" and "interests and information" were found to be significantly predictive for response with the statistical model reaching significance (p=0.015) (Table 7). The logistic regression model showed moderate predictive capacity (AUC=0.662). CART-analysis however did not reveal any significant social disability predictor in terms of response.

Table 5: Comparing patients with/without response regarding social disability at admission, higher scores indicating higher impairment

	Responder **(57%)**	**Non responder** **(43%)**	**p-value**
	Median (IQR)	Median (IQR)	
Patient's self-care	0 (2)	0 (2)	0.92
Underactivity	2 (2)	2 (2)	0.68
Slowness	2 (2)	2 (2)	0.20
Social withdrawal	2 (2)	2 (1)	0.51
Social contacts	1 (2)	1 (2)	0.34
Patient's behavior in emergencies	2 (2)	1 (2)	0.76
Participation in household activities	1 (2)	2 (1)	0.13
Affective relationship to spouse	1 (2)	1 (2)	0.63
Sexual relations with spouse	0 (1)	1 (2)	0.22
Interest and care of child	0 (0)	0 (1.5)	0.18
Relationships with persons other than marital partner	1 (2.25)	1 (2)	0.64
Work performance	2 (2)	2 (1)	0.17
Interest in getting a job	1 (2)	2 (3)	0.21
Interests and information	1 (2)	2 (1)	0.17
Global evaluation	2 (2)	2 (1)	0.59

Table 7: Logistic regression model on the predictive validity of social disability of outcome

	Estimate	**Std. Estimate**	**z-value**	**p-value**
Early response				
Interests and information	-1.4402	0.5551	-2.59	0.0095
Response				
Slowness	0.9045	0.3835	2.36	0.0184
Interests and information	-1.2097	0.4787	-2.53	0.0115
Remission				
Interests and information	-1.58	0.58	-2.74	0.0061
Global evaluation	1.13	0.47	2.40	0.0162

Social disability and its predictive validity for remission

60% of the patients achieved the symptom severity component of the remission criteria with 17% of them suffering from no social disability, 49% featuring some disability and 34% severe disability. In comparison, 40% of the examined patients were not treatment remitter at discharge, with 23% of them having no social disability, 45% having some disability and 32% having severe disability.

Comparing patients with/without remission the patients achieving remission at discharge performed significantly better in terms of the patients' behavior in emergencies and well as the patients' interests and information (Table 6). The item "interests and information" and the DAS global evaluation were identified to be significantly predictive for remission by the logistic regression model with satisfying discriminative capacity (AUC=0.722) reaching statistical significance (p=0.007) (Table 7). The CART-analysis confirmed the predictive validity of the item "interests and information" and further identified the items "interest and care of child" and "sexual relations with spouse" to be significantly predictive of remission.

Table 6: Comparing patients with/without remission regarding social disability at admission, higher scores indicating higher impairment

	Remitter (60%)	**Non remitter (40%)**	**p-value**
	Median (IQR)	Median (IQR)	
Patient's self-care	0 (2)	1 (2)	0.58
Underactivity	2 (2)	2 (1.75)	0.10
Slowness	2 (2)	2 (2)	0.32
Social withdrawal	1.5 (1.25)	2 (1)	0.16
Social contacts	1 (2)	1 (1.5)	0.27
Patient's behavior in emergencies	**1 (2)**	**2 (2)**	**0.04**
Participation in household activities	1 (2)	2 (0.75)	0.07
Affective relationship to spouse	1 (2)	1.5 (2)	0.77
Sexual relations with spouse	0 (1)	1 (2.75)	0.15
Interest and care of child	0 (0)	0 (2)	0.08
Relationships with persons other than marital partner	1 (2)	1 (2.5)	0.24
Work performance	2 (2)	2 (1)	0.23
Interest in getting a job	1 (2)	1 (2)	0.66
Interests and information	**1 (2)**	**2 (1)**	**0.03**
Global evaluation	2 (2)	2 (2)	0.88

Discussion

Social disability in acutely ill patients with schizophrenia

General aspects

In the present study 80% of acutely ill and admitted patients with schizophrenia suffered from social disability. Despite the fact that it is well known that social impairment is a core feature of schizophrenia affecting the patient's social interaction, vocational and instrumental functioning skills, self-care and recreation [25] there are only few studies explicitly examining the prevalence and course of this domain in schizophrenia patients. Wiersma et al. evaluated 349 patients with schizophrenia regarding their social disability over 15 years in six European countries also applying the DAS and found 13% of the patients to have no social disability whereas 69% of the patients were identified to have moderate to severe social disability at study entry [21]. After 15 years only 14% of the examined patients suffered from no social disability and still 59% of the patients from moderate to severe disability [21]. In a similar study with a 15 year follow-up period comparing social disability between patients suffering from schizophrenia, schizoaffective disorder and depression Bottlender et al. [10] reported that 64% of the patients with schizophrenia suffered from at least moderate social disability compared to schizoaffective patients (19%) and patients with depression (5%). These results underline the high prevalence of deficits in social functioning in acutely ill schizophrenia patients, but most important also during the course of the illness. One of the latest biological models proposed to explain social deficits in schizophrenia is the dysregulation of the peptide hormone oxytocin, which was found to be important in regulating affiliative behavior such as social recognition, separation distress or pair-bond information [26].

Influencing variables

Comparing patients with/without social disability we found patients not suffering from social disability to score significantly lower on the PANSS general psychopathology subscore and to achieve early response significantly more often. It might be surprising on the first glance that symptoms not specific for schizophrenia illness were found to be important for social functioning. However, it has been reported before that especially depressive symptoms are significantly associated with social functioning in patients with schizophrenia [27, 28]. Jin et al. examined 202 middle-aged or elderly outpatients with schizophrenia and reported that even after adjusting for severity of other psychopathology, patients with more severe depressive symptoms had significantly worse everyday functioning [29]. Furthermore, depression was found to predict interpersonal and work skills in schizophrenia patients [30]. This is in line with our results of the univariate tests (Table 3) finding patients without social disability to score lower on the HAMD total score by more than 2 points in the mean.

Also, in the present study patients without social disability suffered from less negative symptoms than patients suffering from social disability which has been consistently reported [31, 32]. In contrast to several other studies reporting a significant association between the degree of social disability and work, partnership or family [33] we were not able to find a significant difference between patients with or without social disability in terms of working of family status. One possible explanation for this discrepancy might be that the patients in the present study had a rather low mean duration of illness with more than 60% of the patients suffering from their first illness episode. This patient population might not yet suffer from so much social and vocational consequences of the illness as it might be the case in patients suffering from schizophrenia for a longer time. Interestingly, comparing 969 patients from the F2, F3, F4, F5 and F6 diagnostic groups (according to ICD-10) Rymaszewska did also not find an association between social disability and education, the number of episodes, psychiatric hospitalisation or duration of the disorder [34].

Regarding social functioning and its association with early treatment response our result is less surprising. Early antipsychotic response was found to closely parallel and predict later overall outcome and to be significantly associated with achieving functional remission also for the long-term course of the illness [1, 35].

Social disability and its predictive validity of symptomatic outcome

General aspects

In the present study we found social disability at baseline to be predictive of symptomatic outcome and patients without social disability achieved early response significantly more often. Already in the 1980s the influence of social functioning on the course and outcome of schizophrenia has been stated [36]. Since then, several authors found the patient's functional status to be an important predictor of symptomatic outcome and of response to pharmacologic treatment [37-39]. There is a general consensus that supportive relationships both diminish the effects of stressful events and serve to prevent their occurrence [40] resulting in a favorable treatment outcome. The significance of social functioning deficits is furthermore emphasized by results finding impairments in social functioning and adjustment to be a marker of risk for schizophrenia [41]. Deficiencies in several areas of functioning including behavioral and social domains have also consistently been observed in studies of high-risk individuals supporting the hypothesis that alterations in social development might be a marker for a genetic liability toward the illness [42].

Interestingly, impairments in social functioning have also been found to significantly influence symptomatic outcome beyond the diagnostic boarder of schizophrenia for there are several reports that functioning and remission status are highly associated in patients suffering from depression [43]. The influence of social satisfaction, functioning and deprivation has even been analyzed and reported in patients with somatic illness, such as rheumatoid arthritis [44].

Social disability as predictor of symptomatic outcome

The single items of the Disability Assessment Schedule that were predictive of early response, response and remission overlap to a certain degree since the item "interests and information" was found to significantly predict all three outcome domains. This item was also confirmed significant predictor by the additionally performed CART-analysis. One explanation for this phenomenon might be that almost 40% of the patients achieved all three outcome domains implying that similar influencing variables are relevant for these patients. The item "interests and information" evaluates the interest shown by a patient in local, world events or in other matters within the patient's background, education, and level of intelligence. The importance of the patient's interest in things going on for the course of the illness is also underlined by other study results. Moller & Husby, for example, defined four core dimensions of prodrome in schizophrenia and listed a marked and lasting observable shift of interests as one of them [45]. Also, Dworkin et al. examined social competence in patients at risk for schizophrenia, affective disorders as well as in normal-comparison subjects and found subjects at risk for schizophrenia to have a poorer overall social competence and specifically a significantly decrease in interests [46].

The other DAS items found to significantly predict response and remission by the regression model were "slowness" and the "global evaluation" of social disability. The item "slowness" examines the overall speed of movement and agility in carrying out daily activities and it is not surprising that patients with impairments in this area have difficulties coping with everyday life challenges. This is underlined by several literature reports finding an association between speed and social performance [47]. Bowie et al. reported on processing speed to predict social competence [48]. Also, in high-functioning schizophrenia patients Vaskinn et al. identified that social problem-solving was significantly associated with psychomotor speed [49].

CART-analysis identified further DAS items being predictive of outcome namely "interest and care of child", "relationship with other than marital partner", "sexual relations with spouse" as well as "work performance" and "patient's behavior in emergencies". The importance of partnership and family regarding outcome has already been discussed before and is a well known influencing variable [50]. The significance of this domain is also emphasized by different intervention programs explicitly involving the patient's family which was found to lead to a reduction of stress in families preventing relapse and rehospitalization [51].

When discussing predictor variables like family or work it should be kept that it is not only the patient's illness bringing about social impairments but that also environmental related factors and stigma play an important role [52]. For individuals with a mental illness do not only have to cope with their symptoms and consequences of their illness but also with negative public attitude and prejudices [53]. This can lead to further impairment of those affected by a mental disorder [54]. Stigma can be a major stressor for patients with schizophrenia and has been associated with poorer social performance depending on the patient's individual coping styles [55]. Also, when performing cluster analysis in 75 patients with schizophrenia Lysaker et al. found the patient's functioning to be affected by the degree to which the patient internalized stigmatizing views [56]. This should be kept in mind discussing the influence of the patient's social disability for symptomatic outcome especially when resulting in specific treatment approaches.

Limitations

This study is not without limitations. The patients were treated under naturalistic conditions and such a design does not allow a sufficient control of study results for the effect of different pharmacological and psychological treatments. Furthermore, the patient sample included both first-episode patients and chronically ill patients. Also, the Remission in Schizophrenia Working Group developed the symptomatic remission criteria solely for schizophrenic patients. In this study the criteria were used in a wider spectrum of schizophrenia related disorders. The time criterion was likewise not considered, for the criteria were proposed to define remission as the absence of relevant symptoms for at least six months. Substance use, which was just recently reported to significantly influence the patient's level of social functioning [57], could not be examined for it was defined as an exclusion criterion. The study's recall bias should also be kept in mind since only 107 patients accomplished the semi-structured interview which might overestimate the patients' social functioning.

Conclusion

Taken together, our results underline the important influence of social disability for symptomatic outcome. Significant predictors of the Disability and Assessment Schedule could be identified underlining the importance of the patient's interest in local or world events for outcome as well as the patient's speed when coping with everyday life. These results emphasize the need to implement the evaluation and measurement of the patient's social disability in clinical routine as well as in research trials. Furthermore, the necessity to also incorporate special treatment regimes and rehabilitative approaches to improve social functioning and adjustment is highlighted.

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Recovery and Self-Esteem: Concurrent Validity of the Recovery Assessment Scale

Abraham Mukolo, PhD, MS
Instructor
Vanderbilt Institute for Global Health, Vanderbilt University

Craig Anne Heflinger, PhD
Professor and Associate Dean for Graduate Education
Peabody College of Education and Human Development, Vanderbilt University

Jane Baxter, B
Director
Middle Tennessee Mental Health & Substance Abuse Coalition

Citation:
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Correspondence: Abraham Mukolo, Ph.D.
Institute for Global Health
Vanderbilt University
2525 West End Avenue
Nashville, TN 37203-2738, USA.
E-mail: abraham.mukolo@vanderbilt.edu. Tel. 615-343-2716

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Abstract

The correlation between the Recovery Assessment Scale (RAS) and the Rosenberg Self-Esteem Scale (RES) was examined among adult participants in consumer-directed services. Hierarchical regression analysis was conducted with RES subscales as dependent variables predicted by RAS variables. Controls were race, age, gender, diagnosis and involvement in peer-directed activities. Regression models for global and positive self-esteem demonstrated moderate fit (explaining 48 to 51% variance, p<.001). As expected negative self-esteem models demonstrated poor fit. 'Personal confidence and hope' RAS subscale scores were significantly associated with positive self-esteem. Non-dominance by symptoms was associated with positive and global self-esteem in unadjusted analysis, but attenuated in regression analyses. The RAS demonstrated concurrent validity with the RES in this sample. RAS domains reflective of self-concept correlated with global and positive self-esteem. Reliance on others, non-dominance by symptoms and goal and success orientation might not to be related to self-esteem among participants in consumer-directed mental health services.

Key words: Recovery assessment scale; Self-esteem; Concurrent validity; Consumer-directed services

Introduction:

Recovery is a complex yet increasingly appreciated and insightful concept, particularly in the fields of mental health and substance abuse (Davidson & White, 2007; Deegan, 1988; Essock & Sederer, 2009; Harvey & Bellack, 2009; Holloway, 2008; Mountain & Shah, 2008). Literature suggests two potentially conflicting concepts of recovery, one derived from predominantly biomedical models of illness and the second is grounded in the experiences and aspirations of people directly impacted by illness (Frese, Knight, & Saks, 2009; Holloway, 2008; Lieberman, et al., 2008; SAMHSA, 2006). The former conceptualizes recovery as cure and thus prioritizes clinical remission (Essock & Sederer, 2009; Lieberman, et al., 2008). Literature indicates that the absence of symptoms or illness is the most desirable treatment and rehabilitation outcome (Andreasen, et al., 2005; Boden, Sundstrom, Lindstrom, & Lindstrom, 2009; Corrigan, 2006b; Drake, et al., 2006; Harvey & Bellack, 2009; Robinson, Woerner, McMeniman, Mendelowitz, & Bilder, 2004; Xie, McHugo, Helmstetter, & Drake, 2005). In the case of schizophrenia, for example, clinical remission is widely recognized as one of the many goals of treatment (Harvey & Bellack, 2009). The second concept of recovery, generally attributed to Deegan (Anthony, 1993; Barbic, Krupa, & Armstrong, 2009; Deegan, 1988) and popularized by the Substance Abuse and Mental Health Services Administration (SAMHSA) consensus statement (2006), largely focuses on ability to claim/reclaim full and meaningful life in the community, and so emphasizes functional remission (Corrigan, 2006b; Davidson, Schmutte, Dinzeo, & Andres-Hyman, 2008; Frese, et al., 2009; Harvey & Bellack, 2009; Roberts & Wolfson, 2004).

Consumer-driven conceptualizations of recovery emphasize self-agency (Abbott, 2008; Mancini, 2008; Rogers, Chamberlin, Ellison, & Crean, 1997). Self-agency oriented recovery scales (such as the Recovery Assessment Scale: Giffort, Schmook, Woody, Vollendorf, & Gervain, 1995), constitute dimensions indicative of perceived capability to deal with disease assault and its consequences, hope and optimism about the future (independent of disease severity), internal locus of responsibility for one's own life, and confidence to lead a full and satisfying life (Giffort, et al., 1995; Jacobson & Greenley, 2001; Mancini, 2008; Resnick, Fontana, Lehman, & Rosenheck, 2005; Rogers, et al., 1997; SAMHSA, 2006). Such attributes and capabilities likely engender and sustain the motivation to engage in recovery enhancing activities (Harvey & Bellack, 2009; Mancini, 2008).

SAMHSA has acknowledged the recovery facilitation role of consumer-directed services (SAMHSA, 2006). Participation in consumer-operated services has been shown to correlate with scores on scales assessing recovery and empowerment among a sample of adults consumers (Corrigan, 2006a). Cook and colleagues (2009) observed that participating in peer-led mental illness self-management programs had a positive effect on recovery, self-advocacy and physical health among a sample of adults with serious mental illness. However, theory and empirical assessments of consumer-defined recovery from mental illness are emergent

(Anthony, 1993; Corrigan, 2006a; Davidson, et al., 2007; Lieberman, et al., 2008; Mausbach, Moore, Bowie, Cardenas, & Patterson, 2009; McNaught, Caputi, Oades, & Deane, 2007; Ramon, Healy, & Renouf, 2007; Resnick, et al., 2005; Robinson, et al., 2004; Schennach-Wolff, et al., 2009; Yanos, Roe, Markus, & Lysaker, 2008). The few available assessment scales require testing in diverse samples (McNaught, et al., 2007).

Self-esteem, the feeling of satisfaction with the magnitude of congruence between ones' self-image and his/her ideal self-image, is central to the emergence and maintenance of a recovery orientation(Jacobson & Greenley, 2001); hence its popularity as an outcome variable in psychiatric rehabilitation studies (Cook, et al., 2009; Corrigan, 2006a; Karatzias, Gumley, Power, & O'Grady, 2007; Lysaker, Davis, & Tsai, 2009; Mancini, 2007; Provencher, Gregg, Mead, & Mueser, 2002; Robson, 1988; Rogers, et al., 1997; Torrey, Mueser, McHugo, & Drake, 2000; Van Dongen, 1996; Yanos, et al., 2008). Jacobson and Greenley (2001, p. 483) have hypothesized that the sense of self-esteem (and self-respect) emerges from the recovery process of 'reconnecting with the self', particularly when one gains insight into (an begins to apply) the distinction between the illness and the self. Although most of the recovery literature is drawn from experiences of persons with schizophrenia spectrum disorders (Frese, et al., 2009; Harvey & Bellack, 2009; Ho, Chiu, Lo, & Yiu, 2010; Lieberman, et al., 2008; Mausbach, et al., 2009; Novick, et al., 2007), self-esteem studies involving diverse samples have also been reported (Lysaker, et al., 2009; Robson, 1988; Rogers, et al., 1997; Silverstone & Salsali, 2003; Torrey, et al., 2000; Van Dongen, 1996). For example, the self-esteem oriented study by Torrey and colleagues (2000) involved adults with chronic psychotic illness (46.9% of their sample), severe affective disorders (42.7%) and predominantly severe personality disorders (10.4%). Silverstone and Salsali (2003) found that compared to non-psychiatric patients, psychiatric patients generally had low self-esteem. However, the magnitude of self-esteem has been shown to differ by psychiatric diagnosis. In Silverstone's study, for example, patients with major depressive, eating and substance use disorders had lower self-esteem than patients with anxiety, conduct and bipolar disorders. In addition, co-morbidity with major depressive disorder was associated with even lower self-esteem than having only one of these disorders (Silverstone & Salsali, 2003).

In this study, we examined the extent to which the Recovery Assessment Scale (RAS)(Giffort, et al., 1995) fares against the Rosenberg Self-Esteem Scale (RES)(Rosenberg, 1965) among a diverse sample of adults from consumer-operated mental health services. We intend to add to the growing evidence base for the Recovery Assessment Scale since similar work has been reported (Barbic, et al., 2009; Corrigan, Salver, Ralph, Songster, & Keck, 2004; McNaught, et al., 2007).

Recently, Liberman and colleagues (2008) have advocated for domain-specific conceptualizations of recovery, particularly in relation to schizophrenia disorders. According to Liberman and colleagues (2008), this operationalization of recovery allows investigators and therapists to better circumscribe specific areas in which interventions effectively improve patients' health and well-being. In this study we used the recovery assessment scale that focuses on improvements in self-agency, hope and perceived mastery of symptoms (Corrigan, et al., 2004; McNaught, et al., 2007). These are some of the domains of recovery that our intervention (the Creative Arts Project) also intends to engender (see methods section).

We hypothesized that scores on the Recovery Assessment Scale (RAS) would predict scores on the Rosenberg Self-Esteem scale (RES), in particular, subscales of the RAS that are reflective of self-concept (such as optimism and self-agency) would be associated with high global and positive self-esteem and low negative self-esteem. We anticipated a non-direct relationship between perceived capacity to manage symptoms and self-esteem, particularly given the impersonal nature of symptoms, their specificity to disease, and variance in the clinical prognosis of mental illnesses. Given differences in the causation and implications of different disorders on cognitive function (e.g., self-schema in schizophrenia vs. bipolar disorders), we expected psychiatric diagnosis to be independently associated with self-esteem and to moderate the relationship between RAS and RES scores.

Methods

Participant Description

Data were collected in 2008 from 110 consenting adults (61% females, Mean age =44.05, SD=12.22) recruited at five peer support centers in one southern state. This was part of a larger study to assess the effectiveness of one art training project implemented by the Middle Tennessee Mental Health and Substance Abuse Coalition (MTMHSAC). The Creative Arts Project started in 2005. It facilitates adults with mental health and substance use disorders to develop artistic talent and showcase their works to the general public via public exhibits at local arts galleries, civic and educational establishments. Participation is voluntary and open to all adults at institutions affiliated with MTMHSAC. The project aims to increase the self-esteem, respect and self-worth of artists (Cook, et al., 2009), overcome stigma about mental illness and substance use disorders through public recognition of artistic talent, and to enhance community functioning by connecting participants to local networks of professional artists. All these are aspects of self-concept and recovery tapped into by the RES and the RAS.

Data Collection

Data for this study were collected prior to the commencement of the 2008 arts classes and from all peer support center members who were willing and consented to the study.
Informed consent. The study team administered oral and written informed consent gathering procedures at each peer support center following detailed protocol approved by two institutional review boards.

Survey administration. Participants completed a self-completion questionnaire. Assistance with questionnaire completion was provided as requested by participants.
Measures. The questionnaire constituted the Rosenberg Self-Esteem Scale (RES) and the Recovery Assessment Scale (RAS). Both scales have been validated among comparable samples (Corrigan, et al., 2004; McNaught, et al., 2007).

The Rosenberg Self-Esteem Scale (RES)(Rosenberg, 1965) scale is a recognized self-esteem measure, and has been used to assess the efficacy of psychiatric rehabilitation programs (Rogers, et al., 1997; Torrey, et al., 2000; Van Dongen, 1996; Yanos, et al., 2008). Torrey and colleagues (2000) reported coefficient alphas ranging from 0.88 to 0.90. The scale consists of 10 items: 5 items measure positive self-concept and 5 items assess negative self-concept. The actual number of sub-scales derivable from the RES scale is debatable (Corwyn, 2000; Dunbar, Ford, Hunt, & Der, 2000; Tomas & Oliver, 1999). We used the three conventional categories: (a) Global self-esteem, i.e., the sum of scores for the 10 items (the 5 negatively worded items were reverse coded first before the summation so that higher scores reflect greater self-esteem), b) Positive self-esteem, i.e., the sum of the scores for the 5 positively worded items and, c) Negative self-esteem, i.e., the sum of the 5 negatively worded items (higher scores reflect greater negative self-esteem). See Table 1 for results.

The Recovery Assessment Scale (RAS)(Corrigan, et al., 2004) is a 41-item measure that originally emerged from research conducted by Giffort and colleagues (Giffort, et al., 1995) to derive a consumer oriented measure of recovery. We used the RAS version modified by Corrigan and colleagues (2004). The scale has been used to assess consumers' personal confidence and hope for the future, their goal and success orientation, perceived mastery of symptoms of mental illness, willingness to ask for help, and reliance on other people for help (Barbic, et al., 2009; Cook, et al., 2009; Corrigan, 2006a; Corrigan, et al., 2004). Two studies have re-examined the robustness of the five factor structure of the RAS (Corrigan, et al., 2004; McNaught, et al., 2007). Corrigan and colleagues (2004) reported internal consistency estimates (Chronbach's α) ranging between .74 and .87 among a US sample. McNaught and colleagues (2007) tested the scale among an Australian sample and reported Chronbach's α ranging between .73 and .91. They also found the RAS to have good convergent validity with the stages of recovery measure (SRM)(Andresen, Oades, & Caputi, 2003) and the Mental Health Recovery Measure (MHRM)(Young & Ensing, 1999). Our Chronbach's alphas ranged from .75 to .92 for the five factors described in table 5.

Participants were also asked to self-report their age, race (White, Black, Other), gender, mental health diagnosis, and the peer support center activities in which they take part based on the known list of activities the participating centers generally offer to members, i.e., vocational training & rehabilitation programs, center maintenance activities such as general cleaning and food preparation, health and wellness enhancing programs, life-skills training to facilitate community functioning, and leisure and play oriented activities. Participants were free to include other more generalized activities that did not fit into these categories: all who responded to this portion of the questionnaire mentioned leisure and play type activities or one-off social events that are not part of the formal program of activities. There were no clinical assessments of psychiatric or psychological status or independent verification of self-reports.

Schizophrenia, major depression and bipolar disorder were the most common primary diagnoses reported (See Table 1). A number of participants reported co-morbidity. As would be expected, certain disorders coexisted with some clarity but some did not. We consulted with a generous colleague who is a practicing psychiatrist regarding the classification of co-morbidities. Any bipolar disorder type was then grouped as bipolar, same with schizophrenia. With either of those diagnoses a coexisting depression or anxiety was placed under the primary diagnosis (bipolar or schizophrenia). If they reported all three primary diagnoses, then they were placed under schizophrenia. Those reporting depression and bipolar were grouped under bipolar. Co-morbid schizophrenia and bipolar was treated as a separate diagnosis (9.1% of sample, Table 1). About 42% reported what amounts to symptoms rather diagnosis such as anger, other mood problems, hallucinations or that they are mentally unwell, and 5% either did not disclose any diagnosis/ symptoms or stated they did not know their diagnosis.

Data Analysis

Data were analyzed to assess the extent to which RAS scores would predict RES scores controlling for variance in participant demographics, self-reported mental health diagnosis and involvement in peer support center activities. In regression analyses, each of the self-esteem subscales was entered as a dependent variable. Predictors included the five RAS sub-scales, participant race, age, gender, diagnosis, and participation in peer center activities associated with self-esteem, i.e. leisure and play and generalized activities. Apart from age which was used as a continuous variable, all these data were converted into dummy variables. First, descriptive analyses compared the dependent variables and predictors (Table 1). With the exception of age (in years) demographic, diagnosis and activity involvement variables were categorical. Next, hierarchical multiple regression analysis was conducted. RAS variables were entered first in each of the regression models (model 1), followed by demographic and activity involvement variables (model 2). The diagnosis variable was entered last (Tables 2, 3 & 4, model 3). Data analysis was conducted using SPSS Statistics 17.0 software.

Results

Table 1 provides the unadjusted means, standard deviation, and correlation coefficients of global, positive and negative self-esteem. The self-esteem scale was scored so that scores would range from 1 (low) to 5 (high). Table 1 indicates that the mean scores of self-esteem were above the mid-score of 3.0. The scores generally ranged between 2.7 and 4.15. These self-esteem scores did not differ statistically by demographic, diagnosis or services use variables (Table 1). Self-esteem was related only to leisure and play (statistically significant, $p<.05$) and general activities (marginally significant, $p<.10$). These are unstructured non-programmatic activities and the association observed was with positive self-esteem and not global or negative self-esteem. Post-hoc analysis (results not shown) of the unadjusted relationships between self-esteem and diagnosis indicated that, in the case of global and positive self-esteem, the mean differences between bipolar and undisclosed diagnosis were statistically significant ($p<.05$). The difference in mean global self-esteem between participants self-reporting schizophrenia and bipolar reporters were marginally significant (Mean difference = 0.436, $p<.10$). In the case of negative self-esteem, the mean difference between participants disclosing depression and those with undisclosed diagnosis was statistically significant (Mean difference = 0.344, $p<.05$).

Table 1: Participant characteristics and means, standard deviation and correlations of self-esteem by predictor variables

		Global Self-Esteem		**Positive Self-Esteem**		**Negative Self-Esteem**	
	% (N=100)*	***M (SD)***	***p***	***M(SD)***	***p***	***M(SD)***	***p***
Total Sub-Scale Scores		3.348 (.753)		3.825 (.881)		3.113 (.997)	
Gender			.861		.403		.574
Female	61	3.359 (.756)		3.886 (.893)		3.159 (1.021)	
Male	39	3.331 (.757)		3.732 (.867)		3.039 (.967)	
Race			.654		.810		.240
White Caucasian	72	3.344 (.722)		3.861 (.835)		3.167 (.947)	
Black (African American)	16	3.250 (.810)		3.713 (1.090)		3.213 (1.153)	
Other	12	3.530 (.906)		3.764 (.907)		2.636 (1.019)	
Residence			.554		.066		.279
Rural	55.5	3.301 (.740)		3.913 (.878)		3.286 (1.044)	
Urban	45.5	3.400 (.774)		3.716 (.884)		2.907 (.907)	
Past 3 months Mental Health Treatment							
Case Management			.907		.508		.389
No	40.4	3.337 (.637)		3.897 (.796)		3.221 (.873)	
Yes	59.6	3.356 (.830)		3.775 (.939)		3.039 (1.074)	

Medication Management			.773		.305		.547
No	54	3.326 (.667)		3.736 (.911)		3.053 (.884)	
Yes	46	3.371 (.840)		3.922 (.847)		3.178 (1.113)	
Individualized Counseling			.892		.807		.760
No	77	3.340 (.721)		3.840 (.936)		3.136 (1.013)	
Yes	33	3.363 (.821)		3.794 (.773)		3.069 (.979)	
Group counseling			.308		.201		.622
No	76	3.396 (.719)		3.892 (.887)		3.082 (1.001)	
Yes	24	3.213 (.843)		3.625 (.851)		3.200 (1.003)	
Inpatient hospital			.879		.299		526
No	90	3.352 (.709)		3.855 (.844)		3.143 (.951)	
Yes	10	3.311 (1.136)		3.533 (1.208)		2.911 (1.411)	
Mental Health Diagnosis			.238		.889		.128
Schizophrenia	15.5	3.486 (.910)		3.743 (1.080)		2.771 (1.155)	
Bi-polar disorder	14.5	3.050 (.671)		3.667 (.922)		3.440 (.882)	
Co-morbid Bipolar & Schizophrenia	9.1	3.580 (.839)		4.040 (.793)		2.880 (.944)	
Depression	13.6	3.1		3.8		3.4	

		93 (.753)		40 (.836)		57 (.920)	
Other (unspecified)	42.7	3.339 (.642)		3.821 (.847)		3.135 (.958)	
Undisclosed	4.5	3.950 (.998)		4.150 (1.063)		3.113 (.997)	
Peer Center Activity Involvement							
Vocational rehabilitation program: No	80.9	3.350 (.771)	.989	3.857 (.886)	.780	3.125 (1.002)	.875
Yes	19.1	3.353 (.719)		3.788 (1.006)		3.082 (.993)	
General cleaning/work							
No	71.9	3.336 (.774)	.793	3.887 (.883)	.484	3.180 (.994)	.376
Yes	28.1	3.384 (.727)		3.736 (.967)		2.968 (.999)	
Food service program							
No	85.4	3.313 (.734)	.294	3.814 (.925)	.461	3.155 (.989)	.413
Yes	14.6	3.554 (.868)		4.015 (.794)		2.908 (1.041)	
Health and wellness program							
No	78.7	3.361 (.730)	.821	3.850 (.920)	.903	3.095 (1.002)	.719
Yes	21.3	3.316 (.860)		3.821 (.874)		3.190 (.992)	
Life skills training program							
No	58.4	3.371 (.807)	.842	3.689 (1.041)	.182	2.936 (.997)	.170
Yes		3.337		3.9		3.240	

		(.727)		53 (.787)		(.984)	
Leisure and play			.177		.018		.930
No	41.6	3.222 (.844)		3.578 (1.086)		3.128 (1.040)	
Yes	58.4	3.449 (.674)		4.040 (.691)		3.108 (.970)	
Other generalized activities			.211		.067		.774
No	43.3	3.229 (.779)		3.642 (.999)		3.161 (.995)	
Yes	56.7	3.440 (.734)		4.000 (.800)		3.098 (.998)	
Creative Arts Project Exposure			.370		.176		.801
Never participated	82.2	3.427 (.687)		3.932 (.821)		3.055 (.972)	
Past participant	17.8	3.279 (.805)		3.677 (.913)		3.111 (1.034)	
Over 12 months at Peer Center			.517		.867		.465
No	42.5	3.423 (.880)		3.773 (.843)		2.927 (1.033)	
Yes	57.5	3.297 (.724)		3.737 (.955)		3.102 (.970)	
	***M*(*SD*)**	**r**	***p***	**r**	***p***	**r**	***p***
Age (years)	44.05 (12.22)	-.012	.914	.058	.579	.065	.538
Recovery Subscales							
Reliance on others	4.01 (.853)	.328	.002	.595	.000	.038	.727
Personal confidence & hope	3.35 (.803)	.432	.000	.848	.000	-.284	.007
Willingness to ask for help	4.07 (.852)	.653	.00	.634	.00	-.028	.78
Non-dominance by symptoms	3.61 (.97	.390		.763		-.147	
Goal & success		.511		.646			

orientation Total RAS score	6) 4.11 (.800) 85.36 (16.36)	.624	0.000 .000 .000	.877	0.000 .000 .000	-.077 -.145	9.170 .485 .207

* Data from 10 of the original 110 participants was incomplete. *M*=mean, *SD*=standard deviation. r= Pearson's product-moment coefficient, *p*= P-value. Sample N was reduced by participants who did not provide reliable responses (e.g., not completing more than 90% of the questions) and/or requested that information be not used even if they did not withdraw their completed questionnaires. The latter might be participants' own test of researchers' commitment to informed consent protocols.

As expected, both global and positive self-esteem were positively correlated (p<.05) with the five sub-scales of RAS and the total RAS score (Table 1). The coefficients for positive self-esteem were much higher than those for global self-esteem, with marked differences in the case of personal confidence and hope and non-dominance by symptoms. Apart from the positive relationship between negative self-esteem and reliance on others, RAS subscales (and total RAS score) were negatively correlated with negative self-esteem as hypothesized. However, only the inverse association between negative self-esteem and personal confidence and hope was statistically significant (p<.01).

In regression analyses, the global and positive self-esteem models demonstrated moderate fit, explaining 48 to 51% of self-esteem variance (Tables 2 and 3), and were statistically significant (p<.001). Based on the F-test, the models for negative self-esteem demonstrated poor fit. That is, the RAS and demographic variables considered did not adequately account for observed negative self-esteem.

Unadjusted relationships between RES and RAS variables were not substantially changed by adjusting for demographics, diagnosis, and activity involvement (Tables 2, 3 & 4). In the case of positive self-esteem (Table 3), personal confidence and hope and willingness to ask for help were directly associated with self-esteem (p<.001). The correlations (unadjusted β) were robust at all levels of adjustment (Table 3). Personal confidence and hope was the only RAS variable marginally associated with negative self-esteem (p<.10), see Table 4. However, this negative association was attenuated by demographic variables. In Table 2, personal confidence and hope was also the only RAS variable associated with global self-esteem (p<.05) and remained robust at all levels of adjusting for participant characteristics (Table 2).

Table 2 Regressing global self-esteem against RAS variables

	Model 1 (R^2= .475, df= 5 , F=9.942, P>.001)					Model 2 (R^2= .524 , df=12, F=4.399, p<.001)					Model 3 (R^2= .524, df=13, F=3.983, P<.001)			
	B	*SE*	95%CI for *B*	*p*		*B*	*SE*	95%CI for *B*	*p*		*B*	*SE*	95%CI for *B*	*p*
Recovery subscales														
Reliance on others	-.108	.124	-.358 - .141	.387		-.118	.133	-.386 - .150	.381		-.111	.138	-.390 - .167	.425
Personal confidence & hope	.575	.177	.221 - .929	.002		.521	.184	.150 - .891	.007		.5190	.186	.145 - .894	.008
Willingness to ask for help	.150	.113	-.077 - .376	.191		.139	.122	-.107 - .385	.261		.140	.124	-.109 - .386	.264

Non-dominance by symptoms	.055	.139	-.124 - .334	.693	.123	.149	-.176 - .422	.411	.118	.152	-.187 - .424	.439
Goal & success orientation	-.074	.133	-.341 - .193	.581	-.067	.140	-.347 - .214	.635	-.066	.141	-.350 - .217	.641
Demographics												
Gender (ref=male)					-.204	.177	-.560 - .153	.256	-.195	.184	-.565 - .176	296
Race (Ref=white)					-.125	.121	-.368 - .118	.305	-.128	.123	-.374 - .119	.303
Residence (Ref=Rural)					.214	.169	-.125 - .554	.210	.231	.188	-.147 - .608	.225
Age (yrs)					.000	.007	-.015 - .014	.922	-.001	.008	-.016 - .014	.880
Art experience (ref=nil)					.061	.118	-.175 - .298	.604	.057	.121	-.185 - .300	.638
Activity Involvement												
Leisure & Play					.063	.208	-.355 - .482	.763	.066	.211	-.358 - .490	.755
General activities					.096	.208	-.320 - .511	.646	.087	.213	-.343 - .515	.686
Mental Health Diagnosis									.013	.061	-.109 - .135	.835

Table 3 Regression positive self-esteem against RAS variables

	Model 1 (R^2= .822 , df=5, F=53.600, P<.001)				Model 2 (R^2 = .849, df=12, F= 23.876, p<.001)				Model 3 (R^2= .851, df=13, F=22.026, P<.001)			
	B	*SE*	95%CI for *B*	*p*	*B*	*SE*	95%CI for *B*	*p*	*B*	*SE*	95%CI for *B*	*p*
Recovery subscales												
Reliance on others	-.067	.089	-.244 - .110	.450	-.081	.091	-.263 - .100	.373	-.062	.093	-.249 - .125	.507
Personal confidence & hope	.620	.125	.370 - .870	.000	.598	.125	.346 - .849	.000	.594	.126	.342 - .847	.000
Willingness to ask for help	.345	.081	.183 - .507	.000	.371	.084	.202 - .539	.000	.372	.084	.203 - .541	.000
non dominance by symptoms	.095	.097	-.100 - .290	.332	.128	.101	-.074 - .330	.211	.113	.102	-.092 - .318	.273
Goal & success orientation	.087	.095	-.103 - .277	.362	.063	.096	-.129 - .256	.512	.066	.096	-.127 - .258	.498
Demographics												
Gender (ref=male)					-.163	.121	-.407 - .081	.186	-.135	.125	-.387 - .117	.286
Race (Ref=white)					-.149	.082	-.314 - .017	.077	-.155	.083	-.322 - .011	.066
Residence (Ref=Rural)					-.118	.114	-.346 - .110	.303	-.068	.127	-.322 - .187	.595
Age (yrs)					-.000	.005	-.009 - .010	.943	-.000	.005	-.010 - .009	.890
Art experience (ref=nil)					.054	.080	-.106 - .215	.500	.042	.082	-.122 - .205	.612
Activity Involvement												
Leisure & Play					.036	.138	-.241 - .312	.797	.043	.138	-.234 - .320	.756
General activities					.068	.138	-.211 - .343	.633	.042	.141	-.240 - .350	.764
Mental Health Diagnosis									.037	.041	-.045 -	.369

.120

Table 4 Regression negative self-esteem against RAS variables

	Model 1 (R^2=.080, df= 5, F=.954, P>.10)				Model 2 (R^2 =.164, df=12, F=.784, p<.10)				Model 3 (R^2= .164, df=13, F=.713, P>.10)			
	B	*SE*	95%CI for *B*	*p*	*B*	*SE*	95%CI for *B*	*p*	*B*	*SE*	95%CI for *B*	*p*
Recovery subscales												
Reliance on others	.152	.212	-.273 - .577	.477	.166	.228	-.292 - .624	.469	.169	.236	-.306 - .644	.477
Personal confidence & hope	-.531	.301	-1.135 - .072	.083	-.446	.314	-1.077 - .186	.163	-.446	.318	-1.085 - .193	.167
Willingness to ask for help	.041	.193	-.345 - .427	.832	.076	.209	-.3446 - .496	.718	.076	.211	-.349 - .501	.720
non dominance by symptoms	-.016	.237	-.491 - .460	.947	-.118	.254	-.628 - .392	.644	-.120	.259	-.642 - .401	.645
Goal & success orientation	.250	.227	-.205 - .704	.276	.211	.238	-.268 - .690	.381	.211	.241	-.273 - .695	.385
Demographics												
Gender (ref=male)					.251	.302	-.357 - .859	.410	.255	.314	-.377 - .887	.421
Race (Ref=white)					.093	.206	-.321 - .508	.652	.092	.209	-.329 - .513	.661
Residence (Ref=Rural)					-.509	.288	-1.088 - .070	.083	-.502	.320	-1.146 - .142	.124
Age (yrs)					.003	.012	-.022 - .029	.786	.003	.013	-.023 - .029	.803
Art experience (ref=nil)					-.066	.201	-.469 - .338	.744	-.068	.206	-.482 - .346	.743
Activity Involvement												
Leisure & Play					-.073	.355	-.787 - .641	.839	-.071	.360	-.795 - .652	.844
General activities					-.111	.352	-.819 - .598	.755	-.115	.363	-.846 - .616	.754
Mental Health Diagnosis									.006	.103	-.202 - .214	.955

Table 5 RAS subscales and their reliability estimates

RAS Subscale (and items)	**Cronbach's Alpha**
Personal confidence and hope	0.92
Fear doesn't stop me from living the way I want to	
I can handle what happens in my life	
I like myself	
If people really knew me, they would like me	
Something good will eventually happen	
I am hopeful about my future	
I continue to have new interests	
I can handle stress	
Willingness to ask for help	0.86
I know when to ask for help	
I am willing to ask for help	
I ask for help, when I need it	
Goal and success orientation	0.83
I have a desire to succeed	
I have my own plan for how to stay or become well	
I have goals in life that I want to reach	
I believe I can meet my current personal goals	

I have a purpose in life	
Non-dominance by symptoms	0.75
My symptoms interfere less and less with my life	
Coping with my mental illness is no longer the main focus of my life	
My symptoms seem to be a problem for shorter periods of time each time they occur	
Reliance on others	0.77
Even when I don't care about myself, other people do	
I have people I can count on	
Even when I don't believe myself, other people do	
It is important to have a variety of friends	

Discussion

In this study we used the recovery assessment scale that focuses on improvements in self-agency, hope and perceived mastery of symptoms. We examined the association between these domains of recovery and self-esteem among a sample with several different psychiatric diagnoses. The RAS was associated with global and positive self-esteem as hypothesized. As anticipated the robust association was the one observed between positive self-esteem and RAS subscales that are reflective of positive self-concept. Not all domains captured by the RAS were found to be related to self-esteem. This does not mean that participants in our study did not achieve recovery in those contexts, but rather that the domains of the RAS that are reflective of self-concept were correlated with an established measure of recovery, i.e., the RES.

Scores on the personal confidence and hope subscales of the RAS were significantly associated with positive self-esteem in our study. Participants had above average scores on perceived mastery of symptoms (Table 1, non-dominance by symptoms). Given that the absence of symptoms or illness is generally considered to be the most desirable treatment and rehabilitation outcome (Andreasen, et al., 2005; Boden, et al., 2009; Corrigan, 2006b; Drake, et al., 2006; Harvey & Bellack, 2009; Robinson, et al., 2004; Xie, et al., 2005), it is interesting to note that non-dominance by symptoms was associated with positive and global self-esteem in unadjusted analysis. However, in the regression analyses that controlled for demographic characteristics and participants' scores on personal confidence and hope, this relationship was attenuated. These observations suggest a complex relationship between non-dominance by symptoms and self-esteem. Resnick and colleagues examined correlates of recovery and found a significant association between recovery orientation and lower severity of depressive symptoms.

In our study, negative self-esteem was not related to scores on the RAS in either descriptive or multivariate analysis. The negative correlation between negative self-esteem and personal confidence and hope was not robust. The model fit estimates for negative self-esteem suggest that RAS variables did not explain negative self-esteem in this sample. Adjusting for differences in demographics and mental health diagnosis did not improve the explanatory power of RAS variables, including those RAS variables that are theoretically reflective of self-concept.

However, we observed some relationship between mental health diagnosis and self-esteem only in unadjusted analysis. Most notably between participants self-reporting bipolar disorders vs. those with undisclosed diagnosis (including those who stated they had no diagnosis). The differences in mean global self-esteem between participants self-reporting schizophrenia and bipolar reporters were marginally significant, most likely because of the co-morbidity of schizophrenia and bipolar. It is possible that self-reports might not have accurately distinguished co-morbid bipolar and schizophrenia. In a study reported by Karatzias and colleagues (2007), adults with schizophrenia who had a co-morbid anxiety or affective disorder were observed to have low self-esteem (based on the Rosenberg Self-Esteem Scale) as well as poor functioning and higher negative appraisal of their mental health status. Overall, and contrary to our hypothesis, self-reported mental health diagnosis did not moderate the relationship between RAS and RES variables among our sample.

While other studies have indicated that self-esteem might be influenced by demographic variables of age, gender, educational achievement, income, and employment among mental health samples (Salsali & Silverstone, 2003), we considered age, gender and race variables and found no relationship with self-esteem.

Consumer-operated services have been hypothesized to facilitate recovery. In our study, we observed some relationship between self-esteem and the non-programmatic consumer-directed activities. Programmatic activities such as health and wellness programs, job preparation support, and life skills training were not related to self-esteem in our sample. However, the positive association between positive self-esteem and either leisure and play or involvement in generalized social activities was attenuated by recovery variables. It is likely that personal confidence and hope and willingness to ask for help moderated these relationships with positive self-esteem.

Study Limitations

Data analyzed were obtained just before art classes commenced but after peer center members had had the chance to register for classes. It is likely that the anticipated commencement of art classes might have primed some participants to respond to questions about goal and success orientation more favorably than those for whom current art-class attendance was not a novelty. The mental health statuses considered did not cater for severity of illness/symptoms and how it might moderate the relationship between RAS and RES variables. In other samples, the RAS total score has been shown to correlate negatively with severity of psychiatric symptoms (McNaught, et al., 2007).

The RES is structured to indicate an inverse relationship between negative self-esteem and positive self-esteem. However, we observed some counterintuitive relationships, particularly among female participants. This could have been influenced by the fact that positive self-esteem items preceded negative self-esteem items on our questionnaire. Therefore, some participants might have paid less attention to items differences and so maintained the high scores they were allocating to positive self-esteem items. We had anticipated this error at the time of the study and had informed participants about the differences in the items. It could also be indicative of the fact that the two subscales tap into two different aspects of self-concept (Corwyn, 2000) and that most participants were aware of these and their responses reflect that degree of insight.

Although the RAS has demonstrated convergent validity with other recovery scales, it has been noted that the scale does not consider all the aspects of recovery that have been reported by mental health consumers (McNaught, et al., 2007). It also does not adequately capture objective aspects of clinical remission, captured by established clinician-completed scales/protocols. However, McNaught and colleagues (2007) have advocated for the potential of the RAS to inform consumer-led interventions.

Conclusions

We have attempted to examine the extent to which scores on the Recovery Assessment Scale (RAS) might be related to how adults with mental illness score on the Rosenberg Self-Esteem scale (RES). Our findings collaborated findings that the RAS demonstrates concurrent validity with self-esteem among samples of mental health consumers (Corrigan, 2006a). Based on our findings, reliance on others, non-dominance by symptoms and goal and success orientation might not to be related to the construct of self-esteem among participants in consumer-directed mental health services. Probably the RAS is biased towards positive self-concept. Participants in this study evidently maintained positive self-esteem irrespective of their symptom management capabilities or goal and success orientation. Jacobson and Greenley (2001:483) have theorized that recovery from mental illness entails "recovering the self by reconceptualizing illness as only part of the self, not as a definition of the whole…As consumers reconnect with their selves, they begin to experience a sense of self-esteem and self-respect." Perhaps the RAS is best considered within a stages-of-recovery framework, given its convergent validity with the stages of recovery measure (Andresen, Oades, & Caputi, 2003).

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The Therapeutic Environment of Long-term Rehabilitation Units for Patients with Chronic Mental Illness: A Participant Observation Study in Four Hostels in Greece

Despina Sikelianou
Psychologist, Ph.d in Social and Community Psychiatry
Koumanioti 69, Patras, 26222, Greece

Venetsanos Mavreas
Professor of Psychiatry
Department of Psychiatry, University of Ioannina, Medical School, Ioannina, Greece

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Abstract

The aim of this study was the detailed presentation and study of the factors regarding the organization of the therapeutic environment of four newly-established long-term units for the rehabilitation of patients with chronic mental illness, during their first year of establishment, within the framework of materialization of the ten-year European programme "Psychargos" 1st Phase 2000-2010 aiming at modernizing the mental health care system in Greece. The ethnographic method was used and the research was qualitative using participant observation, interviews and questionnaires. The research process was divided into three phases over one year (March 2001 – February 2002). The results have shown that factors such as good and proper implementation of internal and external supervision, continuous training of the therapeutic group, the application of clear and multidisciplinary roles of the caregivers, the positive attitudes and positively-expressed emotions of caregivers towards patients, etc. lead to a well-organized therapeutic environment within a new long-term unit for patients with chronic mental illness.

Key words: Quality of care, Mental Health Professionals, Organization, Long-term units, rehabilitation

Introduction:

The psychosocial rehabilitation of patients with chronic mental illness has begun to be realized over the last twenty years in Greece, initially with the materialization of the programmes Leros I and II aiming at deinstitutionalizing the chronic mental patients of the mental hospital at the island of Leros and now continuing with the implementation of the European programme "Psychargos" lasting 2000-2010. The aim is the gradual replacement of the institutional system of psychiatric care with a network of alternative preventive and therapeutic services and structures, on the basis of the principle of sectorization and developing community mental health services (MYP 2000). Within the framework of this programme, approximately three hundred sixty nine (369) rehabilitation housing units (104 Long-term units, 91 Boarding Homes and 174 protected appartments) for patients with chronic mental illness are currently available in the fifty-two (52) prefectures of our country. The therapeutic environment of a long-term unit provides appropriate conditions for the residents of these units to be able to regain the abilities and functions negatively affected by the institutional environment or mental illness.

The organization of a long-term unit comprises three developmental phases. In the first phase (Initial Stage), the therapeutic environment is characterized by flexible organization and concurrence of caregivers on objectives and a tendency towards self-administration of the unit while the relations between the therapeutic group and the main institution (mental hospital) are formal.
In the second phase (Expansion Stage), sub-groups are formed and there is a climate of optimism for successful rehabilitation. There is also competition between the sub-groups, and with other similar services and the main institution (mental hospital).

In the third phase (Establishment and Recognition Stage), the long-term unit becomes a decentralized unit. The members of the therapeutic group trust each other and express collective satisfaction, emphasizing on the organizational and social needs and objectives (Madianos 1994).

The function of a long-term unit therapeutic environment is efficient when treatment of mental illness is in accordance with the social changes and developments and the personnel do not show signs of inactivity and passivity. The difficulty to deal with chronic mental illness faced by caregivers is due to their 'fundamental fear of the insane' (the threat posed to the mental health of caregivers themselves) with two predominant feelings, the feeling of intrusion of the mentally-ill patient on the personal inner space of the caregivers and the feeling of emptiness, leading to a significant distance from the psychotic patient. Consequently, patients show signs of institutional behaviour (Hochmann (2003). In accordance with Katz and Kirkland (1990) and Curtis and Hodge (1994), the presence of violence and institutionalized behaviour of the patients results from failure to apply clear and multidisciplinary caregiver roles. In accordance with Damigos (2003) and Anderson (2003), the absence of proper internal and external supervision of the unit leads to the inability of caregivers to play clear and multidisciplinary roles, whereas Foster (1998) points out that caregivers run a risk when playing multidisciplinary roles and behaving 'in the same way as each other'. This can lead caregivers to experience burn out and failure of the therapeutic procedure.
Lack of empathy expressed by caregivers leads them to keep a distance from the patients (Minkoff and Stern 1985). The rejection and criticism of caregivers towards patients results in their receiving poor quality medical care services (Hastings et al. 1995, Morgan and Hastings 1998, Snyder et al 1994), while expression of negative attitudes and feelings towards the patients leads to bad relations between the caregivers and the patients and also to the failure of the latter to accomplish their rehabilitation tasks (Van Humbeek et al 2001, Tartan and Tarrier 2000, Bebbington and Kuipers 1994, Butzlaff and Hooley 1998, Kavanagh 1992). The implementation of training programmes for the personnel of a long-term unit is necessary and effective because it improves the communication skills between caregivers and patients and between caregivers themselves and offers caregivers a 'clear comprehension of their own self-image and that of others' and assists in the direct understanding of the actual therapeutic values of rehabilitation (Van Audenhove and Van Humbeek 2003, Piatt et al. 2002, Rabkin et al 1998, Neilsen et al 1985).

Aims and research hypotheses:
The aim of this research study is to explore the factors for the organization of the therapeutic environment in four

newly-established long-term units for rehabilitation of patients with chronic mental illness, during their first year of establishment.

The evaluations from the European deinstitutionalization programmes Leros I and Leros II, regarding the communication of the caregivers, the presence or absence of the internal and external supervision of the long-term unit, the application of clear and multidisciplinary roles of the caregivers, the attitudes and expressed emotions of the caregivers towards the patients, the implementation of training programmes for caregivers at workplace, the relation of the unit with the Mental Hospital, the level of the long-term unit independence and the handling of mental illness constituted the research questions of this study.

Research Design

Settings and Staff

The long-term units began operating in 2001 in accordance with the European programme "Psychargos" 1st Phase. Long-term units A and B are located in two cities in Western Greece, while long-term units C and D are located in the same city as the Mental Hospital of the area. All four long-term units were established at the same period of time. 46 mental health professionals worked in these long-term units.

Study Sample

The sample consisted of forty-six mental health professionals: thirty-eight women and eight men of various specializations (professional and non-professional staff), such as: Psychologists, Social Workers, Nurses, Occupational Therapists, Trainers and Auxiliary Staff. Long-term units C and D were also staffed with a Special Teacher and a Health Visitor. Ages ranged from 18-50 years old and the majority of professionals were women.

In long-term unit A, there were 11 mental health professionals, aged from 25-50 years old, and 15 residents. 12 mental health professionals worked in long-term unit B, the number of residents being 14. The majority of caregivers in both long-term units was between 18-25 years old and had no university education and all caregivers had no specialization and experience with regard to the rehabilitation of mentally-ill patients. The only difference between the two long-term units was that long-term unit A did not have an Occupational Therapist.

The number of caregivers in long-term unit C was 15 with 22 residents and, in long-term unit D, the caregivers totaled eight with five residents. The caregivers of both long-term units had experience of working with chronic mental health patients, all of them being ex-employees of the Mental Hospital. The personnel of long-term unit D worked simultaneously at the Day Centre of the hospital, which was in the same building as the long-term unit. The personnel of both units were not specialized in the rehabilitation of mentally ill patients. The nursing staff of both long-term units had no university education and did not include an Occupational Therapist.

Method and Data Collection

Qualitative Analysis

The ethnographic method was used for the implementation of this study, as it is the most appropriate method for qualitative research and in-depth investigation and analysis of issues studied for the first time. The approaches used in this study were participant observation and unstructured interviews. The entire research procedure and data collection was conducted from March 2001 to February 2002 and divided into three Phases (1st Phase – A' trimester, 2nd Phase – B' semester, 3rd Phase – C' trimester), with visits taking place once a week during the morning shift from 09:00 am – 14:00 pm.

In the first Phase (March-June 2001) of this study, we were interested in studying the formation of relations between the members of the therapeutic group, their efforts to develop a degree of cohesion and specific therapeutic goals. In accordance with the above-mentioned goals, only long-term units A and B were studied, because the personnel in these long-term units had no professional experience and were unacquainted with each other, unlike the professionals in long-term units C and D, who were skilled and knew each other from their previous employment in the same department of the Mental Hospital. The questions were addressed only to psychologists and nurses because the remaining staff needed time to adjust to their working environment.

The duration of the 2nd Phase (July 2001 – December 2001) was six months, divided into two terms to serve both the proper implementation of the research and the best possible data collection. Its aim was to investigate the maturing of already-existent and established relations among the members of the therapeutic group and those they had with the patients (expressed emotions, attitude of caregivers, the communication level among caregivers and that which they had with the patients, the decision-making procedure, professional boundaries, the level of satisfaction with the therapeutic work) and the emergence of new tendencies and needs. All four long-term units were studied, because at this stage all were progressing and could be studied simultaneously in terms of the objective of this phase. 46 professionals from all four long-term units participated in this phase.

The aim of the 3rd Phase (December 2001 – February 2002) was to investigate the characteristics for the establishment of the level of self-administration and independence of each unit from the implementing body, the 'opening' of the unit to the community and a review of therapeutic goals.

Research Results

Long-term Unit A

Regarding the development of relations among the members of the therapeutic group in the 1st Phase, strong conflicts and disputes were ascertained among members of the scientific and nursing staff. There was no clear designation of internal and external supervisor for the therapeutic group by the implementing body so that these problems could be dealt with. In the 2nd Phase, caregivers began to form three sub-groups, scientific, nursing and auxiliary staff. The conflicts between the members were significantly reduced because they were 'transferred' to the external environment and specifically to the research process. All the caregivers refused to continue to participate in the research process because they feared that "… the results of this study with regard to this particular long-term unit were to be made known to the Ministry of Health and they might lose their jobs…..". The staff nurse, a dynamic and strong personality, undertook the responsibility and supervision for the proper function of the unit. The members of the nursing staff had developed very good co-operation, achieved a large degree of unity and showed flexibility in decision-making and therapeutic work co-ordination. On the other hand, the members of the scientific staff showed signs of fragmentation (groups of two or one) and also signs of a remote and isolated sub-group. In all three phases, it was ascertained that the therapeutic group of long-term unit A did not manage to achieve a large degree of cohesion. The members of the scientific group failed to act in a professional capacity, whereas the members of the nursing staff had adapted to their clear professional role (1st Phase). During the 2nd Phase, tendencies to re-determine and re-assign professional responsibilities were ascertained, a fact that led the members of the nursing staff to have a positive attitude towards expectations of the efficiency of their role, whereas the members of the scientific staff had a negative attitude and expectations (3rd Phase)

Regarding the attitudes of caregivers towards the residents-patients, in all three phases, these were characterized by signs of rejection (scientific staff) and signs of acceptance (nursing staff). The members of the nursing staff showed positive attitudes towards the patients, whereas the members of the scientific staff showed negative attitudes as well as signs of distance and fear of the patients, resulting in some members of the latter presenting with symptoms of stress (2nd Phase). The activity groups working with the patients were introduced in the 2nd Phase and it was ascertained that they showed signs of not abiding strictly by the working hours, lack of specific roles and objectives and lack of a stable co-ordinator. This resulted in signs of violence and institutionalized behaviour from the patients. The therapeutic groups and the activity groups were assisted by a permanent co-ordinator (psychologist) during the 3rd Phase but still demonstrated the above-mentioned characteristics. The main emotions expressed by caregivers towards the patients were stress and insecurity (1st Phase), verbal negative expression of emotions (2nd Phase) and a slight reduction in negative emotions in the 3rd Phase.

All caregivers agreed that there should be training programmes, with the aim of improving their courage and strength.

The attitude of the community was initially negative (1st Phase), while during the 2ndrd phases the attitude of the community was more positive, a fact that coincided with the ‘opening’ of the unit to the community (e.g. summer vacations in the wider region of the community, patient walkabouts, etc.). The caregivers showed signs of becoming independent of the administration of the general hospital in that region; however, independence was not ultimately achieved.

Long-term Unit B

The relations between caregivers of long-term unit B were characterized by mutual trust, high level of cohesion and unity and very good co-operation. The caregivers were particularly flexible in their co-operation in all three phases, and the only difference was that traces of dissatisfaction on behalf of the nursing staff were ascertained during the 2nd Phase, because they believed that the scientific staff did not place due confidence in their group. At the end of the 2nd Phase, a training programme for a period of one (1) month took place within the staff working environment. After the completion of this training programme, the therapeutic group began functioning as a ‘cohesive group’.

Long-term unit B had an internal supervisor (psychologist), who was designated by the administration of the local General Hospital the unit belongs to, according to his scientific qualifications. The main characteristic of the internal supervisor was that he applied himself to flexible co-ordination of actions by taking direct decisions and developing initiatives and innovations to solve problems (3rd Phase).

The direct self-assignment of the caregivers according to their professional roles, the application of their professional and multidisciplinary roles and the positive expectations of their role efficiency in the therapeutic work were also ascertained.

The attitudes of caregivers towards the patients of the long-term unit were generally positive. In particular, the scientific staff maintained formal and positive attitudes, while the nursing staff expressed feelings of fear and a distant attitude (1st and 2nd Phases). After completion of the training programme, more positive attitudes and expectations of all members of the therapeutic group were ascertained (3rd Phase).

The implementation of the therapeutic programme was strictly enforced through the operation of therapeutic groups and activity groups (1st Phase). The groups had clear goals and the patients expressed socially acceptable forms of behaviour. At the same time, caregivers participated in joint activities with patients (e.g. joint walks into the city for shopping, having lunch with them, going for a coffee together in the city, etc.) (3rd Phase). The caregivers agreed on the necessity of training programmes, with the aim of improving the efficiency of their professional and therapeutic roles. Initially, attitudes of the community towards the unit were negative (1st Phase). Later, (2nd and 3rd Phases) it was ascertained that attitudes changed into positive (‘opening’ of the unit to the community). In conclusion, tendencies of the caregivers to become independent of the administration of the general hospital of the city were ascertained and the long-term unit could be characterized as an independent unit.

Long-term Unit C

Co-operation between the caregivers was excellent; they developed trust in each other and complemented one another’s role. The therapeutic environment was organized according to the standards of organization of the mental hospital and caregivers continued to be dependent on the Mental Hospital. The chain of command between the members of the therapeutic group was the same as that of the mental hospital, with the staff nurse designated as internal supervisor.

The relations of caregivers with patients were good, especially on the part of the nursing staff. The scientific staff maintained more formal relations with the patients. The therapeutic programme of the therapeutic and activity groups was consistent and strictly enforced. The nursing staff may possibly have experienced feelings of frustration regarding the effectiveness of their therapeutic work and had reservations about the progress of patients (2nd and 3rd Phases), expressed through an indirect distant or spurning attitude towards the patients. In contrast, the scientific staff expressed more positive and formal attitudes. All caregivers expressed a desire for the implementation of training programmes and were looking for scientific motivation in order to improve their professional roles.

The attitude of the community was negative regarding the presence and operation of the unit in all study phases of the long-term unit (2nd and 3rd Phases). Finally, no tendency for independence (decentralization) of the unit from the administration of the mental hospital was ascertained.

Long-term Unit D

The therapeutic group had developed good relations of co-operation and trust in each other, showing a high level of cohesion. However, the pressure put on the members of the therapeutic group by the administration of the mental hospital to work simultaneously in two units (Day Centre and long-term unit D) led to a situation characterized by fragmentation within the group. The fact that on the whole the caregivers were obliged to render their services to both units simultaneously caused them to feel discontent with and to spurn the patients in this unit. The nursing staff reacted more negatively to working simultaneously in the Day Centre and in a therapeutic environment where the work resembled that of a mental hospital. The scientific staff did not show negative attitudes as they worked fewer hours in the long-term unit, while the nursing staff expressed more negative and distant attitudes towards the patients of the unit. The patients of the unit demonstrated strong negative behaviour resulting in isolation, as they refused to participate in the activity groups. The resistance of patients reduced significantly during the 3rd Phase and this coincided with the simultaneous reduction in the ‘opposition’ of caregivers to working in both units simultaneously as they complied with the orders of the mental hospital (3rd Phase).

The therapeutic staff made efforts to change the therapeutic environment of the long-term unit from that of the Day Centre. This contributed to re-determining how therapeutic roles should be applied, aiming to achieve the best possible performance and efficiency of the therapeutic goals for each unit separately. Moreover, caregivers deemed it necessary to improve their therapeutic roles through implementation of training programmes. The relations of dependency maintained between the members of the therapeutic group and the administration of the mental hospital did not lead to tendencies towards self-administration of the long-term unit.

Discussion

Stagnation in the therapeutic environment of long-term unit A and improper function in terms of the organization of the therapeutic group made it difficult for caregivers to undertake specific responsibilities regarding the organization of the therapeutic programme of the unit according to the needs of in-patients. Flexible organization in combination with the absence of designated internal and external supervisors of the unit, the problems in the relations among staff members, lack of collective effort in therapeutic planning, ambiguity of therapeutic roles and failure in the application of defined professional and supplementary roles led to unavoidable problems for both the smooth operation of the programme in the unit and the achievement of rehabilitation therapeutic goals (Katz & Kirkland 1990). The distance kept by the scientific group between themselves and their patients and the negative expectations for the therapeutic outcome (Cottle et al 1995, Herzog 1998, Stark et al 1992, Kuipers & Moore 1995) led to the development of negative attitudes and emotions (e.g. critical remarks, incorrect arbitrary evaluations of patients, defensive attitude – resistance) (Ball et al 1992, Van Humbeek & Van Audenhove 2003, Snyder et al 1994, Moore et al 1992, Oliver & Kuiper 1996, Finemma et al 1996, Van Humbeek et al 2002). The loose application of therapeutic activities (Watson et al 1980) – and the indifference of patients to what these entailed – led to the development of institutional and violent behaviour by patients (Butzlaff & Hooley 1998, Wearden et al 2000, Van Humbeek et al 2001, Barrowclough et al 2001, Tattan & Tarrier 2000, Weigel & Collins 2000). The expression of negative behaviour by the staff towards patients may be associated with the possible experience of intrusion and emptiness of emotions by the staff itself (Hochmann 2003).

In contrast, the effectiveness of the therapeutic programme in long-term unit B enabled the caregivers to be more flexible and ready to meet new needs resulting from the changes in the social environment of the long-term unit.

The social sufficiency of the long-term unit environment was evident by: i. the direct attention paid by the therapeutic group to patients and ii. the positive interaction between caregivers and patients. The prompt designation of an internal supervisor for the therapeutic group on the basis of scientific qualifications contributed to the maintenance of good relations of co-operation among the staff members, development of therapeutic goals and efficiency of therapeutic work (purposive system thinking) (Foster & Roberts 1998, Adair 1983, Hinshelwood 1989, Rushton & Nathan 1996).

The therapeutic environment of long-term unit B was based upon a well-organized therapeutic plan with the following main characteristics: i. individualized therapeutic intervention and strict application of the therapeutic programme (Curtis & Hodge 1994), ii. encouragement of patients to become independent and express their personal choices (Lavender 1985, Shepherd 1984), iii. positive expectations of staff for a therapeutic outcome together with positive attitudes and positively-expressed emotions towards patients and, finally, iv. socially-acceptable forms of patient behaviour (Betz 1969, McCarthy & Nelson 1991, Hull & Thompson 1981, Kruzich 1985 and Van Humbeek et al 2001). The presence of capable internal and external unit supervisors, the organization of the chain of command in the therapeutic group, the implementation of training programmes and strictly-prescribed therapeutic goals all appeared to contribute to the development of positive characteristics in the therapeutic environment of the unit.

The traditional form of administration of units C and D, based on the standards of administration of the Mental Hospital, was largely due to relations of dependency that had developed between the caregivers and the Mental Hospital but also because they had adopted the 'way of thinking of the mental hospital'. The fixed views of caregivers on chronic mental illness, the continuous interventions by the administration of the Mental Hospital in the organization of the unit and the absence of substantial internal and external supervision of the unit did not help the therapeutic group of unit C to promote their therapeutic work for rehabilitation of patients substantially. Consequently, the members did not use therapeutic techniques and methods for the rehabilitation of patients and did not proceed to any substantial changes in the therapeutic environment of the long-term unit, the organization of which resembled that of the Mental Hospital (Astrachan et al 1970). The therapeutic group of unit D showed signs of inactivity, passivity and lack of initiative because of other reasons, too, such as the pressure applied by the Mental Hospital to work simultaneously in both units (unit D and Day Centre) and the preference of the therapeutic staff members to work only in the Day Centre. Such negative attitude and behaviour probably reflects emotions of intrusion and emptiness experienced in the past due to frequent contact between caregivers and chronic patients (Searles 2003, Hochmann 2003).

Conclusions

The well-organized therapeutic environment of a long-term unit for rehabilitation of chronic mental patients is a significant prerequisite for both normal development of chronic mental illness and efficiency of rehabilitation of patients. A long-term unit should not be isolated from the social and cultural developments of its time and the patients should feel that they are part of the community in which they live and work.

This study showed that the primary and principal factor in a well-organized long-term unit environment was prompt designation of internal and external supervisors for the unit by the implementing body, with regard to not only newly-established long-term units with inexperienced therapeutic staff but also those employing expert mental health professionals. The internal supervisor should be a member of the therapeutic group and be designated only by the implementing body on the basis of his scientific and organizational qualifications. The presence of an internal supervisor is significant because any problems and conflicts that may arise within the therapeutic group can be settled or prevented through regular and weekly meetings with staff. The presence of an internal supervisor encourages caregivers to understand precisely their clearly-defined therapeutic and supplementary roles and apply them. In this way, role ambiguity of caregivers is avoided. Moreover, the presence of a supervisor serves as a 'protective umbrella', because this can help him take decisions after having 'listened to' the needs of the caregivers.

The second yet basic factor in a well-organized long-term unit environment is the continuous training of the staff. Most mental health professionals, including skilled ones, have neither undergraduate nor postgraduate level-specific knowledge in terms of rehabilitation of patients. Of course, it is undeniable that the training programmes that do take place occasionally and unsystematically aim only at the provision of knowledge and skills regarding the treatment of mental illness, based on psychotherapeutic methods and techniques, not enabling caregivers to develop more positive attitudes and behaviors towards chronic mentally-ill patients. The implementation of continuous training programmes within the working environment can help caregivers to: i. deal much more easily with the intensity of their feelings and negative emotions developed in their inter-therapeutic relations, ii. be able to identify and settle possible signs of frustration that may be evident in their inter-therapeutic relations, thus avoiding burn out, iii. have a positive attitude and show empathy for the patient and iv. 'listen to' the needs of the patients. Consequently, the therapeutic work becomes more substantial and resident-oriented.

The third factor in achieving a well-organized long-term unit environment involves the attitude of the implementing body towards the staff of the unit. The presence of the implementing body in the therapeutic environment of the long-term unit should be substantial, its role being a subsidiary and supportive one, not interventional. This can be achieved by: i. prompt designation of internal and external supervisors for the unit, ii. organization and implementation of training programmes for the staff members, iii. staffing of a well-organized therapeutic group, in which all members should be professionally ready to work in such an environment, either applying their current specialization skills to the rehabilitation of psychiatric patients or using their experience from the sector of psychiatric rehabilitation, iv. substantial rotation of staff to various psychiatric units in order to prevent the appearance of burn out syndrome, v. promotion of unit independence and self-administration, vi. substantial support that meets the needs of patients and caregivers, but which does not serve financial interests such as: absorption of funds and unequal allotment of resources.

The fourth factor concerns the rotation of staff to various psychiatric units, in order to prevent the appearance of burn out syndrome. Rehabilitation is difficult and therefore administration has to use this method with the assistance of the internal supervisor of the unit.

The fifth and last factor to play a significant role in a well-organized long-term unit environment concerns the organization of the chain of command. The therapeutic group of the long-term unit functions better when there is a clear-cut chain of command. The members of staff are each separately oriented in accordance with the function of their particular role and feel safe in complementing one another's role.

The above-mentioned findings cannot be put into general use, as they only constitute indicative data with regard to the long-term units studied in this research. However, they could be taken as an impetus for new qualitative and quantitative research.

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The Psychosocial Rehabilitation Needs of Residents of a Half -Way House for Mental Health Care Users in Durban, South Africa

Barbara Simpson,PhD
School of Social Work and Community Development
University of KwaZulu- Natal
Durban
South Africa

Thamary Zambuko, B.S.S. (Social Work)
Masters student

School of Social Work and Community Development
University of KwaZulu- Natal, Durban, South Africa

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Correspondence to: Dr B Simpson
School of Social Work and Community Development
University of KwaZulu- Natal
Durban
South Africa
Simpson@ukzn.ac.za

Abstract

Psychosocial rehabilitation services are not well developed in South Africa. This article examines the psychosocial rehabilitation needs of a group of people living in a half way house in Durban, South Africa. In depth interviews were held with 30 residents. The challenges experienced by residents and the areas in which they required services were identified. Recommendations for the development of a psychosocial rehabilitation programme are made and the role of social work and health care professionals in the field of psychosocial rehabilitation generally is discussed.

Key words: psychosocial rehabilitation, half way house, South Africa.

Introduction:

Half-way houses were originally established to provide intermediary care between hospital and community living for mental health care users (MHCUs). They were intended to provide on-going rehabilitation and support to MHCUs who had been newly discharged from hospital for a limited period of time following which the person would be able to move to independent housing. In many cases, however, this has not happened and half-way houses have become a form of supported housing for people living with psychiatric disabilities.

Grace Home (a pseudonym to protect the identity and privacy of the residents) is a half-way house in Durban that provides accommodation for 45 people. Two care-givers work shifts, a psychiatric nursing sister works half day during the week and a social worker visits once per week. The ratio of male to female residents is approximately 60:40 and nearly 80% of residents are white. Sixty percent of the residents are over the age of 40 and 27% are over the age of 50. More than half the residents have been living at the Grace Home for over 11 years and 25% have stayed there for between 16 and 20 years. For many residents, Grace Home has thus become their permanent home. Grace Home has a number of recreational programmes – an exercise programme every morning is compulsory and residents are encouraged to join in other activities such as music classes. Attempts are made to encourage residents to gain employment and move to more independent living arrangements, but these are ad hoc and seem driven by the motivation of individual residents. The management and residents of Grace Home identified the need for a well developed, comprehensive psychosocial rehabilitation programme.

This article describes the first phase of a research project to develop, implement and evaluate a psychosocial rehabilitation programme at Grace Home. The overall research project uses a intervention research design (Thomas and Rothman, 1994) but this article focuses on the analysis phase which aimed at identifying the psychosocial rehabilitation needs of residents at Grace Home. The article begins with a literature review which describes psychosocial rehabilitation and then discusses the research study. The results are analysed and implications for the development of a psychosocial rehabilitation programme at Grace Home are then discussed.

Psychosocial Rehabilation: A Brief Literature Review

Psychosocial rehabilitation aims at the long term recovery and maximum self sufficiency for mental health service users (Barton, 1999). It differs from acute care which focuses on symptom control and from traditional forms of treatment which include medication and psychotherapy. Psychosocial rehabilitation does not exclude these aspects but expands to include ways to foster social interaction, to promote independent living, and to encourage vocational performance. The focus is on teaching skills and providing community supports so that the individuals with psychiatric disabilities can function in social, vocational, educational and familial roles of their choice with the least amount of supervision from the helping professionals (Littrell & Littrell, 1998; Sheth, 2005)

Psychosocial rehabilitation is underpinned by two essential assumptions. The first is that people are motivated by a need for mastery and competence in areas which allow them to feel more independent and self-confident and the second is that new behaviour can be learned and people are capable of adapting their behaviour to meet their basic needs (Cnaan, Blankertz, Messinger & Gardner, 1988.) In psychosocial rehabilitation, intervention is oriented to empowerment, recovery and competency (Barton, 1999) and programmes should be designed to capitalize on an individual’s strengths (Littrell and Littrell, 1998).

Psychosocial rehabilitation therefore includes a range of social, educational, occupational, behavioural and cognitive interventions that seek to improve the role performance of mental health services users. Barton (1999) states that interventions typically fall into four service domains. The first is skills training which involves systematic skills building through psycho-educational and cognitive-behavioural interventions. The second is peer support which includes self help and advocacy networks and these usually occur in non clinical settings with a minimum of professional support. The third domain is that of vocational services and these services aim to help people work toward recovering vocational roles. The fourth domain is that of consumer and community resource development. This includes direct services such as family education and support but also indirect services which seek to create an infrastructure of community support.

Psychosocial rehabilitation services in South Africa are not well developed and are hampered by a lack of coherent mental health policies. Briefly, the South African situation is as follows. In 1997, the "National Health Policy Guidelines for Improved Mental Health in South Africa" (Department of Health, 1997a) were developed, and read in conjunction with the "White Paper for the Transformation of the Health System in South Africa" (Department of Health, 1997b) advocated a human rights approach and a community based approach to mental health. Unfortunately these policy guidelines were never adopted as formal policy and the National Directorate: Mental Health and Substance Abuse is at present drafting a new national mental health policy (Lund, Kleintjies, Campbell-hall, Mjadu, Petersen, Bhana, Kakuma, Mlanjeni, Bird, Drwe, Faydi, Funk, Green, Omar, & Flisher, 2008). However, services to people with mental health problems are guided by The Mental Health Care Act, No 17 of 2002 which aims (amongst other things) "to provide for the care, treatment and rehabilitation of persons who are mentally ill" which clearly indicates the intention that services should include a rehabilitation focus. A formal psychosocial rehabilitation policy for South Africa still needs to be finalized but in its draft form, it supports a recovery based perspective and provides an overview of the services needed to promote recovery and the social integration of people with mental health problems (Lund, et al, 2008).

The Research Study

Problem statement and aim of the study

No psychosocial rehabilitation programme is currently in place at Grace Home and the need for such a programme has been identified by the management of the facility. Any programme should be based on the needs of the residents and the aim of the study was to develop, implement and evaluate such a programme. The first phase of intervention research is problem analysis (Thomas and Rothman, 1994) and the aim of this phase was to identify the needs, aspirations and hopes of the residents of Grace Home in respect of psychosocial rehabilitation.

Theoretical framework

The research was guided by ecological systems theory which draws on systems theory and ecology to provide a way of understanding how all parts of a system can affect and influence one another. It details the systems in which each individual operates, that is, the micro system (eg family and friends), the meso-system (eg the interactions between the micro systems), exo-system (eg community resources and social networks) and the macro system (eg policies and legislation) and the ways in which they affect and are affected by one another (Jack & Jack, 2000). Ecological systems theory also provides a framework for understanding the balances that exist between stressful and supportive elements at individual, group and community levels, any or all of which might be identified as targets for action (Jack & Jack, 2000). Ecological systems theory thus has much in common with psychosocial rehabilitation.

Data collection and analysis

The initial intention was to interview all 45 residents. This however was not possible and a total of 30 people (17 men and 13 women) took part in the study. Some residents were not available at the times when the interviews were being held, some were not able to participate because they were not well at the time, and some chose not to participate. Those who chose not to participate were not asked to give an explanation as residents had been assured that participation was voluntary and it was felt that this assurance needed to be honored.

Two final year undergraduate social work students collected the data using an interview guide. These two students were doing a fieldwork placement at Grace Home and had established positive relationships with the staff and residents. During the research interview, they explored a number of themes which were identified from the literature, namely skills for daily living, management of the illness and symptom control as well as sources of social support, and vocational and housing aspects.

The researchers wrote detailed accounts of the interviews, including as many verbatim quotes as possible. These were analysed manually by noting similarities and differences in each of the themes. The limitations of this method of recording is acknowledged as quotes may not have been totally accurate. However, as suggested by Babbie and Mouton (2001) efforts were made to ensure the trustworthiness of the data by prolonged engagement (the student interviewers spent a considerable amount of time at Grace Home), peer debriefing (on-going discussions with a social worker in the field of mental health) and member checks (a meeting to present the preliminary findings was held with the residents). This article presents "thick descriptions" of the views of the residents and the research process is presented in detail, all of which contribute to the trustworthiness of the data.

ETHICAL ISSUES

Because of the possibility that the research process might raise psychological discomfort for participants, ethical concerns were given particular consideration. Principles of informed consent, voluntary participation, protection from harm and the protection of their identity guided the study (Babbie and Mouton, 2001). The management of Grace Home supported the research and the project was initially discussed with all the residents at a resident's meeting where all aspects of the research were explained in detail. At the beginning of each research interview, these issues were once again clarified and each participant was asked to sign a consent form. No tape recorders or cameras were used but participants were asked to give permission for notes to be taken during the interview. No identifying particulars were recorded and this article does not identify the half-way house in any way.

DISCUSSION OF RESULTS

Skills for daily living

Skills for daily living are those needed to satisfactorily manage community life including personal hygiene, food preparation, housekeeping, shopping, use of public transportation, money management, and community safety skills.

In terms of personal hygiene, all the residents commented that constant attention was given to this aspect. A typical comment was: "We do have talks about hygiene and we were told that our appearance is important. If we dress up nicely it will make other people realize that we are recovering and are no longer ill."

The half-way house requires all residents to clean their rooms (all the residents have private rooms) and to take care of their personal belongings. There is also a roster and everyone has a turn to clean the bathrooms and remove the garbage. In these respects, then, residents have the opportunity to take responsibility for daily chores. However, only two residents work in the laundry and the main meal of the day is supplied by a catering company. Residents therefore have little chance to practice washing, ironing and cooking which are all important skills necessary for independent living. One participant noted that she wanted to live alone but wondered how she would manage, "I would battle to cook since my mother used to do the cooking for me."

Most of residents were of the opinion that they could use public transport and do their own shopping although one said that he needed help and could only manage going to a nearby petrol station to buy sweets.

Management of illness and symptom control

An important aspect of preparation for community living is learning how to manage one's condition which includes complying with medication and communicating with medical personnel (Umansky, Telias, Tzidon, & Kotler, 1999). Only six participants said they understood their illness and felt that the medication was appropriate and helpful in controlling their symptoms. Most residents were not happy with their medication. They complained that it made them tired and sleepy and in some cases, nauseous. One resident was concerned that this would reduce her chances of getting a job, "Imagine if I fall asleep while on duty!" One resident believed that she had been wrongly diagnosed - after watching a television programme she believed that her symptoms more closely resembled another psychiatric illness. Most of these residents indicated that they did not like speaking to the doctors about their problems with the medication. Doctors, they complained, were busy and not always willing to listen.

At this half-way house, all medication is administered by the staff. Some residents felt that this was unnecessary and wanted to assume responsibility for this. They explained that when they went out for weekends to visit their families, they coped well and were able to manage on their own and they were of the opinion that they should be encouraged to be more independent.

Social support systems

Families

Relationships with families were complicated. Many residents recalled experiences of domestic violence, alcoholism and sexual abuse in their families of origin which they believed contributed to them developing a psychiatric illness. One participant said: "I never had a place I call home. Since from an early age my parents were alcoholics and they moved us from place to place. They used to fight and abused us when angry and I ran away when I was sexually abused by my step dad."

Some residents felt that their families abandoned them because of their illness. One resident described her family as "hating" her. She explained that she had tried reaching out to her mother but that her negative and rejecting attitude had caused her to have a relapse. Another resident, a mother of three children, explained how her ex- husband would not allow her to see the children and how after a particularly nasty altercation, she had a bad relapse which, in the opinion of her ex-husband, proved his point.

Several residents described guilt at "being a nuisance" to their families. "I wouldn't like them to feel obligated" and "I wouldn't want to impose on them" were typical comments.

Four participants felt that their families discriminated against them because they were not able to contribute financially to the family. Family members who were working were seen to be the family "favourites" and were treated with respect, while the person at Grace Home was treated rudely and their opinions about family matters were not taken seriously. A resident described how her family had taken advantage of her when she was incapacitated. They had taken her house and withdrawn her savings and were not prepared to give them back to her. She wanted to consult a lawyer but did not know how to access one.

On the other hand, a number of residents reported good and supportive family relationships. One person said, "I have two sisters, we are very close. One lives close by and I visit her on week-ends. My son also visits me almost every week. " Another described how she spends weekends at her mother's home but feels the place is too small for to move there permanently.

Other residents described their relationships with their families as good but, in fact, had very little contact and seemed to prefer it that way. Some had relatives who live overseas which also made contact difficult.

Friends

The positive impact of quality friendships is seen in the following two quotes from residents: "I have a friend who fetches me every two weeks and we just chill at his house" and "I have a friend who picks me up and we go to play tennis, after that we have a meal and a few drinks. This really makes me feel good and wanted."

For some residents, belonging to a faith community was important and helped them feel part of the community. One resident described her friend from church who she meets at the shopping centre for shopping and tea. Another described her pastor as her friend.

However, most of participants had difficulty making friends outside the half-way house. In some cases, this was attributed to the stigma associated with mental illness. According to one participant: "The moment people know that you come from (the half-way house) they withdraw their friendship because they do not want to be associated with mentally ill people."

In other cases, the residents' lack of social skills made making friends difficult. One resident described how her mind went blank and she couldn’t think of what to say during a conversation. Another simply said “I don’t know how to relate to people who aren’t mentally ill”.

Housing aspects

Most of the residents said they would like to move out of Grace Home with half of them saying that they would like to live in a flat on their own. The reasons ranged from “I am a private person and need my space staying in a flat by myself will give me the peace that I want” to “Staying in a house with my friends gives me the freedom to do my own stuff and enjoying going to have drinks with my friends without being monitored. I think it will be cool.”

For others though, living alone was not feasible. They acknowledged that rent was expensive and that sharing of resources would be important. These residents felt that a group home with a few people would be a good idea. One resident wanted to live in a group home because he felt he would “get into trouble” if he was on his own. One person wanted to go to an old age home.

Two participants who had partners would like to move out of Grace Home and set up home together while others talked about the longing for a partner with whom to share a home - “I would like to find a husband and live in a flat happily ever.” Another resident commented wistfully, “I would like to live in a flat with a girlfriend but it is difficult to have a girlfriend ever since I got sick.”

Vocational aspects

Residents had a wide range of previous work experience. This included civil engineering technician, army officer lieutenant, computer technician, baker, assistant nurse, till operator, salesman, artist, architect, marketing manager, business person, recruiting agent and commodities trading planner. Their illnesses had impacted negatively on their ability to work and very few of the residents of Grace Home were employed at the time of the research. Most of the residents indicated however that they would like to be employed.

Six residents from Grace House work as car guards. They have received training and are registered. One resident has progressed to head car guard and was proud to report that he now gets paid leave. “Now I can live normal life, he commented.” Another resident was proud of her efforts to improve herself. She did a computer course and applied for a supported employment job as an office administrator and now earns about R3000.00 per month.

For many of the residents, being ill had interrupted their education and training and they did not know how to proceed. Fees were identified as barriers to accessing further education and training. Typical comments were: “I passed matric and I have started Information and Technology, I am very good with computers. I dropped because I got sick. But I don’t know how to get a scholarship” and “The problems I have are not knowing where to go in order to continue with adult school and also where to get financial help. I will be very glad to go back to school because I was very clever.”

Not only was the need for vocational training identified, but life skills for coping in the work environment were lacking. Some were concerned about their monthly clinic appointments and how they would explain the need to take time off if they had permanent jobs. One resident said that although he wants to work, he would have a problem waking up for work everyday. Working with other people and having to concentrate would be difficult for some. They were also particularly worried about how they would cope with stress. Typical comments were: “It will be difficult for me to cope with meeting deadlines, pressure, and working quickly. I need to do things in my own time.” and “I can only cope with a minimum amount of stress”.

Discussion And Recommendations

A number of themes, all of which have implications for psychosocial rehabilitation, emerged from this study. The first concerns the importance of individualized treatment which is central to the notion of psychosocial rehabilitation. A basic principle of pyschosocial rehabilitation is that rehabilitation needs must be determined in the context of the individual (Mowbray, Nicholson and & Bellamy, 2003) and that individual treatment plans should specifically be tailored to meet the needs of the MHCU as a unique person (Bachrach, 2000). The research findings indicate clearly that residents did not have individual treatment plans and that there was no long- term planning in respect of the residents. Treatment plans should be based on a comprehensive assessment of the MHCUs strengths, challenges and most importantly, their vision of how they want their future to be.

Drawing up individual treatment plans together with the resident, would serve several purposes. Goal setting, according to Egan (2002:250) helps "clients to focus their attention and action …. (and) helps to mobilize their energy and effort". An individual treatment plan would provide hope and motivation for the individual to move forward. It would also be useful from an organizational point of view and could assist the management of Grace Home in terms of planning future admissions and discharges. Some residents may not be able to live independently and will need on-going support and supervision. Management would need to decide whether Grace Home offers permanent supported accommodation for these individuals or whether transfer to other facilities might be a better option. In view of the fact that just over a quarter of the residents are over 50, planning for their care as older persons in the not too distant future seems to be a priority. Other residents might be able to live, with support, either independently or with their families but unless specific long- term plans are made nothing is likely to happen.

The second theme to emerge was the need for skills training in a number of areas. For many MHCUs, being exposed to institutionalized and custodial care for many years, has resulted in lowered self-esteem, an inability to socialize and interact, lack of motivation, skills, knowledge and resources to function in the community (Ekdawi, 1994). Chan, Lui, Wan & Yau (2002) suggest that skills training and social adjustment to independent living should be the main service objectives of half-way houses. Skills training has been subjected to much research and the available evidence indicates that systematic skills building through curriculum based psycho-educational and cognitive-behavioural interventions has a wide range of outcomes including symptom reduction, community adjustment, relapse prevention, and medication compliance (Barton, 1999).

The following skills training programmes would be useful at the Grace Home:

Skills for daily living: In terms of basic personal self care skills, most residents of Grace Home were coping well. However, it was clear that they have little opportunity to practice skills necessary for home maintenance. Nutrition, menu planning and meal preparation, for example, are not part of the every day experience of residents of Grace Home and more opportunities to be involved in these should be introduced to enable residents to prepare for more independent living.

Stress management: Many of the residents talked about their fear of not coping with stress of being with other people and of being in the workplace. Learning techniques for preventing and coping with stress would be helpful.

Confidence building and assertiveness: In many ways, the residents of Grace Home were fearful. They expressed fear of applying for employment because that will mean having to tell people about their illness, fear of making friends outside Grace Home because of the stigma associated with mental illness, and fear of being burden to others. Developing greater confidence and learning how to approach others in social situations would be important perquisites for more independent living.

Management of illness and symptom control: Understanding one's illness and learning to manage it is an important aspect of psychosocial rehabilitation and the residents of Grace Home would benefit from being encouraged to take more responsibility for their own well being. Educational programmes regarding the nature of psychiatric conditions and the advances in medication are recommended.

Skills training programmes, on their own, however, have not been shown to produce significant employment outcomes (Barton, 1999) and the need for vocational rehabilitation as part of a comprehensive psychosocial rehabilitation programme was evident in this study. International research evidence indicates that vocational rehabilitation enhances non- vocational outcomes such as functional status and activities of daily living (Chan, Lui, Wan and Yau, et al, 2002). Most of the residents expressed the desire to find meaningful employment but only a handful had been able to do so. Given the wide of range of skills and previous experience of many of the residents it would seem that a vocational rehabilitation programme would be essential.

A number of studies have now demonstrated that supported employment is an effective rehabilitation approach (Burns, Catty & Becker, et al, 2007; Bond, et al, 2008). Meaningful employment leads to improved social integration, normalized peer relationships and a source of identity (Warner, 2009). Successful supported employment programmes have demonstrated a commitment to a competitive employment goal (not a workshop placement), rapid job search and placement and jobs selected on the basis on individual preference, together with follow -up support. (Morris & Llyod, 2004). Unfortunately, supported employment programmes in South Africa are underdeveloped and in the area in which Grace Home is situated there are no such programmes. Given the lack of resources at Grace Home, a vocational rehabilitation programme at this time would not seem to be feasible. However, it is an area that deserves further attention and a creative option might involve sharing such a programme with other organizations.

The final major theme to emerge was the lack of social support and in particular, the fractured family relationships that existed for many of the residents. Social support is essential and it has been found that there is a significant association between good social support and perceived quality of life (Sharir, et al, 2009). The reasons for lack of social support especially from families were varied but some residents were clearly hurt by their childhood experiences and by what they perceived to be on-going unfair treatment by their families. Individual counseling would help residents to come to terms with the hurt and to move forward but counseling for families also seems indicated. Even if they are unable to offer the resident a home, education about the needs of their family members and the advances made in the management of mental illness might be helpful in beginning the process of restoring relationships. Healing some of the hurt caused by the behaviour of the resident when ill may also help to improve the quality of life of all concerned.

While the results of this study cannot be generalized to the broader population, they are of interest to social workers and health care professionals in the field of mental health and psychosocial rehabilitation. In comparison to many other facilities for people with mental health problems, especially in township and rural areas, Grace Home is fairly well resourced. In addition, a growing body of South African research indicates that many people who have been discharged from hospital to family care receive almost no services and that the burden on families is excessive (Kritzinger & Magaqa, 2000; Lazarus, 2005; van Rensburg, 2005; Reddhi, 2008). If the residents of Grace Home continue to experience so many challenges in respect of pyschosocial rehabilitation, one can only imagine the scale of problems that still need to be addressed. Social workers have an important role to play in identifying needs and designing programmes to address these at individual, family, group and community levels. In addition, if social workers are to be true to their commitment to social justice, they need to be far more vocal in respect of policy development and advocacy for better services for MHCUs.

Conclusion

Services to people with mental health problems in general, and psychosocial rehabilitation programmes in particular are underdeveloped in South Africa. This article has identified the need for a psychosocial rehabilitation programme at a particular residential facility for people with mental health problems. Programmes which encourage independent living and increase social skills to cope with the challenges of interacting with people in daily life seem to be most needed and would not require extensive resources to implement. More difficult to implement, but equally important for the long term well being of MHCUs would be vocational and supported housing programmes that would require far more resources.

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It's Not Easy Being a Child Lover: Applying Techniques of Neutralization Theory to Case Studies of Intergenerational Intimacy in the Philippines

Billy J. Long, Ph.D.
Assistant Professor of Criminal Justice
School of Social Sciences
Ferrum College
#3 Roberts Hall
Ferrum, VA. 24088

Citation:
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Abstract

This paper addresses the problem of child prostitution in the Philippines. The US military has long contributed to the perpetuation of "red light" districts in ports it visits. Sykes and Matza's techniques of neutralization theory is used to explain why sailors and marines can simultaneously believe that sex with children is wrong while still engaging in intergenerational intimacy. Sailors and marines use five techniques to neutralize the guilt they experience at the thought of violating sexual moral codes that proscribe sex with children. Social and psychological approaches to combat this problem are offered.

Key words: child prostitution, Philippines, military prostitution, techniques of neutralization

Introduction:

Perhaps no topic elicits a more viscerally negative response than that of sex with children. Communities recoil in horror when the quiet man in the house on the corner is exposed as the neighborhood "child molester." Internet sites exist and laws across the United States mandate that released sex offenders report to the police and post their personal information on websites. Even in United State's prisons, child sex offenders are often considered to be the "lowest of the low" and are subjected to ostracization and abuse (Sandfort et al., 1991).

However, this extreme opposition is often relaxed when going abroad. Many people (in this case males in the U.S. Navy) seem to be able to find innovative ways to relax the taboo while abroad. While the prevalence of child sex abuse by U.S. Navy personnel is unclear, it is estimated that there are close to 100,000 child prostitutes in the

Philippines alone (Juvida, 1997; Black, 1991). In other words, while abroad, sailors and marines can sometimes neutralize the moral guides that successfully regulate behavior here at home.

I was enlisted in the U.S. Navy from 1982-1987 and served for approximately two years on a ship that was stationed in the Philippines. I became very acquainted with the local community by living off base and serving as a Shore Patrol petty officer. Shore Patrol petty officers serve as foot patrols in the Olongapo City "red light" district keeping the peace and responding to calls for order maintenance. This allowed me to make copious observations of sailors and marines engaged in questionable behavior involving minors, overwhelmingly young girls.

The U.S. Navy has routinely been criticized for being a corrupting influence for Filipina youth (Beacham, 1993; Lim, 1998; Orejas, 2000; Ralston and Keeble, 2008; Preda Foundation, 1997; Todd, 1993). Once a naval vessel arrives at the Subic Bay Naval Station on the island of Luzon (51 miles from Manila), hordes of young male sailors flood into the surrounding town (Olongapo City) looking for loud music, alcohol and sex. Most of the Filipina girls were engaged in "legitimate" prostitution as "hostesses" vis-à-vis local bars and clubs. The process typically takes place in the following manner.

Immediately after leaving the naval station, sailors and marines must cross the bridge over the Pagasa River. This river is so polluted with human waste that it came to be known simply as the "Shit River" (Mendoza, 2008). As military personnel cross the bridge over the river they are confronted with a flotilla of tiny boats containing girls ranging in age from about 10 to 20 years old wearing white dresses who are begging for pesos to be thrown into the water so young boys can retrieve them and share with the girls. These girls, who also double as prostitutes, came to be known as the "Shit River Queens." Once past the bridge the sequence goes something like this: a) sailor or marine enters a bar, b) numerous adult beverages are consumed while listening to a live local band, c) he is approached by multiple girls willing to provide sexual services at discount rates, sometimes right at or under the table, d) he makes his selection from among the hostesses, and e) decides between a short or long time. The serviceman then pays the "bar fine" to the bartender (usually a hostess who is working her shift behind the bar for 1-2 hours). Bar fines in the mid-1980s in Olongapo City typically ranged from 50-150 Filipino pesos ($2.50- $7.50 USD) for a "short time" (one sexual act – either oral or straight sex within a one hour time limit) and 150 – 200 pesos ($7.50- $10.00 USD) for a "long time" (overnight).

The practice described above was widely accepted by the Philippine government, local police (Baranguy), and the Navy hierarchy. It was not uncommon, for example, for senior petty officers (pay grade E-6 and above) to provide orientation on ships to new servicemen. The orientation consisted of information pertaining to: a) bars with the greatest concentration of young voluptuous teenage girls, b) bars known to have high rates of gonorrhea, and c) locations of local clinics that sold penicillin over the counter so as to avoid having to report to sick bay and having records kept. An excessive number of sexually contracted diseases can be grounds for disciplinary action (considered a form of destruction of government property).

Many servicemen limited their sexual exploits to the accepted practice discussed above. However, an alarming number of servicemen became desensitized and found the traditional nightlife dull and sought excitement with underage girls. As a result of familiarity with the local landscape from living off base, combined with serving in the Shore Patrol, I had the opportunity to become cognizant of sailors and marines engaged in sexual congress with girls as young as 10-years-old.

The Purpose of this Paper

This paper is an illustration of hypothetical sexual situations involving U.S. service members and underage Filipina girls (usually between 10 and 14 years of age). The primary goal is to illustrate how techniques of neutralization theory may be used to explain these events. The types of events described in this paper occurred with shocking regularity but the incidents discussed below should not automatically be assumed to refer to actual individuals. An attempt is made to illustrate the typical nature of sexual relations between underage girls and service members and the social-psychological methods used by service members to neutralize the normal guilt that is created when one violates moral rules in which one genuinely believes.

Sykes and Matza's Techniques of Neutralization Theory

An appropriate theory that can be used to explain the intergenerational intimacy (IGI is sometimes pejoratively referred to as child sex abuse or child molestation) described below is Sykes and Matza's techniques of neutralization theory (Sykes and Matza, 1957). This theory falls into the category of a social control approach. It assumes that all people are motivated toward behaviors that serve self interest (e.g., crime, theft, illicit sex etc.). Most people are, however, restrained from crime and deviance by various mechanisms. Techniques of neutralization theory assumes that guilt is the primary restraining mechanism that keeps most people from breaking the law. However, some people develop techniques to neutralize guilt that will temporarily allow them to violate the law without accepting a deviant self-image. Most people (including most criminals) have respect for the law, in this case the rules prohibiting sex with children, but these rules are deemed to be situational. Laws and moral boundaries are seen not as categorical imperatives but merely as qualified guides to regulate behavior. Sexual deviants, then, insist that there are "degrees of harm" and the techniques of neutralization therefore serve as tools to mitigate culpability by assuaging guilt. There are five major techniques deviants use to neutralize guilt before committing a lewd sexual act against a child: 1) denial of responsibility, 2) denial of injury, 3) denial of victim, 4) condemnation of the condemners, and 5) the appeal to higher loyalties (Sykes and Matza, 1957).

Denial of Responsibility. One of my hypothetical acquaintances in the Philippines ("Wally" from Oregon) had a habit of bypassing the traditional bar scene because he became enamored with a 10-year-old flower girl ("Shayla") who sold flowers on the street corner in front of a patio-style open bar where many sailors congregated during the evening with their newly purchased hostesses. After buying flowers from her, Wally would typically entice Shayla to accompany him to a local hotel (the "Blue Haven" on Magsaysay Drive in Olongapo City) for sex. He routinely bribed the desk clerk to look the other way. Anytime Wally was confronted with the fact that sexually exploiting a 10-year-old girl was inappropriate he would typically respond by employing the technique of neutralization referred to as denial of responsibility. In this case, the deviance was outside of his complete control. Generally, he would state that: a) "I was drunk," or b) "I was expected to build a partying reputation with other sailors." The key to this technique of neutralizing guilt is to create plausible deniability to avoid accepting a deviant self-image.

Similarly, Wally would deny responsibility by stating that sex with underage girls was largely condoned by the military chain of command. Essentially, the military brass neglected its responsibility to provide guidance and oversight; therefore, Wally felt as though responsibility should at least be shared. Along the same lines, Wally routinely pointed out that the Philippine government needs U.S. dollars. Therefore, since both local and national authorities were aware of how rampant IGI was between U.S. military personnel and the local children, responsibility is diffused and, consequently, guilt is temporarily neutralized.

Denial of Injury. Using this technique of neutralization, Wally could assuage the guilt associated with his sexual acts with Shayla. Here, it is assumed that no one is really hurt by the act (at least visibly). Wally once said, "sex with Asian kids is like water treatment (known today as water boarding); it leaves no physical scars." Other notable quotes from Wally include: a) "sex happens billions of times a day and if she's old enough to bleed, she's old enough to breed," b) "I gave her more money than she and her family can earn in six months," c) "I follow the '13 and under rule;' if the girl is 13 or under I give her three times the fee that is paid in bars." By focusing on the compensation given to the child, Wally was able to make the argument that ultimately she and her family were actually better off by his coming into their lives; thus, once again, guilt is neutralized because of the lack of any obvious injury.

Denial of Victim. This technique of neutralization involves another hypothetical acquaintance ("Drew" from Massachusetts). Drew conceded that his child lovers were in fact injured by the sexual exploitation. According to Sykes and Matza, however, the injury is justified to help offset some other real or imagined harm. For example, Drew concluded that underage girls still have free-will to choose whether or not to go with him. As a consequence, a young girl is "choosing" to be harmed by the contact. One could view this as a righteous use of force used to punish morally defective "victims."

In one incident, Drew was discovered by the Blue Haven hotel desk clerk while in the process of sexually assaulting a girl believed to be approximately 12 years old with an unidentified vegetable. The clerk contacted the Shore Patrol and reported shrieks of horror coming from Drew's rented room. Days later when Drew was confronted about the attack he dispassionately said, "no little Flip (slang for Filipina) who was at home doing her homework that night got reamed." The clerk's memory of the event faded precipitously after Drew provided a 1000 peso bribe through an intermediary. Clearly, then, by viewing the 12-year-old girl as someone deserving of punishment, guilt was neutralized long enough to allow Drew's sexual assault to take place.

Condemnation of the Condemners. Using this technique of neutralization, another hypothetical acquaintance ("JG" from New Jersey) neutralized the normal guilt he experienced long enough to violate sexual moral codes of conduct in which he genuinely believed. According to Sykes and Matza, condemnation of the condemners manifests itself in the deviant lashing out at those who criticize him. The condemners are considered to be hypocrites because they have engaged in acts (or alternatively, harbor viewpoints considered to be morally objectionable) as equally repugnant as those they are condemning.

In this case when JG was confronted by fellow military personnel for using obviously underage girls for sexual experimentation, he would deflect the criticism back onto the condemners. It was not uncommon, for example, to hear JG criticize sailors who had married local Filipina women for contributing to the morally repugnant permissiveness toward miscegenation. JG was overheard on several occasions criticizing the miscegenation of fellow sailors because it pollutes the races. He believed that since many of his child lovers were so young that they had not reached puberty combined with the fact that he used condoms so as to avoid contracting gonorrhea, that at least he was not polluting the Asian or white race. Consequently, he believed he had the moral high ground over those sailors who dared to condemn him while simultaneously supporting, or actually engaging in, interracial marriage and procreation. In essence, JG believed that being defined and ultimately labeled a sexual deviant was simply a matter of luck. Miscegenators (and to some lesser extent homosexuals) had simply won the "sexual orientation lottery" because their lifestyles and behaviors were currently acceptable while at this particular point in time, IGI was frowned upon. To JG, IGI in the Philippines was but one of a multitude of sexual appetites that fall under the normal curve but his desires, much to his consternation, simply strayed from the rigid and arbitrary sexual parameters imposed upon him unfairly by the moral entrepreneurs in the dominant U.S. society and offended military personnel in the Philippines. Consequently, this mindset allowed JG to easily neutralize the guilt that he naturally felt as a result of his desire to have sex with Filipina children.

The Appeal to Higher Loyalties. This technique of neutralizing guilt suggests that deviants have loyalties or values that transcend the structure of law. These alliances result in a diminution of guilt associated with IGI (at least while in the Philippines). In the case of JG, for example, guilt was very effectively neutralized by adhering to well established traditions of sailors in the U.S. Navy 7th Fleet. JG believed that it was every sailor's responsibility to drink to excess and to corrupt the morals of the indigenous population. The fact that he involved children in his schemes simply meant that he was more effective at it than was everyone else.

Conclusion

The illustrations above demonstrate that by using techniques of neutralization, sexual deviants can attenuate the effectiveness of social controls. Just as a thief using file sharing software to download music without paying royalties to artists genuinely believes that stealing is morally wrong, he may nevertheless be able to neutralize the guilt he feels by arguing that he is simply redistributing wealth away from the upper class or that his preferred mode of theft really does not hurt anyone (the "everyone is doing it" defense). The point is that the thief or sexual deviant is not fully opposed to the moral codes of conduct but is merely seeking to drift into deviance long enough to satisfy some desire. All this must take place without the deviant being forced to alter his self-image and accept a negative label (e.g., "child molester").

To combat this, the U.S. military could take two approaches: macro and micro. A macro level approach would involve increasing the penalties for these types of violations. The Shore Patrol could cooperate more fully with the Baranguy (local) police of Olongapo City. Similarly, the Shore Patrol could be increased beyond its token levels of the past and be used to seriously monitor bars (i.e., brothels) and report violators.

The Philippine government could also play a role. Singapore, another country where the Navy makes port calls, has draconian punishments available for rule violators. Drug traffickers, for example, may be executed while immigration violators may be subject to caning. As a result, the Navy has implemented bans on its personnel preventing them from venturing into red light districts (Soltani, 2003). Simply stated, according to the philosophy of situational crime prevention, when the opportunity to offend is severely restricted, the frequency of offending is reduced.

> On the micro level, group confrontation therapy involving cognitive restructuring may prove beneficial. There is an extreme dearth of empirical support for individual and group therapies for child sex offenders (Borzecki and Wormith, 1987; Furby et al., 1989). Nevertheless, the assumption here is that treatment must combat the offender's belief that sex with children can, depending on the situation, make sense. Here, offenders come face-to-face with the consequences of these types of offenses. Potential violators (e.g., personnel not yet deployed to Asia) can be shown how young girls can be damaged by repeated sexual exploitation and how this is not offset by the economic gain they "enjoy" as a result of becoming child prostitutes. Group members are also encouraged to confront each other's rationalizations and manipulations to prevent the potential offender from successfully neutralizing the guilt of violating rules that they agree with while at home but are able to violate when they get to the Philippines (Clear et al., 2010).

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Promoting Self management in Indigenous People with Mental Illness and Substance Misuse

Tricia Nagel
Associate Professor
Menzies School of Health Research and Charles Darwin University, Flinders University, James Cook University
PO Box 40196, Casuarina, NT, 0811. E-mail: tricia.nagel@menzies.edu.au

Carolyn Griffin
Aboriginal Mental Health Worker and Senior Indigenous Research officer
Menzies School of Health Research and Charles Darwin University

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Abstract

Objectives: To explore relapse prevention strategies in remote Indigenous people with mental illness.
Method: A mixed methods design in which an exploratory phase of qualitative research was followed by a nested randomised controlled trial and concurrent collection of qualitative data over 18 months. The research team collected detail of early warning signs of relapse from clients at each data collection point.
Results: Indigenous people with mental illness identified a range of warning signs of relapse and those signs were similar to those found in other studies.
Conclusions:
The study supports exploration of early warning signs routinely at assessment as an important relapse prevention strategy. It is important that information and education about common prodromal symptoms of relapse is delivered in language and format which is accessible to Indigenous people.

Key Words: Indigenous, prodrome, relapse, self management

Introduction:

In the face of the high burden of disease in Indigenous peoples there is a need to find and test new strategies for prevention, treatment and relapse prevention (Australian Bureau of Statistics 2005). One important strategy for further exploration is that of self management: a patient’s ability to understand their condition, to recognize early warning signs (EWS), and to work effectively with health care providers and carers. There is increasing evidence that patients with long term illness benefit from self management strategies (Falloon I, Coverdale J H et al. 1998; Wiersma D, Nienhuis FJ et al. 1998; Fitzgerald P B 2001; Bodenheimer, Lorig et al. 2002) and from adoption of a recovery paradigm (Rickwood D 2002; Andresen R, Oades L et al. 2003; Shepherd G, Boardman J et al. 2008) which supports and empowers them to become expert in their own illness (Ellis G and King R 2003; Rickwood D 2004).

Early warning signs are apparent for several weeks before relapse in both schizophrenic disorders and affective psychoses allowing time and opportunity to intervene (Herz MI and Melville C 1980; Yung A and McGorry P 1996; Birchwood M and Spencer E 2001). Early warning signs of relapse (also called relapse prodromal signs) vary between individuals yet key symptoms are consistent across studies (Herz MI and Melville C 1980; Birchwood M, Spencer E et al. 2000; Jackson A, Cavanagh J et al. 2003). Changes of mood, sleep, appetite and behaviour are common (Heinrichs D and Carpenter W 1985; Birchwood M and Spencer E 2001).

Recognition of the same sequential pattern of symptoms in patients each time they relapse, the ‘relapse signature’, has been incorporated into a number of relapse prevention approaches (Hewitt L and Birchwood M 2002; Meadows G 2003). Knowledge about EWS has the advantage of shifting patients from being passive recipients of care to active collaborators in their treatment (McCandless-Glimcher, McKnight et al. 1986; Turkington D and McKenna P 2003). There has not been any examination of early warning signs of relapse in Indigenous people with mental illness, however, and the cross cultural experience of relapse prodrome has not been explored.

There is a particular need to promote self management and relapse prevention strategies for Indigenous peoples given the high rates of hospitalisation and relapse (Nagel T 2005; Nagel T 2006), challenges to cross cultural care and to self advocacy (Australian Indigenous Doctors Association 2004; Eley D, Hunter K et al. 2006; Nagel T, Thompson C et al. 2008), and limited access to specialist services (Bailey R, Siciliano F et al. 2002). This paper reports qualitative findings of a mixed methods study in three remote communities in the Northern Territory. Details of the full design and results of this Australian Integrated Mental Health Initiative (AIMhi) study have been reported in earlier papers (Nagel T 2008; Nagel T, Robinson G et al. 2009). This is the first study of its kind exploring early warning signs of relapse in Indigenous mental illness.

Method

An exploratory phase of qualitative research was followed by a nested randomised controlled trial. Quantitative and qualitative data were collected at 6 monthly intervals between December 2004 and August 2007. Quantitative data included self report and clinician rated measures of well being, psychiatric symptoms, and substance dependence. In addition a self management scale, Partners in Health Questionnaire (PIH) abbreviated to five items measured knowledge of illness, knowledge of treatment, early warning signs, and progress toward goals (Battersby M, Ask A et al. 2003). Ten local AMHWs and one recovered client participated as key informants and co-researchers and assisted in development of psychoeducation and treatment resources (Nagel T and Thompson C 2007). Participants were current patients with chronic mental illness (duration of symptoms greater that six months or at least one previous episode of relapse). The study recruited 49 Indigenous patients and 37 carers. Participants were given an explanation of the project in plain English in spoken, written and pictorial format with local translation where needed. Ethics approval was granted through the Darwin-based Joint Ethics Committee.

The intervention

Two one-hour treatment sessions two to six weeks apart integrated problem solving, motivational therapy and self management principles (Lorig K and Holman H 2000). The research team gathered information about current and past symptoms during semi structured interviews at each data collection point.

Exploration of early warning signs

Clients were shown a pictorial representation of early symptoms of relapse and were asked whether they had experienced any of those symptoms before they ‘got sick’ (Figure 1). Changes in ‘mood’, appetite’ ‘sleep’ and ‘other’ symptoms were explored through three close ended items and one open ended item. The changes were not current experiences but explored symptoms they had noted in the past before an episode of illness. The responses to the close ended items were analysed using descriptive statistics while responses to open ended questions were categorized and frequency counts made of each category.

Findings

The average age of the patients was 33 years and participants were diagnosed with psychotic and affective illnesses (schizophrenia 37%, schizoaffective disorder 2%, and substance induced psychotic disorder 10%, bipolar affective disorder 6%, major depressive disorder 6%). Further detail of the client profiles and outcomes has been reported in earlier papers (Nagel T, Robinson G et al. 2009).

Participant responses were recorded and grouped at each of the four assessment points (Table 1). Most clients were able to identify EWS at baseline and this was maintained throughout the course of the study with all participants identifying at least one sign at the last two assessment points. The participant responses were grouped into seven categories of EWS and compared across time (Table 2). The ‘other’ EWS fell into four other categories ‘psychotic symptoms (e.g. hearing voices) psychomotor disturbance (e.g. ‘restless’ and ‘walking around a lot’), thought disturbance (e.g. ‘mixed up thoughts’) and social withdrawal and diminished energy (e.g. ‘staying inside’,’ not interested in things’ and ‘no energy’). These categories are similar to those of larger relapse prodrome studies (Heinrichs D and Carpenter W 1985; Herz M, Lamberti J et al. 1995).

Mood changes such as ‘feel cranky’ were generally the most frequent symptoms for all individuals across all diagnoses apart from one exception: sleep change was as common as mood change in the setting of Bipolar illness. There was a tendency for clients to identify more ‘other ‘warning signs as time progressed. At baseline 5% of early warning signs identified were ‘other’ and by the fourth assessment at 18 months these were 27% of signs identified. The client rated self management scale (PIH) showed significant improvement in scores from baseline to 18 months .

Discussion

This study confirms the ability of patients to recognise EWS and throws light on the nature of those early indicators of relapse. These early warning signs: mood change, appetite change, sleep disturbance, and psychomotor disturbance match the signs and symptoms noted in other studies of affective and psychotic prodromes. The progression toward increased recognition of 'other' warning signs throughout the study suggests that the clients were becoming more familiar with the concept over time. These 'other' signs were reported in response to an open ended item as opposed to the specific prompts of 'mood' 'sleep' and 'appetite' change.

The concept of relapse is complex and potentially difficult to communicate in a cross cultural setting with differences of language and literacy. These findings support the introduction of a relapse prevention model. They show that with a pictorial tool (and an assessment process linked with local Indigenous mental health workers) clients were able to understand the concept and describe their experiences. An understanding of EWS from both practitioner and client perspectives lays the groundwork for client education and opportunity of self management and relapse prevention.

One of the limitations of this study is the small number of participants and the specific setting in three remote communities. There is uncertainty about the degree to which the findings can be generalised to other settings. A second limitation of the study is that it did not explore change in symptoms over time. Birchwood and Spencer, for example, present a three phase model of symptom development prior to relapse (cognitive, mood, and pre psychotic). This study was not designed to address this aspect of prodrome and did not shed light on change of symptoms over time (Yung A and McGorry P 1996; Birchwood M and Spencer E 2001). These findings nevertheless strongly support integration of early warning signs recognition into the routine assessment and follow up of Indigenous clients in remote communities.

Conclusions

Indigenous people in the NT have high rates of mental illness and high rates of recurrent hospitalisation (Nagel T 2006). Relapse prevention is an important component of care and yet models which address relapse for Indigenous people have not been developed. The majority of Indigenous people with mental illness in this study identified at least one early warning sign of relapse and those signs and symptoms were similar to those found in other studies. It is recommended that exploration of EWS and a 'relapse signature' is routinely undertaken at assessment with patient and family, and that EWS information is incorporated into psycho education resources in language and format which is accessible to Indigenous people. The AIMhi program of research has developed pictorial care planning and psychoeducation resources and continues to deliver related 'Yarning about mental health' training which highlights the importance of early warning signs and self management skills (Nagel T, Thompson C et al. 2009). These developments are important directions for empowering Indigenous clients with mental illness.

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Measurement of Vocational and Educational Aspiration and Satisfaction among Mental Health Clients

Jonathan Rich
County of Orange Health Care Agency, Santa Ana, California

Anthony Delgado
County of Orange Health Care Agency, Santa Ana, California

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Correspondence:
Jonathan Rich
Health Care Agency
County of Orange
405 W. 5th St., Suite 410,
Santa Ana, CA 92701.

Abstract

We developed a 13-item scale to measure work and educational satisfaction and aspiration among mental health clients. The scale was initially developed on a sample of 150 clients, and was validated on a sample of 358 clients. The validation sample was 52% male, mean age was 48 years, 83% had no paid employment, and 79% were high school graduates. Exploratory factor analysis indicated that the scale measures four distinct dimensions: work satisfaction (WS), educational satisfaction (ES), work aspiration (WA) and educational aspiration (EA). The subscales are brief (3 to 4 items each) and demonstrate good psychometric properties. Cronbach's alpha ranged from .79 to .90 across the four subscales. Criterion-related validity was demonstrated for each subscale. WS was higher for employed than unemployed participants; ES was higher among more educated participants; WA was higher for clients who expressed a desire to start working or to move to more competitive levels of employment; EA was higher for clients who indicated a desire for more education. The scale was created to support recovery-based mental health treatment, and is potentially useful in both individual treatment and program evaluation.

Keywords: educational, vocational, assessment, recovery modelMeasurement of Vocational and Educational Aspiration and Satisfaction among Mental Health Clients

Introduction:

Over the last half century, mental health treatment has increasingly emphasized integration of clients into the community. Deinstitutionalization was implemented in the 1960s and 1970s. This led to the concepts of community support and psychiatric rehabilitation in the 1980s. The recovery model of mental health treatment began to take hold in 1990. Central to this model is the idea that many of the limitations due to mental illness can be overcome, and that mental health clients can lead productive lives. A recovery model promotes the development of meaning and purpose as one overcomes the catastrophic effects of severe mental illness (Anthony, 1993).

Adoption of a recovery model may require new tools and new ways of conceptualizing client problems. Ralph, Ridgway and Onken (2004) suggested that recovery programs need to offer replicable, measureable services, and that this requires the creation of new instruments to quantify recovery-based care. Campbell-Orde, Chamberlin, Carpenter, and Leff (2005) echoed that sentiment when they stated, “As the current mental health system begins to undergo fundamental changes based on [recovery], research and evaluation activities are necessary to the successful development and continuous delivery of services that do indeed promote recovery” (p. 10).

Securing employment is a key element of reintegration into society. Marrone, Gandolfo, Gold and Hoff (1998) suggested that, “Any helper's belief system has to include a core value that people with mental illness in our society can, and should, work as part of their citizenship rights and responsibilities” (p. 37). Cook et al. (2005) conducted a randomized trial of supported employment interventions for individuals with severe mental illness. They found that clients who participated in supported employment had better outcomes at 24-month follow-up, including greater likelihood of competitive employment and higher earnings.

The unemployment rate among the mentally ill is typically 90%, exceeding the rate of any other disabled group (New Freedom Commission on Mental Health, 2003). This high rate is in spite of the finding that many mentally ill persons want to work, and could work with modest accommodations (Drake et al., 1999).

A number of existing tests measure vocational interests, attitudes, and job-seeking skills, but a review of the literature did not show any currently available instruments which could validly and reliably measure client desire for both employment and education. The employment satisfaction scale of the Peer Outcome Protocol appears to come closest (Campbell, Einspahr, Evenson & Adkins, 2004). However, this scale demonstrates relatively low internal consistency and test-retest reliability, with Cronbach’s alpha = .70, and two week test-retest reliability = .51. It appears to merge several different constructs into a single score, including items which query satisfaction with employment status, desire to work, employment-related program resources, and self-rated ability to find and keep a job (Campbell et al, , 2004).

The goal of the current study was to identify clients who were dissatisfied with their current employment and educational status, and who were seeking to advance in these areas. This information can then be used for program planning purposes, to target resources, and as a basis for counseling. To this end, we created four scales, measuring satisfaction and aspiration with regard to education and employment.

Instrument Creation

Item Creation

The authors developed 32 items, 8 per factor, covering four factors. An ad hoc committee of mental health researchers reviewed the items and suggested modifications. Each item was to be rated on a 4-point scale from 1/strongly disagree to 4/strongly agree. The four scales are:

- Work satisfaction (WS): Satisfaction with current work situation, whether employed or not.

- Work aspiration (WA): Desire to work, or to improve one's work situation.
- Educational satisfaction (ES): Satisfaction with current level of educational attainment.
- Educational aspiration (EA): Desire to obtain additional education.

Current living situation, current living situation satisfaction, current work situation, desired work situation, current educational level, and desired educational level also were assessed. Demographic and treatment program information, including age, gender and clinic name were recorded.

Data Collection

These surveys were distributed at the five Orange County Full Service Partnership (FSP) programs. FSPs are county outpatient programs, specified by the California Mental Health Services Act (MHSA, 2005), which provide a full spectrum of community services to clients with severe mental illness. Eligible clients are functionally impaired and at risk for homelessness, criminal justice involvement, psychiatric hospitalization or emergency room use for mental health issues. FSPs provide mental health services and supports, including standard, alternative, and culturally specific treatment. Non-mental health services and supports include housing subsidies, food, clothing, and access to educational, social, and vocational rehabilitative services. FSPs are an integral part in the MHSA vision of transforming the mental health system into one that is ever more responsive to the real needs of mental health consumers and one that can support their journey through the recovery process.

The surveys were distributed by program service coordinators. They explained the nature of the assessment and obtained client consent. The study was reviewed and approved by the Institutional Review Board of the Orange County Health Care Agency. All clients attending an FSP during the two-week study period were offered a survey. A total of 130 participants anonymously completed surveys; 119 of these surveys contained no more than 10 omitted items and were retained for this analysis.

Sample Characteristics

This initial sample was 57.1% male with a mean age of 44.8 years (SD = 12.2 years; range 23-72 years). Of the 112 participants who reported their employment status,73.2% were unemployed and 15.2% reported that they did volunteer work. Out of 92 participants who reported their living situation, 47.8% had secured permanent housing and the remainder were in transitional or emergency housing. Level of education was reported by 98 participants, with 75.5% being high school graduates and 11.8% being college graduates.

Item Selection

Because we wanted to create brief scales, we retained the fewest items possible while still maintaining adequate internal consistency ($\alpha > .70$). We eliminated items which sounded very similar to other items and items with significant amounts of missing data. Using factor analytic techniques, we chose items so that four distinct factors would emerge, removing items which correlated with scales other than their own. Thirteen items were retained for the final Instrument Validation

Method

The 13-item instrument was distributed to outpatient mental health clients in FSP programs. A total of 358 anonymous surveys were returned.

Sample description.

Of those reporting their gender (n = 298), 52.0% were male. Age was reported by 350 participants, with a range of 19 – 79 years, mean of 48.2 years and standard deviation of 14.0 years. Work situation was reported by 338 participants: 67.9% did not have paid or volunteer work, volunteer engagements were reported by 14.8%, part-time competitive employment by 8.7%, full-time competitive work by 1.7% and supported employment by 1.4%. Supported employment is paid work with additional support services, such as such as job coaches, transportation, assistive technology, specialized job training, and individually tailored supervision. Of those reporting their educational level (n = 340), 10.7% had a four-year college degree, and 78.8% had graduated high school.

Results

Scale characteristics. Table 1 shows the characteristics of the four scales. In spite of their brevity, they demonstrated adequate reliability, with Cronbach's alpha ranging from .79 to .90. Participants gave mean ratings to the work and educational aspiration scales which were near the "Agree" level. Work and educational satisfaction, on the other hand, were between the "Agree" and "Disagree" ratings.

Table 1 *Scale characteristics*

Scale	*N*	*N of items*	*Cronbach's alpha*	*Mean**	*Std. Deviation*
Work Aspiration (WA)	314	3	.80	2.96	0.74
Educational Aspiration (EA)	319	4	.90	2.89	0.92
Work Satisfaction (WS)	296	3	.79	2.41	0.87
Educational Satisfaction (ES)	324	3	.82	2.65	0.86

**Items are rated from 1 (Strongly disagree) to 4 (Strongly agree). For easier interpretation and comparison, individuals' scale scores are represented as the mean of their item responses.*

Table 2 *Exploratory Factor Analysis Showing Item Factor Loadings*

Item	EA	ES	WS	WA
WA1 I will work hard to improve my work situation	-.01	-.02	-.01	**-.77**
WA2 I am willing to put in effort to have a job I enjoy.	-.01	.00	.01	**-.87**
WA3 Having a good job is important to my sense of well-being.	.05	.00	-.08	**-.67**
EA1 I am interested in attending more school.	**.90**	-.02	-.04	.07
EA2 I am willing to work hard to get more education.	**.82**	-.03	-.04	-.07
EA3 One of my most important goals is to get more education.	**.86**	-.02	.02	-.05
EA4 I would put effort into a school or a training program if it would lead to a good job.	**.51**	.05	.08	-.37
WS1 I have work which is satisfying to me.	.02	-.08	**-.75**	-.01
WS2 I feel as though my work is a good fit for my skills and abilities.	.02	.03	**-.82**	.04
WS3 I do work that is interesting to me.	-.03	.11	**-.68**	-.08
ES1 I am happy with the amount of education I have completed.	-.20	**.72**	.02	-.02
ES2 I am satisfied with my educational accomplishments.	-.07	**.86**	-.05	.01
ES3 I am proud of my education.	.19	**.73**	-.03	.02

Note. Factor loadings with absolute value > .50 are in boldface. EA = Educational Aspiration, ES = Educational Satisfaction, WS = Work Satisfaction, WA = Work Aspiration.

Factor analysis. An exploratory factor analysis was performed using principle axis factoring as the extraction method and direct oblimin as the rotation method. Oblique rotation was chosen because it was anticipated that the factors would have some intercorrelation. A scree test indicated that a four-factor solution was appropriate. Table 2 shows the pattern matrix resulting from this analysis. The scales demonstrated factor structure which was consistent with expectation. All items had high loadings on their own scales, and loaded minimally on the other scales.

Table 3 shows the factor intercorrelations. The aspirational factors, WA and EA, showed a moderately strong negative correlation (r = -.59). The WS factor showed a moderate correlation with both WA and ES, .30 and .34 respectively. Other factor intercorrelations were weak.

Table 3 Factor Intercorrelations

Measure	EA	ES	WS	WA
EA	--	-.17	-.16	-.59
ES		--	-.34	.01
WS			--	.30
WA				--

Note. EA = Educational Aspiration, ES = Educational Satisfaction, WS = Work Satisfaction, WA = Work Aspiration.

Validity.

Work aspiration (WA). The WA scale measures the client's desire to work. It is expected that clients with an interest in working have negotiated a work recovery plan with their counselor. The survey asked clients whether they had a work recovery plan, and they were given response options of "yes," "no," and "don't know." As expected, clients who reported having a work recovery plan had a higher mean WA score than those who responded with "no" or "don't know" (3.43 vs. 2.51, respectively; $t = 13.75$, $df = 304$, $p < .001$, $\eta = .62$).

Clients were asked to describe their current work status and their desired work situation. For both items, the options were 1: not working, 2: volunteer, 3: supported employment, 4: part-time competitive employment, and 5: full-time competitive employment. When clients indicated that their desired work situation was at a higher level than their current work status, they were coded as having a desire for work advancement. For instance, a client who was volunteering but desired supported or competitive employment was coded as having a desire for work advancement; a client who was currently volunteering who would like to continue volunteering or who wished to stop working altogether was coded as not having a desire for work advancement. As expected, clients with a desire for work advancement had a higher mean WA score than clients without a desire for work advancement (3.25 vs. 2.50, respectively; $t = 9.43$, $df = 295$, $p < .001$, $\eta = .48$).

Educational aspiration (EA). The EA scale measures the client's desire for educational advancement. It is expected that clients with an interest in working have negotiated an educational recovery plan with their counselor. The survey asked clients whether they had an educational recovery plan, and they were given response options of "yes," "no," and "don't know." As expected, clients who reported having an educational recovery plan obtained a higher mean EA score than clients who responded with "no" or "don't know" (3.48 vs. 2.36, respectively, $t = 13.26$, $df = 301$, $p < .001$, $\eta = .37$).

Clients were asked to describe their current level of education and their desired level of education. Clients were coded as either indicating or not indicating a desire for additional education. As expected, clients with a desire for additional education scored higher on the EA scale than clients without a desire for additional education (3.25 vs. 2.06, $t = 12.78$, $df = 302$, $p < .001$, $\eta = .59$).

Work satisfaction (WS). Consistent with expectation, clients who were not working obtained a lower WS score than those who were engaged in volunteer or paid employment (2.21 vs. 2.84 respectively, $t = 6.00$, $df = 284$, $p < .001$, $\eta = .34$).

Educational satisfaction (ES). Educational level was coded as 0: No high school diploma, 1: Diploma/GED, 2: Some college or vocational training, 3: Associate's degree, 4: Bachelor's degree, 5: Some graduate school, 6: Graduate degree. As anticipated, ES was positively associated with educational level, $rs = .26$, $df = 313$, $p < .001$.

Discussion

The present study was undertaken to develop measures of vocational and educational satisfaction and aspiration for clients with severe and chronic mental illnesses. Integration into educational and work settings is an important step for many mental health clients. The present scales were seen as important both as clinical tools and a means to track program success in these areas. The scales that were developed are brief and show strong psychometric qualities. They measure four distinct dimensions, show respectable internal consistency, and exhibit criterion-related validity.

These scales could provide a clinician with valuable clinical information. The aspirational scales measure a client's desire to pursue employment and education. High work aspiration with low educational aspiration suggests a preference for work placements requiring little or no additional training. The reverse, low work aspiration with high educational aspiration, could suggest the desire to return to school primarily for personal enrichment. If a client scores low on both the work satisfaction and aspiration scales, this information could serve as a useful focus for therapeutic discussion. This pattern would suggest a client who is unhappy with the current state of affairs, but with little motivation for change. Many clients have become discouraged by what they perceive as limitations imposed by their illness. A skillful therapist could help a discouraged client to explore vocational possibilities. Increasing vocational and educational aspiration could then become a measureable therapeutic goal.

These scales also could be useful for program evaluation. As clients progress through a program and their own recovery, programs would aspire to increase their vocational and educational satisfaction. This could mean different things to different clients, and would not necessarily mean that all clients would be competitively employed or attain college degrees. It would simply mean that they become comfortable with their vocational or avocational pursuits, and feel satisfied with their level of training or education. Programs would also seek a general increase in aspiration, understanding that some clients may have made realistic and well-considered decisions not to move forward in these areas, and other clients may reduce their aspirational levels once they achieve their vocational and educational goals.

As the recovery model matures, there will be an ongoing need for instruments to measure, track and facilitate specific domains of client improvement. Determining areas of recovery that could benefit from assessment and developing instruments to accomplish this could prove a fruitful area of research and would make a significant contribution to both the literature and the quality of clinical care. An area for future research with these scales would be to look at their predictive utility, determining whether clients' levels of satisfaction and aspiration tend to be predictive of the speed and extent of their recovery. It would also be useful to determine whether scores on these tests can be increased through counseling and psychotherapeutic interventions, and whether these increases translate into integration into the workforce.

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Coping with Comorbid Cancer and Schizophrenia:

A Case Series Analysis

Lara Elizabeth Cross BSc, MEd
Doctoral Student
University of Alberta
Department of Educational Psychology - Counselling Psychology
6-102 Education North, Edmonton, Alberta T6G 2G5 Canada
Email: lara1@ualberta.ca

Abraham Rudnick, BMedSc, MD, MPsych, PhD, CPRP, FRCPC
Associate Professor
Departments of Psychiatry and Philosophy, University of Western Ontario (UWO);
Chair, Division of Social and Rural Psychiatry, Department of Psychiatry, UWO;
Physician-Leader, Psychosis Program, Regional Mental Health Care (RMHC);

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Abstract

Many individuals with schizophrenia develop cancer. This case series examined how this comorbidity affects individuals' self-concept, illness perception, and illness outcomes. Coping strategies were studied, inspired by Lazarus and Folkman's problem-focused vs. emotion-focused coping stress-appraisal framework. Four adults diagnosed with schizophrenia and cancer participated. Data was collected by means of individual semi-structured interviews, which were analyzed using thematic analysis. Self-concept was either threatened or unaffected by this comorbidity. All cancer diagnoses were accepted and perceived as the more severe illness. Illness outcomes were perceived as negative due to increased worry and fear about cancer prognosis and worsening of mental health symptoms after cancer diagnosis. All participants utilized problem-focused and emotion-focused coping strategies. Comorbidity was perceived as both improving and complicating coping with both schizophrenia and cancer. Hypotheses were generated for future research, which is needed in relation to experiencing and coping with comorbid cancer and schizophrenia.

Key Words – cancer, comorbidity, coping, experience, schizophrenia

Introduction:

Schizophrenia is a serious mental illness associated with substantial complications to health and well being. Approximately half of individuals with schizophrenia have at least one comorbid psychiatric or general medical condition, which can lead to a worse course and treatment outcome of both the schizophrenia and the comorbid illness (Leucht, Burkard, Henderson, Maj, & Sartorius, 2007). Cancer is of particular importance in this context, since it is the second most frequent cause of mortality in people with schizophrenia (Leucht, Burkard, Henderson, Maj, & Sartorius, 2007). Traditional research on comorbid cancer and schizophrenia has focused on incidence, prevalence and risk factors of cancer and has sometimes yielded conflicting results. Depending on the type of cancer, cancer risk of people with schizophrenia may be the same, less than, or greater than in the general population (Tran et al., 2009). According to Catts and colleagues, when pooled incidence rates were compared between people with schizophrenia and their first degree relatives, the incidence for cancer was not significantly increased in those with schizophrenia (Catts, Catts, O Toole, & Frost, 2008). However, esophageal and breast cancer are significantly more prevalent in people with schizophrenia (Goldacre, Kurina, Wotton, Yeates, & Seagroatt, 2005; Barak, Levy, Achiron, & Aizenberg, 2008; Grinshpoon et al., 2005), whereas colon and skin cancer are significantly less prevalent in people with schizophrenia (Goldacre et al., 2005). Different explanations have been proposed regarding cancer prevalence in schizophrenia, e.g., that schizophrenia includes a vulnerability towards developing cancer (Preti, 2008); that schizophrenia includes a genetic protective factor against particular types of cancer (Catts et al., 2008; Cohen, Dembling, & Schorling, 2002; Levav et al., 2007); and that schizophrenia includes a protective factor against cancer through use of antipsychotic medication (Japlensky & Lawrence, 2001).

Considerably less research is found on psychological aspects of comorbid cancer and schizophrenia, particularly on coping with such a comorbidity. Inagaki and colleagues examined patients with schizophrenia in relation to their adherence to cancer treatment, demonstrating that severe psychiatric symptoms and cognitive impairments interfered with effective management of cancer (Nordenberg, Fenig, Landau, Weizman, & Weizman, 1999). Coping with cancer (Inagaki et al., 2006; Kim, Yeom, Seo, Kim & Yoo, 2002; Kyngas et al., 2000; Link, Robbins, Mancuso, & Charlson, 2005; Park, Edmondson, Fenster, & Blank, 2008; Parle & Maguire, 1995) and coping with schizophrenia (Wonghongkul, Moore, Musil, Schneider, & Deimling, 2000; Cooke et al., 2007; Knudson & Coyle, 2002; Ritsner & Sussner, 2004; Rudnick, 2001; Strous, Ratner, Gibel, Ponizovsky, & Risner, 2005) have been studied as separately occurring illnesses, utilizing established coping frameworks, such as Lazarus and Folkman's problem-focused and emotion-focused coping stress-appraisal approach. This approach categorizes problem-focused coping strategies as those which address the problem, such as by weighing alternatives, determining costs and benefits of certain behaviours, and generating alternative solutions. This method of coping is adaptive in situations where the problem can be resolved.

Emotion-focused coping strategies are those which address the distress caused by the problem, such as by avoidance, minimization, and cognitive reappraisal (Tong, Wang, & An, 2008). This type of coping is said to be more adaptive in situations where it is more feasible to regulate one's feelings towards the problem rather than to resolve the problem. These two types of strategies of coping can be mutually facilitative; however, they can also impede each other.

To date, there is no published research on coping of individuals with comorbid cancer and schizophrenia. Comorbid populations may be distinct, since they have both illnesses and may have complex coping patterns that cannot be predicted from data on those with only cancer and those with only schizophrenia. Since cancer is the second most frequent cause of mortality in people with schizophrenia (Tran et al., 2009), knowledge about the experience and coping of this comorbidly ill population can have important health care implications for illness management and psychosocial rehabilitation. For example, psychosocial rehabilitation approaches have been utilized for those with schizophrenia (Yasrebi, Jazayeri, Pourshahbaz, & Dolatshahi, 2009), as well as those with cancer (Mikkelsen, Sondergaard, Sokolowski, Jensen, & Olesen, 2009) and have yielded positive results. However, this research does not examine coping with such a comorbidity. Recent research in psychosocial rehabilitation for those with serious psychiatric disabilities has integrated physical wellness components into treatment perspectives (Skrinar, Huxley, Hutchinson, Menninger, & Glew, 2005). Hence, a natural continuation of this line of research is to explore this experience of and coping with this comorbidity.

This study sought to explore experience of and coping with comorbid cancer and schizophrenia, using first person accounts. Since this was an exploratory study, a case series and qualitative method were used to help inform future hypotheses. This paper presents focused reports of four individuals diagnosed with comorbid cancer and schizophrenia. Two research questions were addressed: (1) How does the comorbidity of cancer and schizophrenia impact these individuals' experiences of: (a) themselves (self-concept); (b) their comorbid illnesses; and (c) the outcomes of their comorbid illnesses. (2) How do these individuals cope with these comorbid illnesses, particularly in relation to problem-focused and emotion-focused coping?

Methods

Participants recruited for this study met predetermined inclusion criteria: (1) a primary diagnosis of schizophrenia; (2) any cancer diagnosed after their first psychiatric admission and no earlier than five years prior to the date of the interview (to minimize recollection bias), and (3) no diagnosis of autism spectrum disorders, moderate or more severe mental retardation, or dementia (since these particularly serious cognitive impairments could confound findings).

All psychiatrists and mental health care team staff at the participating mental health program were informed of the study and identified appropriate participants that were interested in being approached by the principal author for further information about the study. Five individuals were deemed suitable and were approached by the principal author to explore informed consent. Of these, three agreed to participate. One additional participant was identified at the local cancer center and agreed to participate. All four participants provided voluntary and capable informed consent. This study received ethics approval from the local university's Health Sciences Research Ethics Board.

Data collection consisted of three parts: (1) collection of demographic information (including retrospective clinical chart review); (2) administration of the Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders for Axis One disorders (SCID-I) based the DSM-IV to determine if diagnostic criteria for schizophrenia were met (First, Spitzer, Gibbon, & Williams, 1995); and (3) our novel semi-structured qualitative interview which consisted of seven open ended questions and prompts for clarification addressing experience of, and coping with, comorbid cancer and schizophrenia; this interview was primarily phenomenological (Creswell, 2007). The retrospective clinical chart review included gathering relevant background information, such as cancer diagnosis and treatment. Such information, along with the participants' psychiatric diagnoses, can be found in Table One. The questions for the semi-structured interview inquired about the illnesses effects on the participant's self image, reflections about having two illnesses, outcomes of the illnesses, and how he or she cope with these illnesses. Sample questions included, "How does/did having cancer and schizophrenia affect how you feel and experience yourself?", and "How do you think dealing with your cancer affects/ed how you cope with your schizophrenia?" Pre-determined prompts were used if the patient required more clarification about the question. The semi-structured interview guide is available electronically from the authors on request. All data collection was conducted by the principal author, who received formal training in the administration of the SCID-1.

Table One: Psychiatric Diagnoses, Cancer Diagnoses, and Treatments of Participants A-D

Participant	Schizophrenia Classification	Psychiatric Comorbidities	Psychiatric Treatment	Cancer Diagnoses	Cancer Treatment
A	Paranoid (in remission)	- Bipolar Disorder Type 2 (in remission) - Anxiety Disorder NOS (Not Otherwise Specified – mixed anxiety symptoms)	Antipsychotic Medication	*Breast cancer* Mammary carcinoma (diagnosed 4 years before study participation)	*Past Treatment* Lumpectomy *Current treatment* None
B	Paranoid (persistent auditory hallucinations)	- Recurrent Bipolar Disorder Type 2 (in remission) - Panic disorder	Antipsychotic medication -Cognitive Behavioural Therapy	*Breast cancer* Mammary carcinoma (diagnosed 2 years before study participation)	*Past Treatment* Radical unilateral mastectomy, chemotherapy, *Current treatment* Herceptin
C	Undifferentiated (persistent auditory hallucinations)	- Major depressive disorder (in partial remission) - Panic disorder - Bulimia Nervosa (non purging type)	Antipsychotic medication	*Bowel* Carcinoid (diagnosed 3 years before study participation)	*Past Treatment* Bowel surgery *Current Treatment* None
D	Undifferentiated (persistent auditory hallucinations)	- Bipolar Disorder Type 2(in partial remission) - Cannabis Abuse - Opioid Abuse	Antipsychotic medication	*Oral* Squameous cell carcinoma of left tongue base stage 1 (diagnosed 4 years before study participation)	*Past Treatment* Modified radical neck dissection, radiation *Current Treatment* None

Interviews were tape recorded and transcribed verbatim to prepare for qualitative analysis (Altheide, Coyle, DeVriese, & Schneider, 2008; Creswell, 2007; Yin, 2009). The current study used thematic analysis to identify unique as well as common experiences and coping strategies in relation to: (a) self-concept; (b) illness perception; (c) perception of illness outcomes; and (d) strategies of coping. Such analysis has been used in past studies which have examined coping with cancer in other populations, such as young people (Kyngas et al., 2000) and Iranian women (Teleghani, Parsa, & Nasrabadi, 2006). Such analysis has also been used to study coping with schizophrenia, such as in relation to hope (Klyma, Juvakka, Nikkonen, Korhonen, & Isohanni, 2006) and parents' coping with children who have schizophrenia (Knudson & Coyle, 2002).

Results

Participant 1

Ms. A is a 74 year old divorced woman living in her own apartment. She has some post-secondary education and receives her husband's pension. Her cognitive ability is not impaired (according to her hospital chart). She stated she had the same view of herself before and after cancer diagnosis. Her illness perception consisted of denial of the schizophrenia diagnosis (but recognition of mental health challenges such as auditory hallucinations), acceptance of the cancer diagnosis, and perception of cancer as the more severe illness. Ms. A felt positive about the outcome of cancer and expressed how cancer helped her accept her mortality. Ms. A described problem-focused strategies (such as reading relevant health literature, thinking positive thoughts, talking to cancer survivors, seeking support) and emotion-focused strategies (using relaxation tapes and meditation) to cope with cancer. To cope with mental health challenges, Ms. A adhered to her physician's recommendations to take her medication, which is a problem-focused strategy. Ms. A described coping with cancer as complicating coping with mental health challenges since cancer preoccupied her thoughts. She described mental health challenges as complicating coping with cancer since she feared her auditory hallucinations would return after cancer diagnosis.

Participant 2

Ms. B is a 38 year old single woman who lives with her sister. She completed high school and receives disability allowance. Her cognitive ability is impaired (according to her hospital chart). Ms. B described feelings of insecurity, anger, sadness, and low self esteem due to having two illnesses. Ms. B experienced worry regarding cancer surgery and prognosis due to her perception of cancer as the more severe illness. She also described increased anxiety and hallucinations secondary to cancer and upset stomach due to chemotherapy. Ms. B expressed negative views regarding the outcome of her illnesses due to anxiety and hallucinations worsening throughout the course of the cancer. Ms. B utilized problem-focused (such as reading relevant health literature, and adhering to the physician's recommendations to take medication) and emotion-focused strategies (such as ruminations of suicide, increased worry, wishing the illness would go away) to cope with cancer, but emotion-focused strategies were predominant. However, to cope with schizophrenia, problem-focused strategies were predominant (exercise, going out with family, drawing pictures, and adhering to her physician's recommendations to take medication), and she utilized one emotion-focused strategy (wishing schizophrenia would go away). Ms. B reported her cancer both improved and complicated schizophrenia coping. Nurses gave Ms. B a relaxation tape after cancer diagnosis and she began to use it to cope with schizophrenia as well, which Ms. B perceived as an improvement; however, cancer complicated coping due to predominant thoughts of cancer. Ms. B reported schizophrenia complicated coping with cancer, due to an increase in anxiety and positive symptoms of schizophrenia after cancer diagnosis, which distracted from coping in problem-focused ways with cancer.

Participant 3

Ms. C is a 36 year old single woman who lives in her parents' home. She has an undergraduate degree and is supported by her parents. Her cognitive ability is not impaired (according to her hospital chart). Ms. C reported she did not base her positive self-image on her illnesses. Ms. C's perceptions of her illnesses were complicated since her cancer was initially diagnosed as Chron's disease. She reported the cancer diagnosis did not change her view of herself, and felt relief for the definitive diagnosis for her bowel symptoms. She perceived cancer as life threatening, and thus worse than schizophrenia. Ms. C expressed an increase in worry and fear after discovering she had cancer and experienced delusions not all cancer had been removed during surgery. Ms. C also reported an increase in auditory hallucinations after cancer diagnosis; however, she perceived some of these hallucinations as positive since they comforted her through positive messages. Regarding illness outcome, Ms. C reported her positive auditory hallucinations decreased after cancer surgery, which she felt was disappointing since they helped her cope with cancer. Nevertheless, she reported preoccupation with worry over cancer prognosis. To cope with cancer, Ms. C reported a balance of problem-focused (such as adhering to her physician's recommendations to take medication and reading relevant health literature) and emotion-focused (such as increased worry and wishing the illness would go away) strategies. To cope with schizophrenia, Ms. C reported problem-focused strategies (such as washing dishes, going for walks, car rides, adhering to her physician's recommendations to take medication). Ms. C reported cancer both improved and complicated coping with schizophrenia. It complicated coping due to a medication change (clozapine was temporarily discontinued) to ease bowel problems caused by cancer, which in turn caused an increase in auditory hallucinations (not all perceived as positive). Ms. C also reported preoccupation with thoughts about cancer, which distracted from coping with schizophrenia. Ms. C reported cancer improved coping with schizophrenia since she enjoyed the positive auditory hallucinations, and she enhanced her problem-focused coping after diagnosis (more car rides). Finally, Ms. C reported schizophrenia complicated how she coped with cancer since the positive voices created distraction from coping with cancer symptoms.

Participant 4
Mr. D is a 37 year old single man who lives with a roommate in a subsidized apartment. He completed grade 10 education, works part-time as a janitor, and receives disability allowance. His cognitive ability is impaired (according to his hospital chart). Mr. D reported his illnesses define his self concept, since he has two. He described distrust in God for having cancer in addition to mental health challenges. Mr. D denied a schizophrenia diagnosis (although recognized having mental health challenges), and accepted the cancer diagnosis, which he perceived as the more severe illness. After cancer diagnosis, Mr. D reported an increase in his depressive symptoms (sadness, feelings of worthlessness, thoughts of suicide), worry, and fear since he perceived no positive outcome from cancer pain or from worsening mental health challenges due to cancer. To cope with cancer, Mr. D utilized primarily emotion-focused strategies (such as using illegal street drugs, denial, increased worry, wishing the illness would go away), and to a lesser extent problem-focused strategies (such as adhering to physician's recommendations and reading relevant health literature). To cope with schizophrenia, Mr. D described problem-focused strategies (such as adhering to physician's recommendations to take medication and seeking support from his community mental health worker). Mr. D reported cancer both improved and complicated coping with schizophrenia. Mr. D began writing poetry after cancer diagnosis and continued doing so to cope with mental health challenges after cancer removal. Cancer complicated coping due to increased thoughts of suicide, depressive symptoms, auditory hallucinations, and preoccupation with thoughts about cancer. After cancer removal, Mr. D reported a decrease in thoughts of suicide. Mr. D perceived that mental health challenges complicate coping with cancer due to increased fear the mental health challenges would worsen the cancer.

Discussion

We found that living with comorbid cancer and schizophrenia creates distinct experiences for individuals regarding their self concept, illness perception, illness outcomes, and coping preferences. When cognitive ability of these individuals is intact, it may help preserve their view of self and may be related to a preference for problem-focused coping, both of which may be protective factors in relation to outcomes.

All participants utilized a wide variety of problem-focused and emotion-focused strategies to cope with cancer; however, all participants utilized primarily problem-focused strategies to cope with schizophrenia, which is consistent with some coping literature (Wonghongkul et al., 2000). Since the inclusion criteria required participants to have a diagnosis of schizophrenia prior to a cancer diagnosis, this finding may be attributed to living longer with schizophrenia and learning adaptive coping strategies over time. According to Strous et al

(2005), emotion-focused coping is more likely to be used at the exacerbation phase of schizophrenia as well as if the individual is prone to experiencing high levels of emotional distress in their lives, which would fit participants B and D. Individuals with a high amount of social support in their lives are more likely to use problem-focused strategies to cope with the illness (Rudnick, 2001), which would fit participants A and C.

We found how each illness may affect coping with the other illness. Cancer complicated and improved coping with schizophrenia. Cancer preoccupied thoughts for three out of four participants and was perceived as the more severe illness, hence participants spent more time coping with cancer to alleviate stress and symptoms. Schizophrenia complicated coping with cancer since half the participants reported an increase in positive symptoms of schizophrenia, worry, and fear after cancer diagnosis, which distracted them from addressing their cancer. The presence of other psychiatric comorbidities may have also impacted coping, such as anxiety leading to more emotion-focused coping. This has implications for future customized psychosocial interventions, since this population may experience their illnesses in a unique way compared to those diagnosed with only schizophrenia or only cancer.

This study has limitations. The sample size was small, limiting generalization. Participant recruitment into research was a challenge, as is the case with other research involving people with schizophrenia (Hamann et al., 2007), hence there may have been considerable selection bias, further limiting generalization. The design was exploratory and retrospective, therefore qualifying causal inferences, yet it was conducive to generating hypotheses for future research.

Based on our findings, we hypothesize that: (1) Greater severity of cancer and of positive symptoms of schizophrenia are associated with more emotion focused coping; (2) Level of cognitive functioning and extent of emotion focused coping are negatively correlated; (3) Level of cognitive functioning and extent of problem focused coping are positively correlated. Questions that require further study include, among others, the central question whether schizophrenia impacts differently on coping with cancer, compared to the general population's coping with cancer. Such research may facilitate the development of effective psychosocial interventions for people with comorbid cancer and schizophrenia and enhance their care.

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