International Journal of Psychosocial Rehabilitation

ISSN 1475-7192

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Volume 9

July 2004 - June 2005

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The International Journal of Psychosocial Rehabilitation
Volume 9, Number 1
July 2004– June 2005

Expert Committee on Psychopharmacology:

An Ongoing Experience in Brazil

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Camargo, G.N., Hirdes, A., Goudochnikov, V. I. (2004). Expert committee on psychopharmacology:An ongoing experience in Brazil. International Journal of Psychosocial Rehabilitation. 9 (1), 5-9.

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Abstract

The public administration has considered rather difficult to establish technical criteria in order to supply the increasing demand on the latest drugs, as well as new technologies associated with them. Besides, the high cost of these drugs is hard to fit on the limited budgets of developing countries. Quite frequently, economical and political issues do not correspond to scientific recommendations. In order to solve these problems, the Government of Rio Grande do Sul created an Expert Committee composed by members from the main scientific organizations of the State. The task of this Committee is to establish the dialogue between the local Health authorities and members of the community, to create protocols for the rational use of these high cost drugs and to give advice on issues of high technical complexity. In 2001, the Expert Committee elaborated one protocol to treat refractory schizophrenia and another one to treat affective disorders. Four other technical questions were answered since the beginning of work, showing that the experience of the Committee has been successful.

Introduction

To define public policies, which require specific technical knowledge in a field characterized by rapid evolution and changes, has always been a problem for governments. At present, there is a worldwide sociologic and political trend that imposes a mutual relationship between state administration and pressure groups that appeared in general population. On the other hand, the democratization of highly technical decisions can take those responsible for public policies to choose the options that are against to the scientific knowledge and frequently impossible to maintain on short-term or long-term basis.

This paper intends to show how the current Government of Rio Grande do Sul is trying to resolve this problem in the field of mental health, in order to promote rational use of highly cost psychotropic drugs in public health system of the State.

The solution proposed by the Mental Health Coordinating Group of the State Health Secretary was to call for the assistance of an Expert Committee on Psychopharmacology, to establish a permanent dialogue among governmental organs, scientific community and society.

Aims of the Committee

During the last years, several efficient drugs for the treatment of some mental disorders have been created. These drugs allow severe chronic patients, who required permanent nursing care, to have a quality of life pretty close to normal patterns.

Nevertheless, these drugs sometimes have a very high cost that can make impossible fitting them to the budget of any Brazilian state, if such drugs were used by all patients suffering from mental diseases. But not giving these drugs to the patients with severe disturbances and with the decrease of their quality of life would be, obviously, the violation of these people's rights regarding their health and a better quality of life.

For the State, the problem turns out to be the definition of possible limits for drug supplying and the formulation of concise criteria regarding the rational use of these drugs by the population of patients that suffer from mental diseases, as well as to try to diminish waste with inadequate prescription of drugs or indications of drugs with inadequate cost / benefit ratio to people involved in the process. Among the high cost drugs, one may focus attention on atypical anti-psychotics drugs, prescribed for the treatment of schizophrenia and for mood stabilization, in some complicated cases of affective disorders.

Schizophrenia alone with worldwide prevalence between 0.8 and 1.0% could result in 80,000 patients only in the State of Rio Grande do Sul. Moreover, serious affective diseases and with chronic course could affect more than 100,000 persons in the same State. Constant use of high cost drugs, most of them with prices exceeding 2.5 minimal regional salary per month, by the total population of these patients could make impossible the supply of this medication, if considering the State capacity to gain financial resources.

The decision of Health Sector management is to limit the use of these drugs only for treating more serious cases, particularly the so-called “patients refractory to common medication”. Only rational use of these resources can allow that a fraction of this population previously considered “untreatable” may beneficiate from the resources of modern pharmacology. However, even this decision requires a complex technical detailing, especially as referred to the limits of such approach. The task of the Expert Committee could be, therefore, to help in guiding government policies for detailing such decisions, with scientific counseling.

Through the institutionalization of a rational use policy of psychopharmacologic drugs, there might be undoubted benefits for the society as a whole. The target patients of these proposals generally require special nursing care that removes, at least, one of their relatives from productive processes. Obviously, the same mental patients are not capable to participate, even marginally, in any form of the productive process. Hence, the improvement of their conditions has economical implications. Also, re-establishing the dignity of human beings has one of the most significant values, although it cannot be measured in financial terms.

Methods of Work and Purposes of the Expert Committee

The idea to call for members of scientific community to perform the functions of counseling for public power in the field of their specific knowledge should correspond to a representation pattern of invited persons, preserving their neutrality in relation to the government and offering the amplitude and freedom of action. The invitation is based on a presupposition that those who have the knowledge would like to exert some kind of power and influence on the governmental decisions in the field of their specific knowledge. Therefore, the work is voluntary and consequently not paid. It was necessary to arrange that Expert Committee would not have a lot of bureaucracy and would not occupy the invited persons for excessively long periods of time. This is the reason why meetings of Expert Committee proceed in monthly periodicity.

After defining these principles for actions, some approaches were established to warrant representation pattern and adequate qualification of the invited persons. Considering the last criterion, it was decided that legitimate members of Expert Committee would be university professors possessing the degree of Doctor (PhD) or Master of Science (MSc) in psychopharmacology or related areas, independently of university localization, political orientation or current activities, provided their wish to participate. Considering the principle of representation pattern, each university of the State was requested to delegate one representative to the Expert Committee, always giving preference to persons that were, in some way, involved in functions related to activities in the field of psychopharmacologic knowledge. The universities that do not have strong affinity to this area could delegate representatives with knowledge in psychiatric nursing or sanitary legislation. Besides, the State scientific institutions related to psychiatry and pharmacology, The School of Public Health, LAFERGS (Pharmaceutical Laboratory of Rio Grande do Sul State), the ambulatory units of São Pedro Hospital, Presidente Vargas Hospital and Clinics Hospital of Porto Alegre, as well as the Public Ministry of Rio Grande do Sul were requested to delegate their representatives.

The Expert Committee has a political coordination and an executive secretary. The presence of members is spontaneous, and the decisions made in the meetings should be communicated to all the participants via Internet. Although government decisions can be discordant with those the Experts’, the functions of the last are broad, and in practice, the opinions of Committee have profound reflections in the policies acquired.

The Government considered the following tasks for the Expert Committee:

a) to emit reports

b) elaborate protocols for the use of psychiatric medications in public health system;

c) to suggest some governmental measures in this ambit;

d) to recommend policies;

e) to disapprove some practices considered to be inefficient;

f) to prepare official documents;

g) to send alerting messages to official drug managers;

h) to help in preparation of specific legislation acts;

i) to publish alerting communications for physicians about the risks of inappropriate substance use or drug interactions;

j) to propose teaching programs and continuing medical education for official institutions.

The work of Expert Committee is coordinated by a politician coordinator that mediates interactive dialogues with the State Secretary of Health and sometimes, with other official organs, offering suggestions of the Committee and bringing governmental counseling requirements. In case of specific demand (for example, request for protocols of the use of certain drugs), the Committee can delegate some part of activities to a working group composed of some of its members interested in the question more directly.

Constitution and Beginning of the Expert Committee Work

In order to perform the tasks described above, at first the group was invited in experimental mode, trying to continue a previous experience of another working group composed by collaborators from Clinics Hospital of Porto Alegre and State Secretary of Health that had already elaborated technical protocols of the use of high cost medication for the treatment of patients with schizophrenia, refractory to therapy by common anti-psychotics. It can be said that the success of this experience served as the basis for implantation of the Expert Committee. The first task developed by the Experts was to improve this protocol. Shortly after that, a working group of the Expert Committee, together with a representative of Brazil Health Ministry, elaborated a proposal for public counseling performed by Health Ministry, concerning protocols for the use of atypical anti-psychotics in the cases of refractory schizophrenia. This proposal served as the basis for the official document announced by Health Ministry later on.

Considering the success of previous experience, the Expert Committee was officially recognized by the Government of the State of Rio Grande do Sul by means of Governmental Decree 508 / 2001 of May, 14, 2001. Dr. Gabriel Neves Camargo was elected as the political coordinator of the Committee, and an executive secretary was also employed.

Activities and Functioning of Expert Committee in 2001

The following demands of the technical counseling were presented by the State Government for theExpert Committee in 2001:

1) elaboration of protocols for the use of high cost medication or the drugs not included in standardized list of RENAME (National List of Essential Medicines), for the treatment of affective disorders;

2) improvement of the protocol for use of high cost medications in refractory psychoses;

3) counseling on the use of methylphenidate in public health system;

4) demand to review and publish alerting communicating on drug interactions;

5) counseling on medications used in dementia and anxiety disorders.

Opinions on the Work of the Expert Committee

Although it is not possible to evaluate quantitatively the effects of optimization following the use of protocols on supplying high cost medication (considering also that such supplying is still in the phase of implantation), the pattern of demands for medication by physicians taking care of the patients began to change as the protocols became known by the interested practitioners. Particularly, the demands are closer to the patterns recommended by the algorithms of protocols. Thus, the State officials observed lower number of rejections in the processing of demands.

The precision in rational use of these drugs is really crucial, since only in 2001 the State of Rio Grande do Sul spent R$ 900,000.00 (in Brazilian currency units, the amount equivalent is approximately to 300,000.00 USD) for the supplying of drugs to 2,000 patients. Since there is a tendency of increasing in the following years, it is important not to spend these precious resources with inadequate prescriptions or providing benefits similar to medications supplied by RENAME, as their cost for the State is 45 times lower, on average.

The opinions in the area of administration sciences are also evident. In fact, a form of management for technical questions was created, according to the pattern established by Sanitary Reform in 1988 in Brazil, concerning the necessity of a dialogue between scientific community (including State officials and university researchers) and the society, both directly and by means of elected Government representatives.

Conclusion

The experience initiated with the creation of the Expert Committee on Psychopharmacology in the State of Rio Grande do Sul has revealed an extraordinary form of optimization of the use of financial resources in this field of knowledge and besides, it has established a fruitful dialogue between the scientific community and the Government. The elaboration of protocols for the use of psychoactive drugs in the basic units of care by general practitioners has resulted in the improvement of rational use of psychotropic medicines and consequently, in the diminish of demands for special medication. Nevertheless, more time is necessary for the development of new actions and methods aiming the evaluation of results obtained in a quantitative and a more precise way.

The authors wish to acknowledge the assistance of Lucila Campesatto for the translation into English from its original Brazilian.

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Volume 9, Number 1
July 2004– June 2005

A Table Tennis Tournament in the Psychiatric Hospital: description and suggestion for salutogenic implications

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Citation:
Iancu, I., Strous, R.D., Nevo, N., & Chelben, J. (2004). A Table Tennis Tournament in the Psychiatric Hospital: description and suggestion for salutogenic implications. **International Journal of Psychosocial Rehabilitation. 9,**, 11-15

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Abstract

Psychiatric inpatients are often passive and frequently complain of boredom and apathy. Unfortunately, sports therapy maintains only a marginal position in psychiatric rehabilitation. Therefore, we describe the implementation of a table-tennis contest in a psychiatric hospital and present three vignettes on patients' reactions during the tournament. Despite a paucity of controlled studies examining the therapeutic potential of exercise in psychiatric patients, exercise should be integrated in the treatment of psychiatric disorders. The role of sports in the management of chronically ill inpatients is of great importance and we discuss the positive effects of the tournament and regular physical activity on patients.

Introduction:

The therapeutic milieu in contemporary psychiatric wards comprises sessions with psychiatrists, psychologists and nurses, morning groups, group psychotherapy, occupational therapy, etc (Schjodt et al, 2003; Gutheil, 1985). Despite all the above, decreasing hospital budgets and patients' needs provide the impression that this is not enough. Patients often complain a great deal of boredom and although some of the complaints are defensive and result from negative symptoms of young schizophrenic patients (Csernansky, 2003), one wonders whether there is "lacking" in today's psychiatric hospitals. In addition, patients often report that they expect that their inpatient program will include recreation and sports (Fleischmann, 2003).

Many schizophrenics are characterized by significant passivity, impaired mobility, lack of communication and tendency to "autistic" thinking and regression, which result in reduced physical working capacity and minimal sportive activity (Dencker, 1971). Furthermore, antipsychotic medication may lead to physical side-effects, such as fatigue, circulatory disturbances and extra-pyramidal side-effects, each reducing the ability to exercise. Therefore, physical activity may be considered as a necessary ingredient in mental disease, and especially in the rehabilitation of chronic inpatients.

Sport has been reported to be one of the most beneficial recreational activities, with positive effects on the physical and mental well-being of both healthy and ill individuals (Briazgounov, 1988; Deimel, 1980). The last century was characterized by an abundance of severe metabolic health problems, with many people turning to exercise as a means of controlling body weight, achieving well being and long-term health, and reducing mortality, all serious problems among psychiatric inpatients (Briazgounov, 1988). Various sport activities have been described as being beneficial in psychiatric patients, such as horse-riding, jogging and dancing (Scheidhacker et al, 1991; Lion, 1978, Gunning & Holmes, 1973). The motor behavior, emotionality and social behavior of the patients may be significantly improved (Deimel, 1980). Sports can improve the mood of these patients and can also be a pleasurable part of the rehabilitation program of chronic psychiatric patients (Meyer & Broocks, 2000; Chamove, 1986). Sports may improve self-concept, promote relaxation, and function as a period of "time-out" during the day (Chamove, 1986). Additionally, as many as 78% of patients with schizophrenia have reported that they have used exercise in some way to reduce hallucinations (Falloon & Talbott, 1981).

Chamove (1986) studied 40 schizophrenic patients and compared their subjective and objective sensations in days of activity as compared to low activity days. He suggested that activity is beneficial in the treatment of this population. The greatest improvement was found in less severely disturbed patients, overweight individuals, females and those with lower levels of normal activity (Chamove et al, 1986).

With the above considerations in mind, we present the organization and the implementation of a table-tennis tournament in our psychiatric hospital. We also present three short vignettes regarding some of the participants in this tournament. In addition, we suggest that table-tennis lessons and tournaments on a regular basis can in fact improve the well-being of chronic psychiatric inpatients and might constitute one of the crucial "ingredients" in rehabilitation programs.

Method:

The implementation of such a program derived from the first author's initiative, who is an amateur table-tennis player. The present tournament, the second held in our hospital, was planned to take place during the Jewish Holidays in 2003.

Organization:

The planning was implemented by the first author, with some help requested from two patients. One typed the letter of the contest, announcing the date, the prizes and the fact that the competition will involve both a patients' tournament and also a doubles competition (patient and therapist). The second patient was told to distribute the announcement among the hospital's wards. As the patients were reluctant to do a "bold" promotion (maintaining that they are shy), the first author also visited the wards and talked with both staff and patients.

The prizes totaled the amount of 50$ and included 3 trophies, 2 sport shirts and two hats. The money was received from the Hospital's Friends Committee and the prizes were brought from a local sports shop.

The tournament:

Eight patients participated in the tournament (out of 200 patients in the hospital). All were young males, suffering from schizophrenia. In the Doubles Competition we had 4 therapists, 3 schizophrenic inpatients, and an outpatient, a recently discharged manic patient from the ward who also happened to have been a social worker. After the gathering of the participants, the rules of the tournament were explained and a draw was done. The tournament took place in the ward's lobby, ensuring that it could not be missed by any of the staff or patients.

The matches were one set long, up to 21 points. The patient who won the set qualified for the next round. Patients who won the first three places were awarded prizes and trophies. Due to matters of brevity, we will describe only the singles tournament.

Vignettes:

M., a 24-year-old patient with chronic schizophrenia has been in the hospital for six months due to delusions, serious behavioral problems and negative symptoms. When the competition was announced, he declared that he would win it. He implied with a smile that he was a "dangerous" player and that the rest should be afraid of him. At the tournament, he felt some apprehension concerning the level of the other players, but exhibited good table tennis technical abilities during the warm-up. He easily won the first match and then subsequently disappeared. His absence was discovered during the semi-finals and it was decided to start with the second semi-final match. Meanwhile, a second patient was sent to find him. When back, he reported he thought he had enough time prior to his next match. M. lost the semi-final match and was "in despair". It was explained that he could still win a prize as he would play for the 3-4 place. His mood then improved. During that match, he led by a few points, but was tense. Each time, the opponent closed the gap, he became very fearful. He declared that he must win a trophy, but regarded the prize (a sports hat) with little value. When close to victory, someone said that the trophies will be awarded on the next day. M was stunned and everybody laughed. M won and we calmed him and promised to give
the trophy today. He wished to get it immediately after his win and had some difficulty to wait until the prizes ceremony.

Mi., a 30-year-old schizophrenic patient, who immigrated to Israel one year ago, suffers from severe negative symptoms, has no family in Israel and is during a rehabilitation process. The night before an important interview, he took a heroin overdose during a hospital leave and after returning to the ward, he experienced respiratory arrest. After resuscitation and a short intensive care unit admission in a general hospital, he returned to the ward. The tournament takes place several weeks after this incident. M is the favorite to win the tournament, but he refused to wake up for it. Following firm persuasion, he left his bed and subsequently won the tournament. He smiled heartedly while lifting the trophy.

L- a 33-year-old chronic schizophrenic patient, is performing a diagnostic assessment as his mother, a general physician, does not accept both his illness symptoms ("he makes them up") or the diagnosis. His parents divorced during his childhood, and L. grew up with a nervous and ambitious mother. L. participates in the contest with some fear and encouragement from us, and finally wins the second place. He does not tell his mother about this, as he is not proud of the win. He remembers that winning a trophy during his military service was not joyous as he felt he was not good enough (not a combat soldier).

Discussion

We describe the successful organization of a table tennis tournament in a psychiatric hospital. It is important however to bear in mind that although both staff and patients reacted sympathetically to the tournament, there was significant difficulty to engage patients in the program, especially due to the negative signs of their illness as clearly demonstrated by the clinical vignettes. Nevertheless, patients (both contestants and audience) experienced several hours of excitement, interest and joy.

Our focus is that concentrating solely on occupational rehabilitation (i.e. work), may be less stimulating to patients than leisure activities such as sports and social games. Sports activities may constitute an enjoyable recreational activity during the long leisure time on the wards, and for some might even develop into a hobby, may be even a reminder of a childhood hobby or childhood wish to excel in sports. This intention, if strengthened by regular sport activity, *might* even influence patients' motivation to engage in the rehabilitation process and improve social skills in an indirect way, as sports are characterized by lesser anxiety than social gatherings. Moreover, negative symptoms might affect the occupational function more adversely as compared to sport activities. It would be easier for them in sports, rather than in work activities, to prove that they are still "worth something".

In the therapeutic milieu, the sport activity might provide a projective tool, mirroring the internal world of these patients, with revival of topics of aggression, competition, inter-personal problems, and low level of frustration, etc. Patients could be observed in the weekly game, similar to the observation by nurses in the ward or during bibliotherapy sessions. For the aggressive acting-out patient, the vigor of certain aspects of sports activity may serve to constructively rechannel constructively some of the energy which might otherwise be spent in undesirable, destructive acts (Gunning & Holmes, 1973). Finally, the training could result in mood improvement due to plain pleasure and endorphin secretion (Harte, Eifert & Smith, 1995). It could also affect ward organization, add to the therapeutic milieu and increase the closeness between therapists and patients, thus decreasing alienation characteristic of many patients. Since these patients experience serious regression and even ego disintegration, coordinated motor activity might have a beneficial effect on fostering the ego. It is important to stress at this point that the construction of the body ego and its boundaries is a cornerstone for further developments.

Table-tennis requires motor engagement and coordination, technical abilities, cognitive processing (knowledge, exploration, planning, mental rehearsal, decision-making, disguise of strong and weak points), all the above in a setting of substantial time pressure (Lees, 2003; Seve et al, 2002, 2003). One question that can be raised here concerns how these issues might apply to the psychiatric hospital setting and to inpatients who have motor and cognitive problems. Nevertheless, table tennis really is an **ideal activity for patients**, as its motor and cognitive demands are not excessive. This activity might improve motor and cognitive abilities, even if expectations are somewhat low. Also, sport activities provide an excellent opportunity for studying and influencing certain components of human actions (Seve et al, 2003).

Finally, sports activities as part of the care of chronically ill psychiatric patients are effective, as well as cost-effective and should receive more attention in both practice and research. Due to our experience from these tournaments, it is the intention of our clinical team to introduce a weekly table-tennis lesson with the tutorship of a professional coach in the hope of finding someone who is both patient towards these patients and could also influence them with some of his charisma and energy. In doing so, patients will be assisted in the rehabilitation process and experience.

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Volume 9, Number 1
July 2004– June 2005

Sex Differences in Sex Attitudes Among Hispanic College Students: Findings From a Texas University Near Mexico

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Eisenman, R. & Dantzker, M.L.(2004). Sex Differences in Sex Attitudes Among Hispanic College Students: Findings From a Texas University Near Mexico. **International Journal of Psychosocial Rehabilitation. 9,** 17-21.

Abstract

Several studies by the authors have looked at differences in sexual attitudes between Hispanic males and Hispanic females. All the studies, using a 42- or 38-item sex attitudes scale, designed by the authors to cover a wide variety of sexual attitudes, find many sex differences. The Hispanic males come across as wanting sexual freedom for themselves, while the Hispanic females come across as conservative regarding sex. Several implications are discussed, including possible behavior vs. attitude differences.

Introduction

Recently, M. L. Dantzker and R. Eisenman developed a sex attitudes scale, designed to cover a wide variety of sexual attitudes. Published studies with this sexual attitudes scale show consistent but small differences between Hispanic males and females (Dantzker & Eisenman, 2003; Eisenman & Dantzker, 2003, 2004). The scale has been pared down from the original 42 items to 38 items, after finding 4 items which failed to show sex differences or to fit, via factor analysis, with other items. We have given this scale several times to students at the Univesity of Texas-Pan American, (located in Edinburg, Texas, about 15 minutes from the Mexican border) which has the largest number of Mexican-American students in the United States. It also has the second largest number of Hispanic students in the United States, second only to Florida International University in Miami, Florida, which has a large Cuban enrollment. The Chronbach Alpha reliability usually comes out around .55, suggesting that many different types of sexual attitudes are being assessed.

In one of the currently unpublished studies that we did, there were 56 males and 70 females in the sample. Most, 114, identified themselves as Hispanic, 8 as non-Hispanic, and 4 did not answer this question. Thus, the sample was overwhelmingly Hispanic. The 126 surveys were analyzed using a 2x5 Chi Square (2 genders: male or female x the 5 items on the 1-to-5 scale) to assess the differences. For the Chi Squares degrees of freedom=4 (df=rows-1 x columns-1).

The Findings

A statistically significant difference for 19 of the 38 statements was found. Among the 19 statistically significant differences, 8 found males to be more agreeable to the statement than females. The statements were rated on a 1-to-5 scale, with 1 indicating “strongly disagree” and 5 indicating “strongly agree.” Thus, the higher the score, the more the agreement with the statement. These 8 statements where males scored statistically significantly higher (more agreement) than females included the idea that:

> Premarital sex acceptable for males (male mean score=3.23, female mean score=2.70)
>
> Oral sex before marriage is acceptable (male mean score=3.27, female mean score=2.69)
>
> Males should have sexual experience prior to marriage (male mean score=2.85, female mean score=2.43)
>
> Forcing person to have sex if spouse is OK (male mean score=1.59, female mean score=1.23)
>
> Marriage should not stop person from having sex with other people (male mean score=1.79, female mean score=1.31)
>
> “Topless clubs” are acceptable places for adult entertainment (male mean score=3.41, female mean score=2.60)
>
> Condoms interfere with the pleasures of sex (male mean score=3.11, female mean score=2.21)
>
> Prostitution should be legalized in all states (male mean score=2.61, female mean score=1.83)

Females agreed with 11 statements more than males, to a statistically significant extent. These ideas included:

> When growing up, parents told me premarital intercourse unacceptable (female mean score=3.75, male mean score=2.98)
>
> When growing up, parents told me any type of sexual behavior before marriage is unacceptable (female mean score=3.83, male mean score=2.84)
>
> Sex should only occur with a person you love (female mean score=4.30, male mean score=3.55)
>
> Lust and love are two different emotions (female mean score=4.73, male mean score=4.38)

> If I were to have sex, would always practice safe sex (female mean score=4.54, male mean score=3.80)
>
> Clubs that promote all nude dancing should not be allowed to exist (female mean score=3.31, male mean score=2.38)
>
> Magazines such as Playboy are demeaning to women (female mean score=3.43, male mean score=2.66)
>
> Magazines like Playboy are pornographic and should not be published (female mean score=3.32, male mean score=2.50)
>
> Pornographic material causes males to become sexually aggressive (female mean score=3.13, male mean score=2.38)
>
> Masturbation is wrong (female mean score=2.88, male mean score=2.32)
>
> I would be jealous if my partner had sexual intercourse with someone else (female mean score=4.76, male mean score=4.48)

Explaining the Sex Differences

How are the two sexes different? The males would seem to have a pleasure-oriented viewpoint about sex, in which they should have a lot of freedom to do whatever they want. The females seem to have learned a very conservative approach to sex, in which many things are taboo. An important question is whether the males are as independent and free as their answers seem to indicate. Would they really inflict sexual intercourse upon an unwilling spouse? If yes, perhaps this is part of the machismo that the male has learned, and he feels he has a right to dominate his spouse and impose his will upon her. Or, it is possible that the males feel that they should act this way—either through learning or through biological urges--but would not necessarily act this way in a real-life relationship. Also, are the females as sexually inhibited as their answers imply? Would they really not have sex outside of love? In another study (Eisenman & Dantzker, 2004), we found that our Hispanic female sample was likely to say that if aroused they had to have sex. This seems to be a totally different view than the one presented here, where sex appears to be permissible only if in love. Perhaps the Hispanic females feel guilty about having sex outside of love or outside of marriage, and want the males to appear to take the lead and cause sexual intercourse to happen. Then, they can say they were swept away, or that it was the male's fault. In either case, if this speculation is correct, they limit their perception of their own responsibility or guilt for sexual behavior. Perhaps that is one way that people who have guilt about something that they also desire cope with the conflicting emotions: by finding a way to do something but to limit their own self perceptions of responsibility.

Attitudes vs. Behavior

It may be that the attitudes that people have do not always correspond to their behavior. Behavior and attitudes are two different things, and while they may often be in harmony, there is no necessity that such is always the case. In some instances, where there is conflicted feelings/thoughts about something, a person may have an attitude that one way is correct, but may also have urges that take them in the opposite direction. If they act on those urges, then their attitude and behavior about the event are in conflict with each other.

Small Differences

In all of our studies with the sex attitudes scale, we find two things:

1. consistent sex differences in our samples of Hispanic students.
2. small differences between the Hispanic males and females, even when the items are statistically significantly different.

If there were no statistically significant differences, we would conclude that Hispanics males and females think pretty much alike regarding sex attitudes. However the statistically significant differences suggest that they may be different in their attitudes. But, the differences are not huge at all. They are often less than 1 scale point difference. For example, the Hispanic males are not strongly endorsing forcing your spouse to have sex even if she does not want to, but they are endorsing it to a statistically greater extent than the Hispanic females, with a mean score of 1.59 for males vs. 1.23 for females, where 5=strongly agree and 1=strongly disagree. In other words, one could say that both males and females tend to disagree with the idea of forcing your spouse to have sex. However, the difference of 0.36 between males and females is statistically significant, as the males disagree less with the idea than do the females. Perhaps the differences are minor, and talk of sex differences is basically unjustified.

Or, perhaps the differences are really greater than is shown on the sex attitude scale, but is not fully revealed by a questionnaire, or at least not by our sex attitude questionnaire. Perhaps in-depth interviews could reveal more of the sex differences than is shown by getting people to answer a sex attitudes questionnaire. People will not always reveal risky behaviors or attitudes on their part. For example, Hispanics have a high rate of AIDS, compared to Anglo-Americans, apparently due in part to failure of many Hispanics to practice safe sex (Fierros-Gonzalez & Brown, 2002; Selik, Castro, & Pappaioanou, 1988). But, there might be reluctance on the part of some Hispanics to admit to these practices, at least on a general sex attitudes questionnaire, especially if the questionnaire seemed to be calling for the admission of unacceptable behaviors. Either the questions on a questionnaire have to appear unthreatening to the participant, or some other means of assessment may be needed, to get at the true attitudes and behaviors.

Cultural vs. Biological

The results could be explained in both cultural and/or biological terms. From a biological standpoint, evolutionary psychology has presented a description of men as favoring sexual freedom, in order to have many sexual partners, and thus to send their genes into future generations (by impregnating many women; at least this is the unconscious wish). Women, on the other hand, get pregnant, and so cannot keep having sexual relationships which would, if pregnancy occurred, send their genes into future generations. Thus, men and women have derived different sexual strategies, and these are biologically based, trying to ensure the survival of their genes. The male strategy favors having many sexual partners, especially young, attractive ones, while the female strategy favors finding a male who will have money and high status and will protect the woman and their offspring (Buss, 1989, 2004; Eisenman, 2003; Palmer & Palmer, 2002; Shackelford, Buss, & Bennett, 2002).

However, there appear to be cultural aspects too, to the findings of sex differences. Males and females are brought up differently in Hispanic cultures, where the male is typically taught to be a strong person and to be in charge of things, while the female learns many inhibitory lessons about what it means to be a proper girl/woman. Thus, the sex differences in sex attitudes found here could reflect the differential upbringing of Hispanic males and females. Of course, it is quite possible that the results reflect both cultural and biological realities.

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The International Journal of Psychosocial Rehabilitation
Volume 9, Number 1
July 2004– June 2005

Factors Predicting Overall Life Satisfaction for People with Long-Term Mental Illness Factors

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Citation:
Young , K.M. (2004). Factors Predicting Overall Life Satisfaction for People with Long-Term Mental Illness Factors. **International Journal of Psychosocial Rehabilitation. 9,** 23-35.

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Abstract

This study attempts to explore those factors and program elements leading to better overall life satisfaction for people with long-term mental illness. The research sample included 88 patients, coming from mental hospitals and a large residential home in Hong Kong. Quality of Life Interview, Perceived Social Support and Sense of Freedom were modified, developed and adopted for data collection purpose. Most of the studied sample suffered from schizophrenia and had been ill for more than twenty years. Results showed that three factors including: number of hospitalization, perceived sense of freedom and social support could explain about one third of the variance in overall life satisfaction of research sample. Based on these findings, a quality of care model, which emphasis on preventing relapse & hospitalization, enhancing sense of freedom and strengthening social support, has been proposed. This quality of care model is suitable for residential home care setting which aims at promoting the quality of life for people with long-term mental illness.

Key words: Quality of Life, Mental Illness

Introduction

Few studies have been done in identifying those program elements predicting subjective life satisfaction for people with long-term mental illness. Mental health research is often confronted with the problem that the intervention or program under study takes place in a “black box”, which makes it difficult to assess the relative importance of various components of the intervention [1]. Moreover, even with programme that have demonstrated successful outcomes, it is difficult to specify which components of the intervention are responsible for the observed outcomes [2]. This study attempts to explore those factors and program elements leading to better overall life satisfaction (below referred as Overall QoL) for people with long-term mental illness.

Research Design and Sample

People with long-term mental illness, who were living in two traditional mental hospitals and a large residential home in Hong Kong, were invited to join in this research project. Finally, 88 people with long term mental illness had given their written consent to this research project and had been successfully interviewed by the author, including: Hospital group (n=43), and discharged group (n=45). The Hospital group was those who were ready for discharge and interviewed by researchers when they were living at two large traditional mental hospitals. Discharged group was those who had lived in a large residential home for about one year. That large residential home has been opened on 1-4-1996. It can accommodate two hundreds people with long-term mental illness. Various kinds of professional and non-professional staff have been employed to provide 24-hour personal care services for its residents. Staff to resident ratio is about 1:3. The QoL data of the research sample was collected during between April 1996and December 1997.

Data Collection

Several measuring scales have been used in this study.

A) Quantitative Measuring Instruments Used

1) *Quality of Life Interview (Modified)*

Quality of Life Interview [3] is adopted and modified in this study. The reliability and validity of the scale are well established [4] and the scale has been widely used [5-9]. There are two modifications. The first modification is the addition of two domains, i.e. staff and vocational training, with their related objective and subjective indicators. The second modification is the modification of the objective indicators of living environment so as to suit the special living environment in mental hospital and residential home settings in Hong Kong. The modified scale has 56 items, and contains objective QoL indicators, subjective QoL indicators as well as overall life satisfaction.

2) *Perceived Social Support Scale*

The multi-dimensional scale of perceived social support [10] is adopted and modified in this study. The validity and reliability of the scale has been tested to be satisfactory [11]. In this study, respondent is asked whether family, friends and staff would provide assistance in seven occasions which are adapted to hospital and residential care setting.

3) *Sense of Freedom*

The author has developed this measuring scale for the use in hospital and residential setting. It divides into two main sub-scales: perceived sense of freedom and perceived restriction. The perceived restriction sub-scale is a binary yes / no scale. The perceived sense of freedom sub-scale covers nine areas: money management, going out, bed time, bathing time, dressing, hair cutting, meal and vocational training as well as overall freedom. Each of these items is measured in a four-point scale.

4) *Social Behaviour Schedule (SBS)*

The Social Behaviour Schedule (SBS) is chosen for use in this study as this scale is especially designed for measuring the functioning in 21 areas such as hygiene, initiating conversations, depression, violence, etc. for long-stay psychiatric patients [12]. The reliability and validity of the scale has been reported to be satisfactory.

5) *Specific Level of Functioning Assessment (SLOF)*

The Specific Level of Functioning Assessment (SLOF) is designed to measure more directly observable behavioural functioning and daily living skills of people with chronic mental illness [13]. The reliability and validity of the scale has been reported to be satisfactory.

Reliabilities of the Measuring Scales

The reliabilities of self-developed scales, including: Quality of Life Interview (Modified), Perceived Social Support, Perceived Sense of Freedom and their respective sub-scales are measured by means of internal consistency using Cronbach's alpha. Table 1& 2 gives the results.

As shown in the Table 1 & 2, the internal consistencies of these scales and their subscales have reached an acceptable level of reliability for statistical analyses purpose. In addition, the internal consistencies of Quality of Life Questionnaire and Quality of Life Interview [12] are comparable.

Table 1 Comparison of Cronbach's alpha (a) of Quality of Life Interview (Modified) and Lehman's Quality of Life Interview

	Cronbach's alpha (a) of Quality of Life Questionnaire (current study)	**Cronbach's alpha (a) of Quality of Life Interview (Lehman, 1983)**
Subjective QoL Indicators		
Living Situation	.80	.83
Daily Activities	.89	.81
Family Relationship	.65	.89
Social Relationship	.86	.80
Staff	.82	N.A.
Finance Situation	.93	.87
Work / Vocational Training	.79	N.A.
Legal and Safety Issue	.65	N.A.
Health	.74	.83
Objective QoL Indicators		
Daily Activities	.55	.67
Family Relationship	.74	N.A.
Social Relationship	.68	.76
Finance Situation)	.69	.81
Overall Life Satisfaction		
Overall Life Satisfaction	.62	N.A.

Table 2 Cronbach's alpha (a) of Perceived Social Support and Sense of Freedom

Measuring Scale	No. of Item	Internal consistency (Cronbach's alpha)
Perceived Social Support		
Perceived Social Support Scale (Whole Scale)	21	.92
Perceived Family Support Sub-scale	7	.94
Perceived Friend Support Sub-scale	7	.87
Perceived Staff Support Sub-scale	7	.80
Sense of Freedom		
Sense of Freedom (Whole Scale)	18	.77
Perceived Restrictiveness (Sub-scale)	9	.61
Perceived Sense of Freedom (Sub-Scale)	9	.66

Construct Validity of the Quality of Life Interview (Modified) scale

There is a consistent finding in literature that subjective and objective QoL measures are only weakly inter-related in the same life domain [14]. This study would like to test the construct validity of the scale by exploring: whether or not the subjective and objective quality of life data obtaining by the Quality of Life Interview (Modified) scale, are inter-related in the same domain.

Results showed that the subjective QoL and objective QoL are not related in the domains of daily activities and social relationship, family and social relationship, while they are weakly or moderated related in the domain of staff relationship (r =-.208, p=.028), and finance (r =.429; p=.000) respectively. This result shows that the Quality of life Interview (Modified) scale pass the test of construct validity and it can be taken as a valid measure.

Characteristics of the research sample

Below describes the characteristics of the studied group. Results showed that the hospital and discharged groups did not differ in almost all areas of life, including demographic factors, psychiatric impairment and social functioning. They differed in their sex ratio and physical functioning only. The hospital group was predominately male while discharged group was predominated female. Also the hospital group was found to have poorer ability in their use of legs and hands as compared with that of discharged group. Thus the characteristics of these two studied groups were more or less the same.

Taking together, the studied groups were predominately male, schizophrenic and single. All of them were under 65 years of age (mean 47-48 years). Most of them had reached primary school level or above. In term of social handicap, most were single or divorced, and lack of social support had few contacts with their families. Also most of them lack of employable skills and had to rely on governmental social security schemes to support their lives.

In term of psychiatric impairment, almost all of them suffered from schizophrenia. Their illnesses were so chronic that most of them had been ill for more than 20 years, and all of them had a current continuous hospital stay for more than one year. Over one fifth showed at least one significant behavioural problem, including both positive and negative symptoms, that needed staff's intervention, as measured by SBS. In terms of social functioning, over half of them showed at least three problems in their functioning, especially in work skills, community living skills, and interpersonal relationships, as measured by SLOF.

Research Results

Correlation Analysis

A. Demographic and Medical variables

All of the demographic variables including sex, age, education, income, marital status, religion, place of birth, income, having a physical illness and attending a vocational training, etc, are found not related to subjective overall life satisfaction (below named as Overall QoL) Similarly, most medical variables including: diagnosis, onset of mental illness, recent place of hospitalization, and recent period of hospitalization are not related to Overall QoL. Only one variable, i.e. number of hospitalization is found to be negatively correlated with Overall QoL (Pearson correlation coefficient =-.441, p=.000).

B. Current Symptomatology & Functioning

Overall QoL is found to be correlated with current psychiatric symptoms as measured by the Social Behavoural Schedule. It is negatively correlated with acting out of bizarre idea (positive symptoms) (Pearson correlation coefficient =-.324, p=.007)., and under-activity (negative symptoms) (Pearson correlation coefficient =-.243, p=.044).

Overall QoL is positively correlated with physical functioning (Pearson correlation coefficient= -.270, p=.025) and inter-personal skills (Pearson correlation coefficient= -.297, p=.013), but not in other skills including: personal care, social acceptability, community living and work as measured by SLOF.

C. Objective & Subjective QoL Indicators

Overall QoL is significantly positively related to the objective QoL in living environment (Pearson correlation coefficient=.233, p=.037).as well as daily activities & functioning (Pearson correlation coefficient=.375, p=.000)., but not in domains of family relationship, social relationship, finance, vocational situation and health.

Overall QoL is found to be significantly related to most subjective QoL indicators, including: satisfaction with the living environment (Pearson correlation coefficient= .248, p=.020), daily activities & functioning (Pearson correlation coefficient= .427, p=.000), social relationships (Pearson correlation coefficient=.358, p=.001), relationships with staff (Pearson correlation coefficient= -.535, p=.000), finance(Pearson correlation coefficient= .243, p=.023), and safety & legal issue (Pearson correlation coefficient=.440, p=.000).. However, Overall QoL is found not related to three subjective QoL indicators in family relationships, vocational training and overall health condition.

D. Social Support & Sense of Freedom

Overall QoL is found to be relating to overall staff support (Pearson correlation coefficient=.323, p=.002)., but not the overall support from family members not friends. Overall QoL, however, is related to patients' overall sense of freedom (Pearson correlation coefficient=.306, p=.040), but not related to the total number of perceived restrictions.

Although the above factors have been identified in relation to subjective overall life satisfaction, it does not necessary imply that they are the contributors to Overall QoL. To determine which of the above factors do lead to a better Overall QoL, regression analysis should be used, which is to be discussed in next.

Factors leading to a better Subjective Overall Life Satisfaction - Regression Analyses

A variety of regression models can be constructed from the same set of variables. In selecting those variables entering into the regression analysis, theoretical consideration plays a very important role. Regression models are specified in SPSS for Windows using forward selection procedures. Two regression models are constructed.

First Regression Equation

The first model constructed examines the best predictors of subjective overall life satisfaction for the studied sample. Three types of variables are selected and entered into the first regression equation. The first group is the clinical variables, i.e. number of hospitalization. The second group involves the objective QoL indicators, mainly objective daily activities and functioning. The final group involves subjective QoL indicators, including: satisfaction with daily activities and functioning, satisfaction with safety at current living place.

Then by using hierarchical analyses, we can explore the relative importance of different category of variables in the regression equation. In doing this, clinical variables i.e. number of hospitalizations, is first entered into the equation, followed by the objective QoL indicators (objective daily activities and functioning) and finally the subjective QoL indicators. The regression analysis is then done step by step for the above categories of variable.

The results show that these variables altogether could explain about half (46.7%) of variance of subjective overall life satisfaction. Also it shows that the clinical variables accounted for 18.4 % of variance in Overall QoL. Objective daily activities and functioning explains an additional 8.2% of the variance, and the subjective QoL indicators explain an additional 20% of the variance. (Please refer to Table 2 & 3 for reference). Thus the individual subjective QoL indicators are the strongest variables in explaining the variance of Overall QoL. This result is consistence with other research studies which have found that subjective QoL indicator is the strongest predictor of Overall QoL [15-17].

Hierarchical Regression Analysis

Table 3 Model Summary of the hierarchical regression equation

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	0.441	0.195	0.185	1.2589
2	0.534	0.285	0.267	1.1934
3	0.702	0.493	0.467	1.018

a Predictors: (Constant), Number of hospitalization
b Predictors: (Constant), Number of hospitalization, Objective QoL in daily activities & functioning
c Predictors: (Constant), Number of hospitalization, Objective QoL in daily activities & functioning, Subjective QoL in daily activities & functioning, Subjective QoL in personal security.

Table 4 ANOVA of the hierarchical regression equation

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	31.039	1	31.039	19.584	0
	Residual	128.377	81	1.585		
	Total	159.416	82			
2	Regression	45.486	2	22.743	15.97	0
	Residual	113.929	80	1.424		
	Total	159.416	82			
3	Regression	78.582	4	19.645	18.957	0
	Residual	80.834	78	1.036		
	Total	159.416	82			

a Predictors: (Constant), Number of hospitalization
b Predictors: (Constant), Number of hospitalization, Objective QoL in daily activities & functioning
c Predictors: (Constant), Number of hospitalization, Objective QoL in daily activities & functioning, Subjective QoL in daily activities & functioning, Subjective QoL in personal security, Subjective satisfaction with freedom
d Dependent Variable: Overall QoL

Second Regression Equation

A key interest in this research is in exploring those factors, which could be modified by staff, in producing better subjective overall life satisfaction for people with long-term mental illness. In order to do this it is necessary to re-analyze the data omitting the individual subjective QoL indicators as independent variables in the regression equation.

Three variables are selected for entry by the forward selection procedure. These variables are: number of hospitalizations, perceived staff support and overall sense of mastery. This second regression equation explains about one third (30.2%) of the variance in Overall QoL, which shows that predictive power of this second regression equation is acceptable (Please refer to Table 5 to Table 7).

If predicting Overall QoL individually, these three variables also yield satisfactory predictive power (please refer to Table 9). Number of hospitalization has the strongest predictive power and could explain about one fifth (18.5%) of variance in Overall QoL, while sense of freedom explains 10.4% and perceived staff support explains 9.4% respectively.

Regression Analysis 2

Table 5 Model Summary of the 2nd regression equation

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	0.445	0.198	0.188	1.2641
2	0.539	0.291	0.273	1.1963
3	0.572	0.327	0.302	1.1723

a Predictors: (Constant), number of hospitalization
b Predictors: (Constant), number of hospitalization, perceived staff support
c Predictors: (Constant), number of hospitalization, perceived staff support, sense of freedom

Table 6 ANOVA of the 2nd regression equation

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	31.543	1	31.543	19.739	0
	Residual	127.836	80	1.598		
	Total	159.378	81			
2	Regression	46.326	2	23.163	16.186	0
	Residual	113.052	79	1.431		
	Total	159.378	81			
3	Regression	52.189	3	17.396	12.659	0
	Residual	107.189	78	1.374		
	Total	159.378	81			

a Predictors: (Constant), number of hospitalization
b Predictors: (Constant), number of hospitalization, perceived staff support
c Predictors: (Constant), number of hospitalization, perceived staff support, sense of freedom
d Dependent Variable: overall life satisfaction

Table 7 Predictive Power of individual variables of: Staff Support, Sense of freedom, Number of hospitalization

	Variable	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	Sense of freedom	.306	.115	.104	1.3187
2	Staff Support	.323	.104	.094	1.3036
3	Number of hospitalization	.441	.195	.185	1.2589

a Predictors: Staff Support, Sense of freedom, Number of hospitalization

b Dependent Variable: overall life satisfaction

In addition, sense of freedom and perceived staff support are found to have mediating effects on the relationships between patients' subjective overall life satisfaction with objective and subjective quality of life in living situation. As mentioned above, patients' objective and subjective quality of life in living situation are found to have a significant and moderate correlation with subjective overall life satisfaction (Table 8). However, after controlling sense of freedom and perceived staff support, these correlations turn to be non-significant (Table 8). It seems that when patients evaluating their living situation, they would use these two factors i.e. sense of freedom and perceived staff support as two important criteria in evaluating their objective and subjective quality of life in this area.

Table 8 Correlations of Overall subjective life satisfaction with Objective and Subjective QoL in living situation

		Without any controlling variables		Controlling for Sense of freedom and Perceived staff support	
Item	Test	Value	Significance	Value	Significance
Objective QoL in living situation	Pearson Coefficient	-.223	.037**	-.1356	.216
Subjective QoL in living situation	Pearson Coefficient	.248	.020**	.1582	.148

** Correlation is significant at the 0.05 level (2-tailed).

Discussion

The first regression model explains about half of variance of subjective overall life satisfaction and finds that the individual subjective QoL indicators are the strongest variables in explaining the variance of Overall QoL. These results are consistence with other research studies which have found that subjective QoL indicator is the strongest predictor of Overall QoL [15-17]. This finding adds evidence to the validity of the modified Quality of Life Interview used in this study.

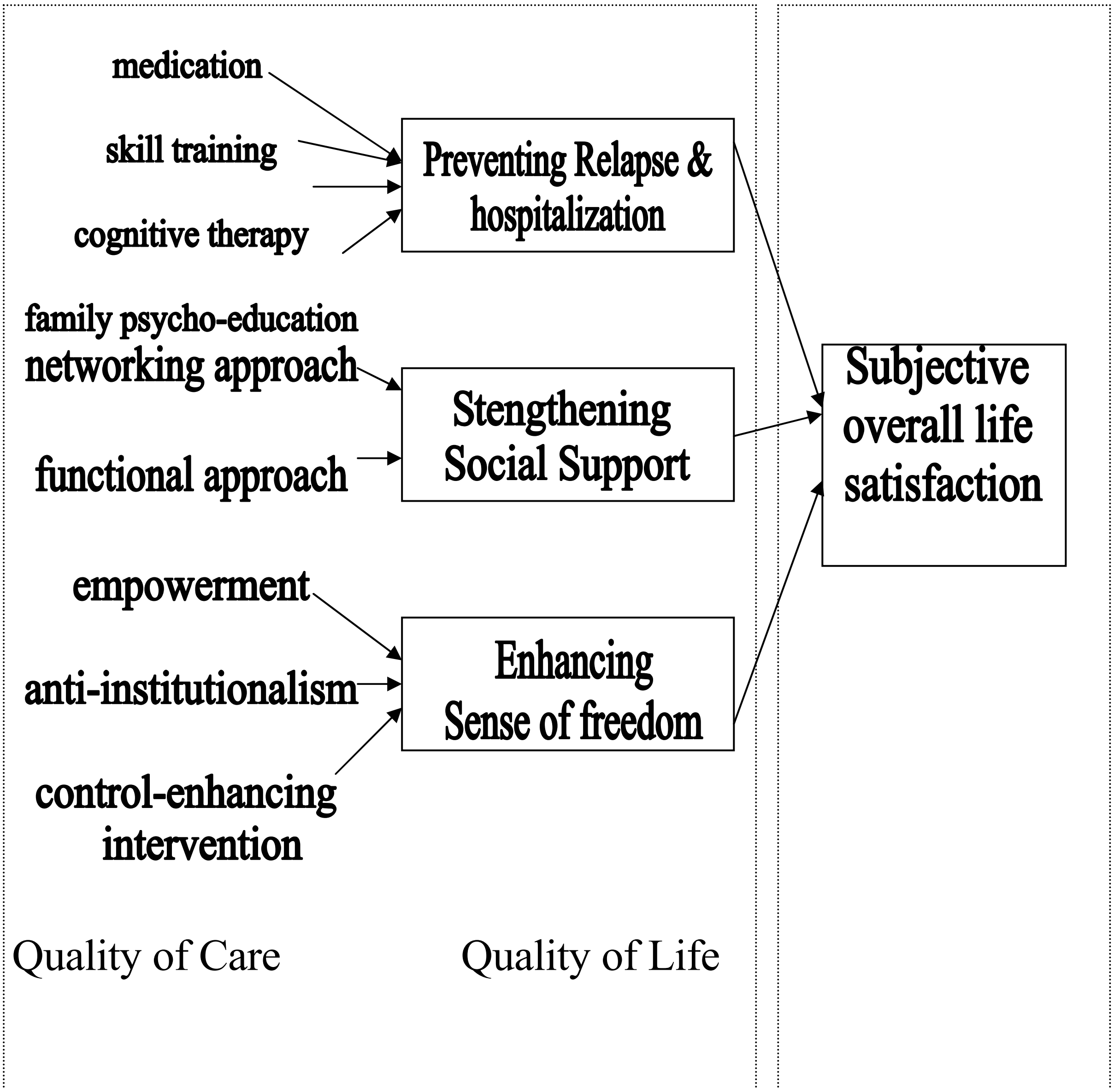
The second regression model consists of three variables, including: number of hospitalizations, perceived staff support and overall sense of mastery, and can explain about one third of the variance in Overall QoL. This finding is very helpful in identifying those program elements leading to a better Overall QoL for people with long-term mental illness.

A Quality of Care Model for residential home

Based on the findings of the second regression model, a quality of care model is proposed to include those program elements as well as intervention methods leading to a better Overall QoL for people with long-term mental illness. This quality of care model is particular useful for residential services. Figure 1 gives a graphical presentation of this model.

There are three core programme elements in this model. These three core elements are: preventing relapse and hospitalization, strengthening social support and enhancing sense of freedom. For each core program element, there are various kinds of related intervention methods. For example, in preventing relapse and hospitalization, medication, social skill training, cognitive behavioural therapy and family psycho-education are well known effective intervention methods [18-22]. For detail discussion, please refer to the unpublished thesis written by the author [23].

Figure 1. A Quality of Care Model for long-stay psychiatric patients.



Reflection on methodology

The study of subjective quality of life is largely based on the life satisfaction model as proposed by Andrew & Withey [24] as well as Campbell [25] and then adopted by Lehman [26] in the study of quality of life for people with mental illness. According to this model, quality of life is a *cognitive* experience in which an individual compares his perception of his present situation to a situation which he aspires to or expects. WHOQOL group pointed out that quality of life is both subjective and sensitive to the cultural and value systems where they live [27]. In exploring the predicators of subjective quality of life, it is difficult to identify suitable predicators as different respondents may have totally different value systems which affected their expectations, goals and standards in relation to their quality of life.

In mental health field, few studies have been done in identifying program elements predicting overall life satisfaction for people with mental illness. Levitt [16] was the first study to explore this issue. In his study, subjective satisfaction with adult education of rehabilitation service was found to predict overall life satisfaction for people with mental illness receiving adult education. However, in that study, the reasons why respondents were satisfied with adult education program remained unanswered. Rosenfield [28] successfully identified specific program elements in predicting overall life satisfaction for people with mental illness attending a clubhouse. It was found that vocational rehabilitation, financial support services and an empowerment approach to psychiatric treatment were good predictors.

As shown in this study, three key program elements, including: preventing relapse and hospitalization, promoting social support and enhancing sense of freedom are found to be good predicators of overall life satisfaction for people with long term mental illness. The identification of these key program elements with the related quality of care model could then be generalized to other residential homes.

In this study, it is shown that it would be easier for study in exploring predicators of quality of life to include a more or less homogeneous studied sample receiving in a similar kind of supportive service. As shown above, the characteristics of both studied groups, i.e. hospital and discharged group were very similar. Also, they lived in the same residential home or mental hospitals with similar characteristics. In such case, each individual respondent of a homogeneous studied group may share similar value system with each other and has similar expectations and common concerns about his quality of life. So, the identification of predicators of quality of life for such a homogeneous group would be easier and feasible. This kind of research strategy seems promising in identifying predicators of quality of life. Thus more research using similar kind of research strategy are needed in this area so as to find out the ways to further promote the quality of life for people with mental illness supported by different community care programs.

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The International Journal of Psychosocial Rehabilitation
Volume 9, Number 1
July 2004– June 2005

Managing Neuroleptic Weight Gain: Consumers' Perspectives

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Citation:
Tweedell D.E., Sutter, R.N. & Doran, K.(2004). Managing Neuroleptic Weight Gain:Consumers' Perspectives. **International Journal of Psychosocial Rehabilitation. 9,** 37-40.

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Acknowledgments:
This project was supported financially by St. Joseph's Healthcare Hamilton, Centre for Mountain Health Services, Hamilton, Ontario, Canada.

Keywords
listening to patients' stories, recovery, motivation

Abstract

Mental health consumer involvement in planning, delivery and evaluation of mental health services continues to be more a vision than a reality. Consumers expressed an interest in sharing with clinicians their experiences of taking second generation neuroleptic medications. During three discussion groups, twelve consumers discussed their concerns about weight gain, and their struggles to reduce its impact and to gain control over their lives. The opportunity to share with clinicians and each other their experiences and suggestions for managing weight gain was a valuable one for all involved.

Introduction

Weight gain is an adverse effect of many psychotropic medications, occurring in 50% of patients using these medications over the long-term (Baptista, 1999). Second generation neuroleptics offer advantages over traditional antipsychotics, but their potential to produce considerable weight gain is a serious concern (Taylor & McAskill, 2000; Kawachi, 1999). Development of obesity and its related co-morbidities, non-adherence to medication and the return of psychosis are potential outcomes. Stigma and reduced quality of life are also reported anecdotally.

To gain an understanding of the problem locally, a chart audit was conducted on 20 inpatients of a tertiary care psychiatric hospital. Identifying data included: current medication dosages, length of time on medications, initial weight and BMI, current weight and BMI, diet prescribed and level of activity. Weight gain was evident in 87% of this inpatient population. Length of time on second generation neuroleptics ranged from 4 – 24 weeks. All but one ate a regular diet and 56% were described as having excellent to good participation in the recreation program offered.

Based on the apparent extent of the weight gain issue, a series of discussion groups was held with individuals taking a second generation antipsychotic medication. This initiative was supported financially by the hospital administration, whose mission includes involving clients in evaluating care.

We sought to determine the impact that weight gain had had on their lives and, in turn, the impact that they had had on the weight gain. Our ultimate purpose was to understand: what weight gain had meant to them, what they had tried to do themselves, and what might be helpful and efficacious in managing weight gain in the early stages of taking second generation neuroleptics.

Method

Discussion groups are well suited for use in psychiatric settings due to their informality and potential for perceived support of peers who have many similar concerns. Neuroleptic medication users are the experts on their own experience. The group setting invites participants to explore each other's experiences.

Three discussion groups were held in three different settings in a city in southwestern Ontario in the spring of 2000. In total, 12 individuals participated. All had a diagnosis of serious mental illness. All participants were taking second generation neuroleptic medications and had been stable on these medications for a minimum of one year and were living in the community. Participants ranged in age from 23 to 48 years, and one third was female.

Participants were solicited by a telephone call to three sites asking health care providers if they knew individuals who might be interested in participating in a group to talk about weight gain and/or weight loss and lifestyle changes. Each individual who agreed was sent an invitation to attend a group. At the completion of the discussion group each participant received $10.00 for their time and travel, an assortment of low calorie/low fat snack food and an insulated mug. Facilitators took notes during the group discussions, and the discussions were audio taped and transcribed.

Findings

No group members identified exactly how much weight they had gained or lost. They were pleased with the second generation neuroleptic they were currently taking, feeling "more motivated", "energetic", "enthusiastic, stable and enjoying life more". In spite of this experience three people admitted they had considered stopping the medication due to weight gain. They ascribed a strong therapeutic alliance with their case manager as preventing this potential treatment interruption.

Group participants eagerly shared their experiences and ideas with the facilitators. Four dimensions of weight gain emerged:

- Almost 50% of the participants revealed a serious lack of knowledge about nutrition and how the body uses nutrients.

This was of concern as more than half lived on their own in the community, and were responsible for grocery shopping and meal preparation.

- People with severe mental illness want to look and feel well, no matter how long they have been ill and are not willing to compromise on either aspect.
- All participants had useful ideas about developing a fitness program and were eager to discuss this with others.
- Even in the early days of their illness, individuals were thinking about and looking for opportunities to become more active and involved in their own recovery.

Weight gain concerns fell into three domains:

- Physical concerns such as “feeling sluggish, bloated and being out of breath” with little exertion,
- Self-image and resultant social isolation concerns, such as “feeling unsure of myself and abilities” and “I stopped going out as much”,
- Unsuccessful coping experiences described as “weight loss-gain cycles” and “having an eating disorder”.

All participants, except one individual who did not gain weight, identified that they decided to "take on" their weight problem. This decision was a result of self-determination or, in two cases, due to negative comments made by concerned friends who also offered to lend a hand. Several were motivated by possible health risks that could threaten their new found freedom. Others envisioned themselves at an earlier, more active, physically healthy time, and were determined to reclaim it. “I was thinking about how I was before, I was more active and outgoing, stronger, and I looked at my strengths like I had before and I gradually did certain things like push-ups.”

In each of the three groups, members were eager to share successful and unsuccessful strategies they had tried. They had suggestions for the health care team regarding resources and supports that would be helpful to them while in the hospital: "exercise bikes that work and [are] kept in good repair" and "carpets on the floor near the TV where you could do sit ups and push ups while watching a program". One participant commented that "nurses exercising along with you to a video tape was helpful and fun". In addition, "evening snacks that include fruit, veggies and dip rather than bread and peanut butter or donuts" were highly endorsed. Access to healthy, inexpensive snack food in the hospital, as an alternative to high fat and high carbohydrate snacks like potato chips and chocolate bars, was also suggested.

Their recommendations were consistent with suggestions found in the literature (Baptista, 1999; McIntyre, McCann, & Kennedy, 2001; Aquila & Emanuel, 2000; Masand, 1999; Ganguli, 1999) proposing that nutritional counseling and exercise be introduced early in treatment of novel neuroleptics to deal with the problem of weight gain. Participants strongly encouraged professionals to address weight gain early with an approach emphasizing regularity, repetition, and support.

When asked what advice they would give to a friend who was thinking about starting a medication that had the side effect of increased weight gain, participants responded: "most importantly, do not lose hope", "[try] a medication that is less likely to make you weight gain, before taking the medication most frequently associated with weight gain", “accept help from staff", and “prepare yourself for the likelihood of weight gain and feel proud of yourself when you achieve one of your goals for the day".

Discussion and Conclusion

Clinicians, working in institutions, have an important role to play in encouraging, educating and actively instilling hope for successful outcomes for clients early in their treatment. Efforts directed at increasing activity levels, making healthy lifestyle choices and managing weight gain are highly valued by clients and they identify these efforts as important in their recovery. Consumers of mental health services are as interested in recovering their physical health as their mental health. Where services are not directly available, working with community partners in an advocacy role is necessary.

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The International Journal of Psychosocial Rehabilitation
Volume 9, Number 1
July 2004– June 2005

Second Generation Neuroleptic Weight Gain: Evaluating Early Intervention Strategies – A Feasibility Study

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Citation:
Tweedell D.E., Sutter A., Dunphy S., & Landeen J.(2004). Second Generation Neuroleptic Weight Gain:Evaluating Early Intervention Strategies – A Feasibility Study. **International Journal of Psychosocial Rehabilitation. 9,**, 41-46.

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Acknowledgments:
This study was supported by Eli Lilly (Zyprexa Research Fund) #F1D-CA-O142, Novartis Pharma Canada Inc., the Father Sean O'Sullivan Research Centre of St. Joseph's Healthcare Hamilton, the Hamilton Chapter-Schizophrenia Society of Ontario, and the Volunteer Association of the former Hamilton Psychiatric Hospital.

Presented as a poster at "The Art, the Science, and the Ethics of Psychiatric and Mental Health Nursing", Canadian Federation of Mental Health Nurses, Toronto, Ontario, October 30 – November 1, 2003.

Abstract

Objective: This case series study evaluated the feasibility of a six-month weight prevention program, involving nutritional counseling and an individualized exercise program monitored by a personal fitness trainer, for individuals with serious mental illness.Methods: Fourteen adults with a serious mental illness, who were inpatients at a specialized tertiary care psychiatric facility, entered the study. All had begun taking a second generation neuroleptic within the previous four months and were overweight. Primary outcome measures included weight, waist-hip ratio, and body mass index. Secondary outcome measures included several diet and fitness instruments. Data were collected at baseline, three and six months.Results: Six individuals fully completed the program and eight dropped out. There were no statistically significant differences on any measures. Although there were no statistically significant differences between the dropouts and the completers on age, duration of illness, or initial weight or BMI, the older age of the completers neared statistical significance. The completers experienced a variety of interruptions, which caused them to disengage temporarily from the study. Follow-up at one year indicated that all six subjects were involved in some form of physical activity on a regular basis.Conclusions: This study highlights the challenges of weight prevention and lifestyle change in this population and suggests directions for further research.

Introduction

Weight gain has been a side effect of many antipsychotic medications. While the newer second generation antipsychotics offer advantages over conventional neuroleptics in the treatment of schizophrenia and mood disorders, weight gain remains a problem (Taylor & McAskill, 2000). Anecdotally, evidence suggests that antipsychotic-induced weight gain increases the risk of medication nonadherence, and thus the return of psychotic symptoms. Weight gain associated with second generation antipsychotics has been particularly linked to glucose intolerance and non-insulin-dependent diabetes mellitus (NIDDM) (McIntyre, McCann, & Kennedy, 2001). Despite recommendations for early interventions to prevent weight gain in this population (McIntyre et al., 2001; Baptista, 1999), research has been sparse. One recent study reported that a 12-week weight control program incorporating exercise, dietary, and behavioural interventions is feasible and effective with this population (Vreeland et al., 2003). However, the gold standard of the effectiveness of weight loss programs indicate that interventions should be of at least 6 months duration to determine if they are truly effective in maintaining the desired outcomes (Committee to Develop Criteria for Evaluating the Outcomes of Approaches to Prevent and Treat Obesity, 1995).

We conducted three discussion groups with individuals living in the community on second generation antipsychotics who had maintained or lost weight. Based on their recommendations (reported elsewhere) we developed an intervention to prevent weight gain for the inpatient population of a specialized tertiary care psychiatric facility in south central Ontario. The purpose of this study was to address the following research questions:

1) Is an early weight prevention program feasible with this population?

2) What changes occur in the participants over the course of the study?

The weight prevention program consisted of dietary counseling with a registered dietitian and an individualized exercise program. To address the unique challenges of our population, a personal trainer provided ongoing, individualized support and motivation to participants in the exercise program. Participants met with the personal trainer at the hospital gym or at a YMCA. Both the dietitian and the fitness trainer continued to provide support and encouragement when participants were discharged from hospital.

Methods

This case series feasibility study used the following outcome measures at baseline, three, and six months. Primary outcome measures included weight, waist-hip ratio, and body mass index (BMI). Secondary measures were a 24-hour dietary recall, the Food Frequency Questionnaire (Block et al., 1986; Advisory Committee on the Dietary Guidelines for Americans, 1995), the Rockport VO2 Max Walking Test, and a number of cardiac fitness, strength and flexibility tests (Cotton, 1997). Demographic information and measures of fasting blood sugar level and fasting lipid profile were also completed. The dietitian, personal trainers, and the research assistant kept anecdotal records regarding feasibility issues.

All subjects were new starts on second generation antipsychotics ie. Clozapine, Olanzapine, Risperidone, or Quetiapine. Additional inclusion criteria were: a diagnosis of schizophrenia, schizo-affective or bipolar affective disorder; 18 to 55 years old; BMI < 27; medically cleared to participate in an exercise program; and able to comprehend English. Exclusion criteria were: on a second generation antipsychotic > one month; on multiple neuroleptics; BMI > 27; a DSM IV diagnosis of an eating disorder, drug/alcohol related psychosis, or mania; diagnosis of a major medical illness; an abnormal electrocardiogram; pregnancy; or current enrolment in a fitness program. Approval was obtained for this study from the ethics review board of the participating institution and all participants provided informed consent.

Results

Feasibility. Subjects were recruited from a population of 160 potential subjects who were taking one of the target medications. These included 96 men and 64 women, whose ages ranged from 18 to 55 and whose BMIs ranged from 19.4 to 66.8 kg/m². Of this group, 37% were diagnosed with schizophrenia, 11% with major depressive disorder, 13% with dual diagnoses, and the remainder had complex, multiple diagnoses. Subjects were recruited from April 2001 to November 2002. Nineteen individuals were eligible for our study. Five declined to participate: two were too ill to commit, one declined traveling the distance once discharged, and two were not interested. Twelve months into the study, we amended inclusion criteria to include patients who had been on a second generation antipsychotic for up to one year, and had a BMI of up to 30. When we had initially designed this research, many of the potential subjects had just started taking second generation antipsychotics. However, by the time we began the study, very few individuals were eligible using our original inclusion criteria, as many had been on the medications longer than one month. Other reasons for exclusion included initial medication nonadherence with repeated restarts, concurrent substance abuse, BMI over 30, or presence of physical conditions such as diabetes or neurological disorders.

Fourteen individuals, who were all in-patients at the tertiary care hospital at recruitment, entered the study. Fifty seven percent (n=8) was male, 43% (n=6) was female. Marital status was: 71.5% (n=10) single, 21.5% (n=3) separated or divorced, and 7% (n=1) married. Following discharge from hospital, six individuals (43%) were living with their family of origin, seven (50%) were living in supported housing with meals provided, and one was living independently.

Six individuals completed the full six months of the intervention and all outcome measures. However, three experienced interruptions due to physical illness or injury, one experienced disruption due to an increase in symptoms, one needed to take time out to focus on family, and one temporarily disengaged from the study during discharge from hospital.

Of the eight individuals who dropped out, the average number of days of participation was 56.5, with a standard deviation of 26.28, and a range of 30 to 100 days. Reasons for withdrawal included: ceasing to take one of the study medications; being discharged outside the region of the facility; having a treatment conflict; and being non-adherent and using illicit substances. There were no statistically significant differences between the drop-outs and the completers on age, duration of illness, or initial weight or BMI, although the older age of the completers neared statistical significance using t-test for analysis (see Table 1).

Table 1 Comparison of Drop-outs with Subjects Completing the Study

	Completers		Drop-Outs				
	Mean	SD	Mean	SD	t	df	*p*

Age	39.0	12.0	28.3	8.1	2.0	13	.067
Duration of Illness (in months)	148.2	59.1	160.88	41.9	1.4	13	.185
Initial Weight	79.6	12.8	75.3	12.3	0.6	13	.540
Initial BMI	26.2	2.1	25.5	3.0	0.5	13	.630

Observations by the dietitian and personal trainers highlighted some issues related to participation in the intervention. The nature of the relationships between the subjects and the clinicians influenced the subjects' commitment to the program, including remaining in the study. While the subjects were in the controlled hospital environment, adherence to all aspects of the intervention was easier. The personal trainers were based in the hospital, which facilitated initial rapport building. All subjects experienced difficulty adhering to physical activity programs in the weeks immediately following discharge. Contact with the clinicians after discharge tended to become more sporadic. The personal trainers and dietitian had to actively develop strategies to overcome communication challenges. Six months to one year following completion of the intervention, subjects reported that they continued with some form of physical activity.

The experience with the various measurement tools was a mixture of benefits and challenges. With the Food Frequency Questionnaire and the 24 hour dietary recall, subjects were required to remember what they had eaten. Items may often have been missed, which may have reduced the accuracy of the data. However, the use of food models was helpful in assisting participants to visualize foods and in accurately showing food amounts. Outside of the controlled environment of the hospital, subjects' dietary patterns were more difficult to assess. Several subjects displayed increased anxiety prior to formalized fitness tests. The location of the fitness testing presented a challenge for some subjects.

Changes in Subjects. All completers remained on their prescribed medication for the duration of the study. Repeated measures ANOVA were used to compare outcomes in the primary outcome variables (weight and BMI) and the lifestyle or dietary outcome variables (total calories, carbohydrates, proteins, and fats consumed daily). There were no statistically significant differences on any measures over time, indicating that the participants did not significantly increase in their weight or BMI over the course of the six months of the study (See Table 2).

Table 2 Comparisons of Outcome Measures over Time using Repeated Measures ANOVA

	Initial	3 Months	6 Months	F	df	*p*
Weight	0 = 77.1 SD = 12.2	0 = 84.2 SD = 13.3	0 = 84.7 SD = 12.4	1.11	2	.348
BMI	0 = 25.8 SD= 2.6	0 = 26.7 SD= 2.4	0 = 26.5 SD = 2.1	0.38	2	.686
Daily Calories	0 = 1896.6	0 = 1857.9	0 = 1645.7	0.31	2	.740

	SD = 483.4	SD = 872.8	SD = 579.8			
Daily Carbohydrates	0 = 52.9 SD = 8.8	0 = 50.7 SD = 7.7	0 = 49.3 SD = 14.8	0.27	2	.765
Daily Proteins	0 = 16.1 SD = 2.2	0 = 19.0 SD = 5.3	0 = 17.7 SD = 2.6	1.71	2	.206
Daily Fats	0 = 31.1 SD = 8.4	0 = 30.4 SD = 7.7	0 = 33.0 SD = 16.6	0.09	2	.910

Discussion and conclusions

On average, there was a 7.6 kg weight gain over six months. Most of the weight gain occurred in the first three months. While not statistically significant, the likelihood of a type II statistical error is high, given the extremely small sample size. Although the purpose of this study was one of feasibility, rather than a comparison over time, it is interesting to note that while some weight gain occurred, the reported total daily calories consumed decreased. Either there were flaws in the dietary assessment, or the weight gain was not directly related to an increase in caloric intake.

Our results highlight the challenges of implementing a weight gain prevention program for individuals with severe mental illness who are beginning second generation antipsychotics. Given that lifestyle changes are difficult even for the regular population, we acknowledge the immense challenges faced by individuals with severe mental illness who undertake such commitments. The difficulties we experienced in recruiting individuals for this study may in part reflect these challenges. Recruitment was a struggle due to the need to accommodate staff rotation. For individuals who entered the study, a variety of factors—including physical illness, discontinuation of medication, family priorities, and relocation after discharge—intervened in and delayed study participation. In particular, subjects' participation in the study consistently waned after discharge, as the immediate needs of making the transition to living in the community took precedence. Our experience suggests that allowing a period of recovery once an individual has started on the medication may improve commitment to healthy lifestyle changes. It was notable that our recruitment flyer drew many requests from interested outpatient young men and middle-aged women who had been on their medications for one year or longer. The relative cost of healthy food choices given a limited budget may have resulted in consumption of less expensive empty calories. Given the discrepancy between weight gain and reported total calories consumed, dietary recall may be especially challenging in this population. Daily contact with the dietitian might have ensured greater compliance with and accuracy of the nutritional measures. The commitment to make lifestyle changes may also be facilitated by support provided by a full-time, mobile fitness trainer.

Our feasibility study indicates that more research on diet and exercise interventions with this population is needed. The focus of this research needs to expand from weight prevention to include healthy weight management after significant weight gain has occurred.

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The International Journal of Psychosocial Rehabilitation
Volume 9, Number 1
July 2004– June 2005

Peer Support Groups for People With Bipolar Disorders in New Zealand: A Pilot Study on Critical Success Factors

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Citation:
Tse, S., Doughty, C., Bristol, F. (2004). Peer Support Groups for People With Bipolar Disorders in New Zealand: A Pilot Study on Critical Success Factors. **International Journal of Psychosocial Rehabilitation. 9**, 1, 47-58.

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Acknowledgements:The authors would like to express our gratitude to group facilitators who participated in this survey and the New Zealand Bipolar Network for their support of this study.

Abstract

Individuals with bipolar disorder may be at risk of not maintaining positive social networks that are essential for health and wellbeing. Peer support is an intentional form of social support that may help individuals to develop new perspectives on one's illness and access information, including specific training. The aim of this pilot study was to describe the running of peer support groups for people with bipolar disorder in New Zealand and from the group facilitators' point of view, to examine the critical factors that determine their success. Data were collected via a descriptive survey of known bipolar support groups within New Zealand. Three key elements of successful peer support group emerged from the study: Firstly, a close partnership between group facilitator and core group members; secondly, defining the roles for mental health professionals in peer support groups; and finally establishing the credibility of the group within the community.

Key words: recovery, social support, self-help

Introduction

Bipolar disorder (BD) is a disruptive major mental disorder. It affects approximately one in 100 adults at some stage in their lives in New Zealand and has a lifetime prevalence in the general population of between 0.3 and 1.5 percent across the world (Silverstone & Romans, 1995, Weissman, et al., 1996). BD has a relapsing and remitting course, in which some individuals have full recovery between manic, depressed or mixed episodes of illness. Nevertheless, research data to date generally points to the relentless nature of BD (Staner, et al., 1997; Winokur, et al., 1994), for example, eight out of 10 patients who reached full recovery from their first episode went on to develop a new episode within the next 10 years. Some clinicians and researchers have suggested that relapse of illness may be related to the scars of the episode themselves, the absence or inadequacy of treatment, the presence of an organic syndrome, ongoing use of alcohol or unprescribed drugs and/ or the absence of social support (Goodwin & Jamison, 1990). More recently it has been suggested that the dominant aspect amongst people who had one episode, and then no further hospitalizations, was the person's acceptance of responsibility for their own wellness (Copeland, 1998).

In an analysis of Global Burden of Disease, BD features in the top ten most disabling conditions in the world (Murray & Lopez 1996). BD is regarded as a psychiatric disorder is characterised by low prevalence and high life span disease burden. The economic burden of BD alone in the United States in 1990 was estimated to be US$15.5 billion in diminished or lost productivity in work performance (Hitley, Brady & Hales, 1999). In a recent Australian study, it has also been found that mood disorder, which affects 100,000 Australians, costs the health system A$300 million each year, with indirect costs of A$1.3 billion (Pezzullo, 2003). In modern workplaces, the leading source of workers' disability is depression (Stewart, Ricci, Chee, Morganstein, & Lipton, 2003). A common thread that cuts through the optimal management of BD is the need to minimize the intensity and duration of the individual episodes and if possible, prevent the occurrence of future episodes (Romans & Silverstone, 1994).

Social support has been associated with good health, well-being and functional performance of individuals with BD (Edmonds, et al., 1998; Goldberg, Harrow, & Grossman, 1995; Keck, et al., 1998; Michalak, Wilkinson, Hood, Dowrick, & Wilkinson, 2003; McPherson, Dore, Loan, & Romans, 1992). Social support generally refers to help that is provided by one's family or friends that facilitates the individual's ability to cope with stressful life events. It has an element of intimacy, and an opportunity for reciprocal and socially motivated behaviors (Berkman, 1995). However the question of whether and in what form social support may be available is of particular importance for individuals with BD because the social networks are at greater risk due to a variety of reasons such as the stigma associated with mental illness, the lack of effective social skills, the presence of socially undesirable behaviors when the person is manic or depressed, and/or other social sequelae wrought by the illness (e.g., loss of life roles, financial hardship, unemployment).

People with BD sometimes find support, acceptance and comfort in discussing their experiences with other individuals who have experience of similar illness in peer support or mutual-help groups. Davidson and colleagues (1999) defined peer or mutual support as a process by which people come together to help each other address common problems or shared concerns. It is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful. It is about understanding another's situation empathically through the shared experience of emotional and psychological pain. Mead, Hilton and Curtis (2001) added that when people find affiliation with others they feel are "like" them, they feel a connection. This connection, or affiliation, is a deep, holistic understanding based on mutual experience where people are able to "be" with each other without the constraints of traditional (expert/patient) relationships. One of the main differences between peer support and naturally occurring social support may be the intentional way in which it occurs, that is, there is usually a specific setting involved where new information, perspectives, training, skills and a supportive social climate are fostered. Some types of peer or mutual support are offered in the context of particular world-views and ideologies that are aimed at assisting people to make sense of their experiences.

There has been increased popularity in the use of peer support groups for people with mental health problems such as bipolar disorder, schizophrenia, alcohol and substance abuse disorders (Corrigan, et al., 2002; Felix-Ortiz, Salazar, Gonzalez, Sorensen, & Plock, 2000; Kingree & Thompson, 2000; Powell, Yeaton, Hill, & Silk, 2001). Several studies examined the attitudes, behaviors and experiences of mental health professionals toward psychiatric peer support groups (e.g., Chinman, Kloos, O'Connell & Davidson, 2003; Powell, Silk, & Albeck, 2000). For instance, Powell and his colleagues (2000) found that whether or not psychiatrists made referrals to peer support groups depended upon several factors, the presence of such groups in the same facility as the psychiatrists' clinics, the psychiatrists' receipt of information about peer support groups and his or her beliefs about its benefits and limitations. A number of other variables may dictate who gets involved in peer support. Some individuals with BD may avoid face-to-face support groups or fear discrimination if employers, workmates or friends learn about their difficulties. Some of these have turned to cyberspace in the form of Internet support groups (ISGs) (Lamberg, 2003). Researchers have found that, both face-to-face and online support groups offer emotional support (it is often considered by group members as the chief benefit), encouragement and information (Hoston, Cooper, & Ford, 2002; Klemm, Reppert, & Visich, 1998; Powell, et al., 2001; Rappaport, 1993). Corrigan and his associates' (2002) work was the first that the authors are aware of to examine the recovery processes that might account for the positive outcomes occurred in peer support groups for people who have serious mental illness. Yet despite the vast literature on social support and mental illness, there is paucity of research on critical factors influencing the outcomes of peer support groups for people with BD.

There were two aims of the present study. The first was to describe the running of peer support groups for people with BD in New Zealand. How many groups existed in New Zealand and how were they distributed over the country? What were the common types of activities? What was the background of the group facilitators? The second objective was to examine, from the group facilitators' perspective, what were the critical factors determining the success of peer support groups for people recovering from BD?

Method

Procedures and participants

This study was implemented as part of the evaluation framework for the New Zealand Bipolar Network which is a voluntary, charitable organization governed by consumers with mood disorders (primarily bipolar disorder) in New Zealand. The network is funded by membership, donations and community funding agencies (but not the central government). The present descriptive survey used a naturalistic design and the sampling frame was all the nineteen support groups (in some regions there are multiple groups) within New Zealand. This included groups identifying themselves as depression support groups, where these groups were also members of the New Zealand Bipolar Network. To be eligible for inclusion groups could be professionally facilitated, peer-run support groups or groups that adopted a combination approach but they needed to incorporate some aspect of social support, broadly defined. Of these support groups, five were excluded due to there being no group in existence or the former group being in recess. A further member group was identified as not specifically a BD support group and was not asked to return the survey form. Groups offering support primarily to relatives or family members were also excluded. A total of 13 surveys were mailed to the key contact person or group facilitator in each region, further copies of the survey were also emailed as an attachment to online members of the newsletter mailing list to maximize the chances that any unknown groups might also respond. Two reminders were circulated by email to group facilitators in order to improve the response rate. From the 13 groups surveyed, ten groups (77%) responded.

Measures/Instruments

Key questions for the present survey were formulated based on a forum held in 2003 at the National New Zealand Bipolar Conference. That particular forum was about an update on peer support groups in each region which gave useful clues on what should be covered in the questionnaire. The first author took notes of the session and discussed the drafted questionnaire with the research team. The finalized questionnaire included following areas:

- General description of the bipolar peer support group in each region (e.g., background of group facilitators, frequency of meeting, time of meeting);
- Types of activities organized in the meetings;
- A reflective question on how the group facilitators rated the overall functioning of the group(s). “1” denotes “close to not functioning at all, and “10” indicates “achieving the group set objectives”;
- An open-ended question pertained to what were the critical factors to successful peer support group.

Analyses

Data from the 13 returned questionnaire were analysed using a general inductive approach to identify key themes relevant to the research objectives. This analytic strategy is similar to grounded theory and leads to a theoretical framework developed inductively from data and emerged themes (Strauss & Corbin, 1990, 1998; Thomas, 2003; 2000). The first and second author reviewed the data individually and then the whole research team examined the overall results. Studying the written data repeatedly enabled the development of themes and sub-themes and their linkages. Analyses were performed primarily by cross-case analyses of each returned responses and the constant comparative method (Huberman & Miles, 1998). Focus for the present data analyses included: general description on peer support groups, respondents’ opinion on critical factors to successful peer support groups. Special attention was given to possible meanings of each emerging theme and sub-theme. All these findings were then synthesized into a framework to explain the keys to successful peer support groups for individuals recovering from bipolar illness.

Results

Bipolar peer support groups in New Zealand

Four of the ten respondents came from New Zealand metropolitan cities (Auckland, Wellington, Christchurch, Hamilton and Dunedin). Only one out of the ten groups was led by mental health professionals whereas the rest were facilitated by people with experiences of BD or co-led by both professionals and service users. The average meeting attendance was ten people. The average self-reported rating by facilitators on the overall functioning of the peer support groups was about “7” out of a ten-point scale, where a high score indicated optimal functioning. Other key findings are summarized in Table1.

Table 1. Survey on Bipolar peer help Groups in New Zealand

Respondent[1]	Facilitation style	Frequency of meeting	Meeting time	Average number of people attending	Impression on overall functioning: 1- very poor; 10- very well
1, NMC	Combined- led by peer and professionals	Weekly	Evening, (i.e., after 7pm)	8	9
2, NMC	Peer facilitation	Fortnightly	Evening	12	7
3, MC	Combined	Weekly	Combined	5	Did not complete
4, NMC	Peer facilitation	Weekly	Both- evening & day time meetings	15	10
5, NMC	Peer facilitation	Monthly	Evening	6	4
6, MC	Professional facilitated	Monthly	Day time	14	10
7, NMC	Peer facilitation	Did not complete these items[2]			0
8, NMC	Peer facilitation	Weekly	Day time	7	7
9, MC	Peer facilitation	Monthly	Evening	10	5
10, MC	Combined	Did not complete	Both	Did not complete	10

[1] NMC Non Metropolitan City, MC Metropolitan City

[2] This respondent provided useful descriptive data so her responses were not discarded in this survey.

The topics for education, sharing of personal experiences and opinions were grouped as follows:

- Medication (values, benefits, side effects)
- Early warning signs (what they are when noticeable? when to act? what to do and where to seek help?)
- Nutrition for the mind (use of food and supplements that affect mood)
- Cognitive-behavioral therapy
- Spiritual well-being

- Life style issues (e.g., energy level, sleep pattern, diet, opportunity for making life-style changes)
- Managing family (spouse/ partners, children) and friend relationships
- Alternative treatments (what have people heard? where to get information?)
- Dealing with discrimination and stigmatization (how to deal with? what to say?)
- Diagnosis and its replications
- Housing
- Employment
- Talks from other non-government organizations about the services they provided
- Talks by health professionals, social welfare agencies and income support services
- Privacy law
- Educational video on people's recovery journey
- Update on changes in mental health services or system
- Report on national organizations and conferences

During the peer support group sessions, a range of activities was also used to promote mental health. They are: yoga and meditation, physical exercise, training in time and stress management, sharing of jokes, recovery and depression awareness course.

"Informal tea/ coffee and biscuits time" was the most commonly used activity to promote social interaction and emotional support among group members. Some groups had set time for each attendee to discuss how things have been in between the meeting time with special emphasis on how they were coping instead of why they are not. Shared dinners, meals and festival gathering were also very popular social activities. Occasionally friends, partners and family members were invited to come along and they brought a different social dimension to the peer support groups.

Critical factors contributing to the success of bipolar peer support groups from group facilitators' perspective

There were three major factors or themes emerged from the results. Factor one was related to the qualities of group facilitators and how they worked with their core members in the group. Factor two captured key issues arising from the group that members and facilitators alike have to deal with in order to run the group successfully. Peer support groups do not exist in a vacuum. Respondents identified additional issues external to the group in factor three, which would potentially determine the outcome of peer support groups.

Factor one: Group leaders and group members

- Successful group can benefit from support provided by professionals or mental health services during the establishment phase.
- "Adequate support from faithful and dependable group members was equally important" (group facilitator 9). "It often starts with the energy and commitment from one person but to ensure sustainability this person needs the backing and support of others" (group facilitator 3). Group facilitator 4 added "Good, strong collective leadership and communication among leaders and core group members".
- Characteristics of effective facilitator or speaker were: providing ideas, to empower, not to control group members or take over the group, good listening skills, unconditional positive regard and congruence, effective interpersonal skills, no "talking down" attitude to group members, good role models, effective organization skills, networking skills with relevant agencies.

Factor two: Coping with internal challenges arising within the group

The most important challenge identified by facilitators has been to ensure confidentiality and trust is maintained among group members. One respondent mentioned that having clear rules about safety in the group, knowing how to manage differences in opinions was a useful way to reinforce that. Coping with different level of wellness among group members or people at different stages along the recovery continuum of bipolar affective disorder was mentioned as another important challenge.

Another key factor to successful peer support group was related to the group's ability to strike a balance in group size, and a right mix of gender and people with different personalities and energy level. "Getting the right mix of people for each group and keeping groups small" (group facilitator 10). It also needs to have a balance of structured (i.e., had set topic, format and process) versus free, open discussion. Respondent 4 added, "Variety is a spice and having a variety of activities, speakers, and group members makes for no two nights being the same".

Along a similar vein of findings, some respondents mentioned how it was important to manage the balance in terms of the group being facilitated by mental health professionals (that usually do not have experience of mental illness) or peers who have experience of bipolar illness. If professionals led the group, people attending peer support group would start looking to paid mental health practitioners for opinions and support rather than peers. Tension did start to happen as the peer support group went in a different direction to a recovery model. One respondent reflected on the value of adopting the recovery model in peer support group such as the principles of promoting personal responsibility, individual and collective self-determination, instilling hope.

"I think that support groups have the most to offer if they run on a peer support model and that health professionals have an important role to play in building the capacity of group members to take the group over for themselves. Having said this, from personal experience it can be very hard to extricate yourself once people have come to rely on you" (group facilitator 3).

Some respondents showed reluctance in accepting input from professionals who did not have appropriate interpersonal and communication skills. One example is:
"The group had difficulty with a mental health professional talking down to attendees with a condescending attitude. The need for good listening and conversational skills, an unconditional positive regard for others in the group and good congruency became very apparent in both group and individual support" (group facilitator 2).

On a practical note, having good up-to-date library resources and solving group members' transport problem were important issues in enabling people to attend and stay involved in a peer support group.

Factor three: Coping with external challenges

The greatest external challenge for a bipolar peer support group is to create credibility among the people the group seeks to give support to, and importantly with the government mental health services and other non-government mental health service providers such as family doctors through whom referrals come. Group facilitator 4 elaborated, "It is important for the group to have a good front people who can represent the group well in the community and as people first make contact through the telephone people who have a good phone manner and knowledge of the group". Ongoing success of the peer support group in each region depends on the group's ability in obtaining funding to cover the ongoing costs for venue hire, staff costs and information provision and other specific activities like educational workshops, festival gatherings, and small research projects. "We have good leadership among the group members however funding has become a limiting factor in the effectiveness and versatility of the group" (group facilitator 4). Recently, there has been a challenge from funders about the value of having a peer support group specifically for people with BD as opposed to a group supporting the full spectrum of mental illness.

Discussion

While the mental health recovery movement appears to have gained significant momentum in countries like the United States and the United Kingdom, its impact on mental health sector is gradually becoming more visible in New Zealand. The recovery approach was developed and endorsed in New Zealand by the Mental Health Commission as a new and fresh approach to working with people suffering from mental health problems (Mental Health Commission, 1998). The New Zealand Mental Health Commission (1999, p. 1) defines recovery as “the ability to live well in the presence or absence of one’s mental illness (or whatever people choose to name the experience)” and emphasizes the importance of acknowledging one’s cultural background, in particular the Maori culture (the indigenous people in New Zealand). “Recovery orientation is compatible with Maori mental health models, in that a balance is sought between the body, person, whanau (extended family), and the environment and ecologies within which they exist” (Lapsley, Nikora, & Black 2002, p. 2).

If people with bipolar illness are going to get well and stay well, ongoing education about the principles of recovery and elf-management skills specific to bipolar disorders is important. Individuals should be encouraged to obtain as much information as possible, through books, educational videos, health professionals and talking with other people recovering from BD. Results from the present study highlight three aspects support group facilitators see as paramount.

Firstly, this study found that in addition to personal qualities and effective skills of a group leader, it is important to create a close partnership between group facilitator and core group members to ensure successful running of peer support groups. This study challenges the conventional view that the group facilitators or leaders in clinical settings hold the key to successful group experiences. The group leader is seen as having the primary responsibility to manage behaviors and reduce anxiety inherent in bringing together a group of strangers who enter the group because they are in need (Dies, 1983; Yalom, 1985). In this study, according to group facilitators, a successful group experience requires strong commitment of certain members to the caring community created in the peer support group. These core group members need to work closely with the group facilitator regardless of whether the facilitator is coming from a service user’s background or not. This finding is consistent with recent work on recovery processes in mutual-help groups. In a study on a structured educational program and a caring community found that “(to) decentralize from self and participate in community” was one of the key recovery processes inherent in peer support group (Corrigan et al., 2002, p. 291). In turn, participation in a sharing and caring community helps lighten the group facilitators’ workload thereby contributing to the long-term survival and successful outcomes of the peer support group.

Secondly, some respondents in the present survey indicated their reluctance in accepting help from mental health professionals in facilitating bipolar peer support groups. This comment equates with the findings of Kurtz (1990) that stated over-involvement of the professional, including leadership or facilitation, risks professionalizing the group and reducing the opportunities for members to help one another. Doughty (2002) argued this was not meant to undermine mental health professionals’ expertise and knowledge about the nature, or clinical treatment, of psychiatric symptoms, but simply to acknowledge that experiential wisdom and personal struggle are important facets in helping others to seek their own wellness and recovery. However other studies suggested that professional leadership could have a positive impact (Stewart 1990, Stewart, Banks, Crossman, & Poel, 1995) while others found few or no differences between peer-led and professional-led groups (Shepherd et al., 1999). We tend to agree with Shepherd and associates that the dichotomous view of comparing peer-led versus professional-led support groups was artificial and that professional involvement in mutual aid was a continuum, with most groups having a moderate level of professional involvement. Furthermore one should not ignore the fact that the number of people with a mental illness taking up professional training in mental health sector is on the rise, both in New Zealand and internationally (Hansen, 2003). It was suggested that professionals should be engaged in a dialogue with peer-led support groups about the realities of the potential benefits and conflicts for example, what to do when a peer support group gives a service user a suggestion contrary to the advice of their treating psychiatrists or mental health workers (Chinman et al., 2002).

The third major finding of this study was about establishing credibility of the peer support groups for people with bipolar illness. Indeed without a good reputation in the community, it is very difficult to secure continuous funding for the group. Credibility of a peer support group for specific illness is often associated with helpfulness perceived by group members. It was found in a recent study that members' perceived helpfulness of a mutual help group was strongly correlated with ratings of referent power (influence based on sense of identification among members, peer leaders and mental health professionals) and expert power (influence based on knowledge and expertise) (Salem, Reischi, Gallacher, & Randall, 2000). Group members reported experiencing high level of referent power with their fellow members and peer leaders. They reported higher levels of expert power for mental health professionals and peer leaders than for fellow members.

Implications for implementation

Chinman et al. (2002) and Powell et al. (2000) drew attention to the encouraging nature of research on the utility of peer support groups for those with serious psychiatric disabilities, including bipolar disorder. Specifically, they highlighted research that related participation in such groups to lower hospitalization rates, fewer days spent in hospital, less substance use, reduced symptomatology, more positive social functioning, enhanced social networks and promoting advocacy. Despite overwhelming anecdotal evidence (e.g., Lish, Dime-Meenan, Whybrow, Prince, & Hirschfield, 1994, Doughty, 2002) that illness-specific peer support groups play an integral role in allowing individuals and families timely access to information, there still are relatively few New Zealand organizations that receive funding for peer support. To date less than one quarter of the peer support groups surveyed in the present study received adequate financial support. Employing people with a mental illness as group facilitators reflects a recognition that professionally credentialed and formally trained health professionals cannot meet all of the needs of people with serious mental illness and that service users themselves bring something distinctive to the service process (Mowbray, Moxley, & Collins, 1998).

In a survey of 1,100 mental health professionals, it was found that participants tended to view professionally led groups more positively than they did peer support groups on a number of dimensions (Salzer, Rappaport, & Segre, 1999). Their analyses suggested that the curative factor associated with professionally led groups was valued over factors associated with peer support groups. Salzer and colleagues (1999) suggested that one of the implications of their study is that professionals may be less willing to provide much needed resources and referrals to peer support groups as long as they are evaluated from a professional services framework. Adoption by funders and policy makers of an alternative framework that values the benefits of both professional and consumer-run initiatives would recognize their unique contribution to mental health services (Salzer & Shear, 2002).

Strengths and limitations of the present study

One of the strengths of this study is it is a pilot study to explore critical factors contributing to successful outcomes of peer support groups. This study also provides a description of a range of activities used in peer support group to promote education, enhance social networking and support among people with BD. However, the study is limited by assessing only one perspective on critical factors to successful peer support groups.

Conclusions

In summary, the present study provides a useful account of the key factors that make up a for successful peer support groups from a facilitator's perspective. What seems to work best is that the peer support group has clear purposes, a simple group process and a suitable governance structure. It especially highlights the need to manage any tensions that arise and strike a balance in the area of working cooperatively with health professionals. Future studies should seek to incorporate some elements of experimental design. For example even if random allocation to groups was not possible it may be useful to examine psychosocial outcomes for individuals by making comparisons between those participating in a group with factors critical to successful peer support and those assigned to control group without additional qualities. The demographic and cultural background of people attending the bipolar peer support groups was not included in this study. Further studies of factors predicting the success of peer support group should aim for more heterogeneous samples inclusive of indigenous people, ethnic minorities, different age groups and men .

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The International Journal of Psychosocial Rehabilitation
Volume 9, Number 1
July 2004– June 2005

A slab over my head: Recovery Insights from a Consumer's Perspective

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Citation:
McGrath, P. & Jarrett, V. (2004). A slab over my head: Recovery Insights from a Consumer's Perspective. **International Journal of Psychosocial Rehabilitation. 9,** 59-73.

Abstract

It has only been in very recent times that the notion of 'recovery' from mental illness has begun to gain wide acceptance. The 1990s was labelled the 'decade of recovery' to signify a paradigm shift from the notion of mental illness as a predictable deteriorative/ maintenance course to an understanding of the potential for recovery. It is now considered possible for individuals to recover fully from even the most severe forms of mental illness. Increasingly in the literature it is emphasised that insights from the lived experience of individuals who have recovered from mental illness should be central to considerations of mental health care planning and reform. The case study presented in this article is one response to the call within the literature for consumer accounts to direct and guide the development of a recovery oriented system. The findings emphasise respect for individual strengths, along with self-advocacy, assertiveness, finding the right support and having choice.

Keywords: Mental Health; Recovery; Rehabilitation.

Introduction

It has only been in very recent times that the notion of 'recovery' from mental illness has begun to gain wide acceptance (1,2,3). The 1990s was labelled the 'decade of recovery' (4) to signify a paradigm shift from the notion of mental illness as a predictable deteriorative/ maintenance course to an understanding of the potential for recovery. The work of researchers such as Harding and associates (5,6,7) led the way to indicate that the factors other than the illness were influencing progress, with the consequence that recovery was a possibility. It is now considered possible for individuals to recover fully from even the most severe forms of mental illness (8). Drake and associates' (9) survey of current treatments indicates that interventions are now more patient-centred and emphasise autonomy and recovery.

Historically, personal accounts from consumers have provided a strong impetus to putting the notion of recovery on the mental health agenda (1). The present metaphor is that of recovery as personal journey, rather then the biomedical notion of 'cure' from 'disease' (10). Increasingly in the literature it is emphasised that insights from the lived experience of individuals who have recovered from mental illness should be central to considerations of mental health care planning and reform (11, 12, 13). In Australia it is now government policy to include consumer participation in all levels of mental health service provision (14).

However, the concern is that although the notion of consumer-led recovery is on the mental health agenda there is little consensus about the nature of this phenomenon (15, 16). This article is one response to the call within the literature for consumer accounts to direct and guide the development of a recovery oriented system (17). The findings presented in the article are from a research project exploring the process of recovery from mental illness through qualitative interviews with consumers. The data from one of the interviews in the study is so rich in information and insight that it is presented here as a stand alone case history in order to do it justice.

The Research

This case history is part of a research project funded by a Central Queensland University Merit Grant. The aim of the grant is to explore through qualitative methodology the factors that contribute to recovery from mental illness. This arm of the research involves interviews with individuals who are chosen because they are articulate about their recovery from mental illness. The participant interviewed for this case study is a highly articulate consumer advocate who is presently studying psychology at university level. As a consequence the data from the interview is extensive and rich and requires the space of a full article in order to be dealt with in sufficient depth to do the findings justice.

Full ethical clearance has been obtained for the interview from the university ethics committee. The interviewee was provided with a written project description, informed verbally of her rights as a research participant and signed a written consent form at the point of agreeing to participate. The participant has had the opportunity to be involved at all stages of the development of this article.

Demographic

The case study interview was conducted with a female person who was diagnosed five years ago with type one rapid cycling bipolar disorder during a severe depressive episode experienced after the birth of her second child. The diagnosis was identified by the local general practitioner, followed by a referral to a psychiatric consultation eight weeks later, and confirmation of the diagnosis in 1999. The evidence of recovery is provided in the findings section.

Methodology

The ten (n=10) participants for this arm of the study represent a purposive sample of individuals who are chosen on three criteria: first, they have an official DSM-IV psychiatric diagnosis for a mental illness; second, they are able to demonstrate recovery from that illness; and, third, they are articulate and sufficiently motivated to express in words the experience of recovery. Participants are enrolled through the snowballing techniques of networking within the mental health consumer network. The intent behind such a purposive sample is to provide an opportunity for articulate mental health consumers to provide leadership in the way of providing insights on recovery for those who are less able to express themselves.

Data was collected through a non-directive Rogerian interview that proceeded at the interviewees pace, with constant checking by the interviewer that the material dealt with remained within the comfort zone of the participant. At times the interviewer would ask for clarification of statements and would also make summaries of the progress of ideas to affirm that the interviewer understood the ideas expressed correctly. The interview lasted for approximately two hours. It was audio-recorded and transcribed verbatim. The language texts were then entered into the NUD*IST computer program and analysed thematically. A phenomenological approach was taken to the recording and analysis of the data. The aim of phenomenology is to describe particular phenomena, or the appearance of things, as lived experience (18). The process is inductive and descriptive and seeks to record experiences from the viewpoint of the individual who had them without imposing a specific theoretical or conceptual framework on the study prior to collecting data (19). All of the participant's comments were coded into free nodes (free nodes is a technical term for the categories created on the QSR NUD*IST N5 program to store statements that relate to a similar topic), which were then organized under thematic headings. There were thirty three (n=33) free nodes created for the interview and, with the exception of the nodes on spirituality and stigma, all of the findings are presented here.

Findings

The focus for the findings presented will be on the recovery coping strategies. However, it is important to first explore the information on the participant's distressing childhood experiences in order to set the context for understanding the recovery discussion.

Family Background

During the first seventeen years of her life at home the participant had to deal with a controlling father who was often depressed and had problem with gambling. He would isolate the family from other members of the community and hold them under a realistic threat of death as he possessed a gun and shooting licence. In later years the participant came to understand that her mother felt frightened and powerless to protect her children in the face of such threats. The following two examples of distressing childhood experiences are provided as background information to demonstrate the significant family-evoked distress with which this interviewee had to deal.

- My father would put a light in my eyes and make me stay up and do maths homework all night long because that is what he would do when he was manic. And if I got anything wrong the threat was to always be shot.

- There was one day when my mother dressed me up and said 'I want you to get in the car. Now your father has told me he wants to drive both of you off a cliff and kill you because I've been bad. So I want you to get in the car and if you think he is going to kill you I want you to run away.' And so we went … I have vivid memories of the amount of the anxiety that I had .

Aspects of mental illness as functional response to distress

In the context of such a traumatic childhood, it is possible to view many dimensions of the bipolar condition as functional coping mechanisms for such a dysfunctional situation. As the following texts demonstrate, the hyper-arousal and depression associated with bipolar disorder can be seen as a response to the continuing fear associated with a life-threatening situation.

- (You really did have parents with very difficult problems) I might have had a predisposition; maybe it might never have been triggered. But there is that having to be hyper aroused (Yes, you were on alert for your own life basically) … I had a skill to stay awake when I was stressed.

- So when our father was threatening our lives, being depressed meant that I didn't care if I died.

Personal isolation and lack of childhood spontaneity, also characteristic of mental illness, can be seen as responses to the family situation,

- To wanting to isolate myself in the back corner of the house to actually use that to cope.

- Also it reinforced that adult identity I needed to have when I got home.

So successful were the participant's coping strategies that it was not until adulthood (27 years old) that the underlying condition (onset age 7) was manifest and diagnosed. During this time the participant did not have access to counselling, psychiatry or medications.

- I had lived with it for, I found out, two and a half decades. I was diagnosed at 27, I'd been sick since for two decades because my onset was the age of seven.

Strategies for Recovery – Part 1: Personal Strengths

The following discussion will outline the full range of coping strategies that contributed to recovery, starting with those developed during childhood.

A. Coping strategies – insights from childhood

The participant spoke of significant insights from childhood experiences that informed her method of coping and later recovery. As can be seen by the following statement, a mature concern for others and a belief that suicide was inherently 'wrong' provided a defence against taking her own life, in spite of suicidal feelings.

- I remember I was ten when my next door neighbour gassed himself in a car in the garage. I thought to myself 'Gee, that would be a really good way to go', and then I thought to myself as I watched the whole process 'No, I don't think I could ever do that to anyone'.

That experience combined with moral insight translated into a workable modus operandi

- I think these are the thoughts I had: that I would want to die and I think they are wrong. And I don't ever want to think like that again. So actually at the age of ten I decided that I was never going to be suicidal again.

In such a frightening family situation, precocious maturity and the ability to think quickly about complex situations are advantageous,

- She (mother) was trying to get me to grow up to fend for myself. I suppose at the age of four I was quick thinking on my feet and from that day I just thought 'I have to grow up'.

The precocious maturity extends to assuming responsibility for the fathering role for sibling and providing an anchor for the mother,

- My mother said I was an emotional rock.
- I took up the fathering role of my younger brothers and sisters….

Part of the 'adult-like' maturity included the ability to make long-term plans and use delayed gratification as a means of enduring hardship.

- I actually made a long term plan to earn as much money as I could and at the age of 17 I would move out with my mother and siblings. My mother didn't have the courage to do it by herself. And that is what happened, in the end we ended up doing it. So by the age of nine I made that long term plan to move.

B. Coping strategies – Self initiated cognitive strategies

The participant spoke in considerable detail about the energy she invested in developing effective cognitive strategies for recovery. Such strategies depend on personal insight and a willingness to explore cognitive solutions. An example of such a strategy and its effectiveness in relation to depression is as follows,

- (The doctor) gave me a depression questionnaire and I didn't answer 'yes' to anything because I realise now that I had already developed ways to cope with not thinking that way. I was actually trying to stop myself feeling depressed by thinking the other way. My strategy was to not think suicidally as I wanted to live. That is why I didn't rate on the depression scale because I learned to deal with the depression quite competently.

Another example is seen in her struggle with suicidal thoughts,

- I learned to overcome suicide, that feeling of wanting to die. I probably learned a sense of humour. I learned how sometimes my intelligence worked for me or against me. To be a little creative.

C. Coping strategies – understanding of others

The sense of understanding also extended from self to other. The participant indicated that insights into others emotional lives assisted the recovery. Of particular importance for this participant were insights into her father's psychology,

- The abuse we suffered as children was a result of him (father) having severe bipolar disorder.

And also her mother's inability to protect her,

- As a child maybe what hurt me more is, 'I don't understand why my loving mother is doing this?' As I got older I realised how scared she was. Of him, because he had a shooting licence… was able to kill her.

D. Coping strategy – Obtaining information

Access to information from varied sources such as books and the Internet, is an important factor informing the understanding of self and other. Information from others coping with mental illness is vital. Mention was also made of the importance of books of hope, information on relationships and psychology.

- I do think the sharing of information between consumers or advocates does help. It is not something any professional would ever teach you.
- Psych degree… really loving it, really loving studying it. There are concepts that are really helpful there are others that are really useless.

One important coping strategy obtained from the Internet that was discussed in detail was called the 'Survival Techniques for the Mentally Ill'. This included learning to cope with others reactions to a psychiatric label.

E. Coping strategies – forgiveness

Forgiveness based on understanding and information was recorded as a factor contributing to recovery.

- I felt forgiveness for my father because I had never understood what was wrong with him. Relief because I could forgive him more easily knowing there was something I thought biologically wrong with him. That he wasn't necessarily a bad person.

F. Coping strategies – sense of humour

From an early age the participant discovered that humour was an important strategy because it provided relief and good feelings, the space to face difficult realities, and the opportunity to reframe challenging realities in a safe way.

- I probably learned a sense of humour. It was a safe way to talk about anything. My mind was very quick at picking up things that make me feel good and don't have consequences. Humour is a way of looking at anything and being real to the fact that it exists. And finding a way of thinking of it differently.

G. Coping strategies – fitting the cultural stereotype

In a society with high expectations on the role of women, the 'manic' dimension can be an advantage in coping.

- I was super efficient… I was generally super woman. . I totally fitted what other people wanted me to be. … As a housewife and I was also a construction manager.

H. Coping strategies – spirituality

The participant provided a rich discussion of the central role that spirituality played in her recovery. Because of the limitation on space available in an article, this wealth of information will be published elsewhere. It will have to suffice here to indicate that spiritual values, prayer and involvement in the church community were important dimensions of the recovery process. As the participant sums up,

- Everything deep down is related to my spiritual beliefs

I.Coping strategies – finding ways of connecting with others

With a background of isolation as a child one of the challenges in recovery was to learn to connect with others. The freedom to express emotions as they occurred played an important role in managing stressful situations.

- I thought 'well if I can talk to my psychiatrist can I talk to other people?' I could I was experimenting. So then I'd come back to the psychiatrist and I'd go, 'Oh well I tried. I had a breakdown with the pastor at church. I got myself a French accountant who can tolerate a lot of stress. I'm getting a good support network going here.

Strategies for Recovery – Part2: Dealing with the Mental Health System

The journey from diagnosis to recovery was recorded as a direct result of the participant's self-initiated struggles to work creatively and assertively with the mental health system. As the following discussion explains, the participant's insight, intuition and drive were met by a serendipitous connection with a psychiatrist prepared to listen, affirm and take risks. It was that healing combination of consumer initiative and compassionate professional response that assisted with the process of recovery. This journey started with many unhelpful connections with professionals.

From diagnosis to drugs

From the beginning of this account there is a tension between a mental health system where the primary modus operandi involved compliance with medication and a consumer with an intuitive sense that talk therapy would be a more productive alternative. The system pressure was expressed as,

- I wasn't offered any other options. Just told you to take (drug name). So one year past I was on every type of medication. At the end of one year I was seeing a psychiatrist every week with no therapy. A huge cost per hour too I must say.

And the intuitive drive was described as,

- I'm not going to kill myself, we already knew that. What is the risk in … and I wanted therapy. And week after week I would say, 'Can I please have therapy?' I needed to recall what happened to me in my childhood.

The ambivalent compliance with medication incorporated an optimistic hope that the drugs may provide a solution,

- I wanted to fix that so I prayed that his little pills would work

However, the ambivalent optimism was also accompanied by difficult drug side effects from up to nine pills a day, for example,

- I was thirsty all the time and I did not feel like myself.

- I think that this is really bad'. Like I've swollen up. I can't even walk on the soles of my feet, because I got spots and everything. I'm like really sick. Physically really sick as well.

The intense medication resulted in anaphylactic shock and cessation of all medication,

- I went into an anaphylactic shock in the end. So I blew up. I went to the psychiatrist and said, 'Look at me' and he said, 'Oh, you had better go off everything' and then I was on the pill to control my hormones, I was on so many things, I was even on thyroid tablets. I was on everything; I had to go cold turkey off everything.

During the period of cessation of medication there was no appropriate support other than a psychiatric appointment in two weeks.

- You are telling me I have chronic bipolar disorder and you are going to take me off all of this medication and return me to a family of two young children and a husband with no one to help me. At that point I sacked him.

As seen by the following statement, the control by the system is experienced as a repeat of the cycle of abuse,

- For me it was abuse happening all over again. It was 'I don't have control', I have someone else controlling my life. I know what I am doing… I am not going to kill myself…

Feeling better without drugs

The period without medication is recorded as positive, in spite of physical problems, because of the return to self and the opportunity to be in touch with present emotional pain and past memories considered necessary to access for healing.

- I was on nothing. I felt like myself again. Even though that might be bad, but it was better than the worst (on drugs).

- For me my memory opened up. The pain and suffering I was now in because now I was not medicated. …To me it was all of a sudden my memory was coming back and that is where I needed to be.

Need to do therapy without drugs

The participant reported having a strong intuitive sense that talk therapy without medication would be the most effective means to recovery. The rationale being,

- I felt that the trauma I suffered was so bad it was what was affecting my life more than the bipolar disorder was. … It is like a band aid on a boil. The boil just needed to be lanced. And that is so much more painful and takes so much more skill. There is no easy way. I have had others who have gone through this and I am aware that this is not just true for me, it is also true for other people.

- I needed to do that without medication because that is how my memory was most active, especially when I was in the current emotional state.

Efforts to find a psychiatrist willing to engage in this process were blocked by gaps in the system.

Gaps in the mental health system

The expectation was that a serious diagnosis of type one rapid cycling bipolar disorder would provide direct access to help. This expectation was thwarted for the participant by the fact that the private psychiatrists contacted were not taking new patients and in the public system she did not qualify for the criteria for the local mental health service as she was not a suicide risk. The gaps in the system created confusion and fear,

- I didn't know how this worked. Because I thought the diagnostic history was enough to get me help. But I was afraid of getting locked up. Now I had fear of getting locked up. I thought there was a danger of me getting locked up trying to seek help. Now I had this fear I didn't have before.

It was a combination of her self-advocacy and pure serendipity that she eventually negotiated a self-referral to a sympathetic psychiatrist at a public forum,

- I went to a public forum and asked psychiatrist, 'How does this work? Do I need to attempt suicide in order to use your services?' I said, 'because I am really sick I need help and I know there surely has got to be someone around here who can help …I can't afford private health insurance. Can you tell me how I do this?' And that was the point he took me on as a private patient. (You created the referral yourself?) This is me finding my own life buoy.

The creative therapeutic process

As the following description will outline, a significant part of the recovery process eventuated through the therapeutic psychiatric relationship. There were a number of factors that facilitated this process and they included turning points that provided an emotional openness to work on difficult issues, the courage of the psychiatrist to engage in a degree of therapeutic risk, the creative use of drugs, and nourishing elements in the counselling relationship.

Turning point

The participant spoke in detail of a number of factors that converged in her life that made her open to, and insistent on engaging in talk therapy. First amongst these was the grief she experienced from her sister-in-law's suicide,

- It was my sister in law, probably committing suicide that actually probably got it all going, because at the end of the day it triggered off so much other stuff for me.

Second, her emotional devastation and the fact that she was no longer on medication provided access to memories that energised the therapeutic exploration,

- I was back in emotional devastation of how I felt when I was a child. For me my memory opened up. The pain and suffering I was now in because now I was not medicated. The very extreme emotions were a memory trigger. I could remember everything so to me it was like a good thing as well.

Thirdly, the trust she experienced in her relationship with her psychiatrist gave her the confidence to begin the therapeutic process,

- The catalyst was probably trust occurring in that (psychiatrist) relationship. …I remember him (psychiatrist) consoling me over her death. And when he supported me in that he gave me the insight to know that he could support me retrieving the past.

Need to take risks

A theme underlying the discussion was the idea that the use of medications not only have their problems from side effects, but they also have another level of problem in that they stop the patient from entering the therapeutic space needed to unpack childhood trauma and move on. Consequently, to some degree the prescription of medication operates on the principle of risk management, keeping the person locked into the present status quo. The participant expressed appreciation for the fact that the psychiatrist who helped her to recover countered this by taking risks (albeit responsible and calculated risks).

- So having a psychiatrist that was quite happy for you to take the increasing and decreasing and your own prescribed amount of anti-psychotics because you are experimenting with them. (He wasn't your usual conservative psychiatrist?) No.

The boundaries of the risk taking were discussed and agreement reached as to the limits and strategies to ensure the risk taking was within ethical boundaries of the profession.

- Psychiatrist would make me aware of when he had an ethical problem in letting me go out of his office. I found creative ways to talk about this that I could reassure him that he would feel unobligated by his ethical responsibilities.

The important outcome of the process is that the patient felt in control of, and thus responsible for, her own healing process.

Experimenting with and without drugs

An important part of the therapeutic freedom that the participant valued and attributed as part of her recovery process was experimenting with medications. Not all experiences were positive as can be seen by the reference to anti-depressants,

- I tried anti-depressants. They did send me off the deep end so that was a bad idea.

A positive example is her use of anti-psychotic drugs to understand, for a brief time, the feeling of not being in a psychotic state. As the participant explains, it is this feeling, not the drug, that is used for the recovery process,

- I knew that if I took an anti-psychotic it would have a chemical effect of reducing those chemicals in my brain … I'd get a feeling of what it would be like to not be in a psychosis if I took them. I've got to say that to some degree it felt good but I did not like the side effects. … I experimented with them.

The use of medication became a tool to self-learn about the effect of chemicals in her system.

Effective therapy process

Once the talk therapy began, there were many factors within the therapeutic alliance that fostered recovery. First and foremost is the sense of trust creating a safe space,

- I started the therapy process and three or four months into that; I suppose it probably took me that long for the trusting to start occurring. But the catalyst was probably the trust occurring in that relationship.

- (Previously) there is all this stuff I'm trying not to remember because if I do I will fall apart. I've not really been in a place where I felt safe where I can fall apart.

Second, is the importance of having control over the therapeutic space,

- I needed control over my lifelines. Maybe I can put it that way.

Third is the emotional openness obtained without medication,

- I needed to do that (therapy) without medication because that is how my memory was most active.

Fourth, was the sense of having someone with a solid base in the present from which to explore the past,

- The psychiatrist gave me somebody who was in the present …he kept pulling me back to the present. Sometimes I felt I could just get lost back there … rather than 'lets go deeper', a lot of my therapy was, 'you have dug too deep'.

The process involved revisiting a frightening past with a message from the present that there was no longer anything to fear,

- As a child a lot happened under intense fear. Sometimes I needed to retrieve it right out. Just not be afraid of it anymore. I need to circle that around in my head, 'There is nothing to fear'.

The medium for such exploration is simply talking in a safe space for reflection and integration of fearful past memories,

- So if I can get through this I can put the pieces back... I've had friends who have gone through this and I'm aware that this (talk therapy) is not just true for me. It is also true for other people (Just talking did help you?) Yes.

An essential element of the process was to do this with someone, rather than alone,

- I wanted someone to be with me. I had always been alone. Alone, doing it myself.

One of the disadvantages of being innately independent had been others would not see the need to offer support.

Recovery

The outcome of the above detailed process is that the participant moved from being a consumer of the mental health system to a consumer advocate involved in education of psychiatrists and other mental health professionals and organisations at local and national level. The indications that the participant is in recovery include A. a letter from her psychiatrist affirming her successful coping abilities and releasing her from therapy as she no longer needs psychiatric follow-up; B. the fact that she remained symptom free and without relapse since 2001; C. her success in undertaking a university degree; D. her strong contribution to the welfare of others through her important work as mental health consumer advocate (eg. National depression initiative); E. her ability to develop an extensive support and friendship network; and, F. psychiatric and educational evidence that her children are demonstrating emotional adjustment and educational success.

Recovery reinforces recovery

There are many benefits from recovery that help to affirm the individuals sense of self worth and thus further reinforce the recovery process. In this case there were two areas of life where this positive process is demonstrated - as mother, and consumer advocate.

The central role of mothering

> *A concern for the welfare of her children is the central force driving and maintaining recovery.*
>
> - *And having my children. That is really important to me. And I probably didn't emphasise that enough.*

The participant spoke of her pride in that fact that since her recovery her children had progressed past early adjustment problems and were now doing well.

- Every parent wants to know that they have done the right thing by their kids. I want to emphasise that – that is one of my driving forces. All the fears of what your parent did to you as a child - and my child was now becoming depressed and sick at the age of seven like her mother. But now I had the opportunity to do things right.

- (After discussing prior problems with children) Both of my children are now ahead in all aspects at school. And the parent teacher night is always wonderful.

Consumer advocate –seeing how far you have come

The participant is a well respected consumer advocate who uses her energy from recovery to make a difference to the lives of others. The advocacy role provides further opportunity to reinforce her progress and present strong position.

> - I ended up an interpreter between the professional and the consumer. A skill I am really enjoying developing. It is wonderful to be able to value how far you have come. You don't realise that until you see somebody who is just diagnosed. And all of a sudden you realise what a hole that they are in and what information we have. And you remember how hard it was and within a very short period of time you are able to show people how to turn on the light.

The Mental Health Metaphor

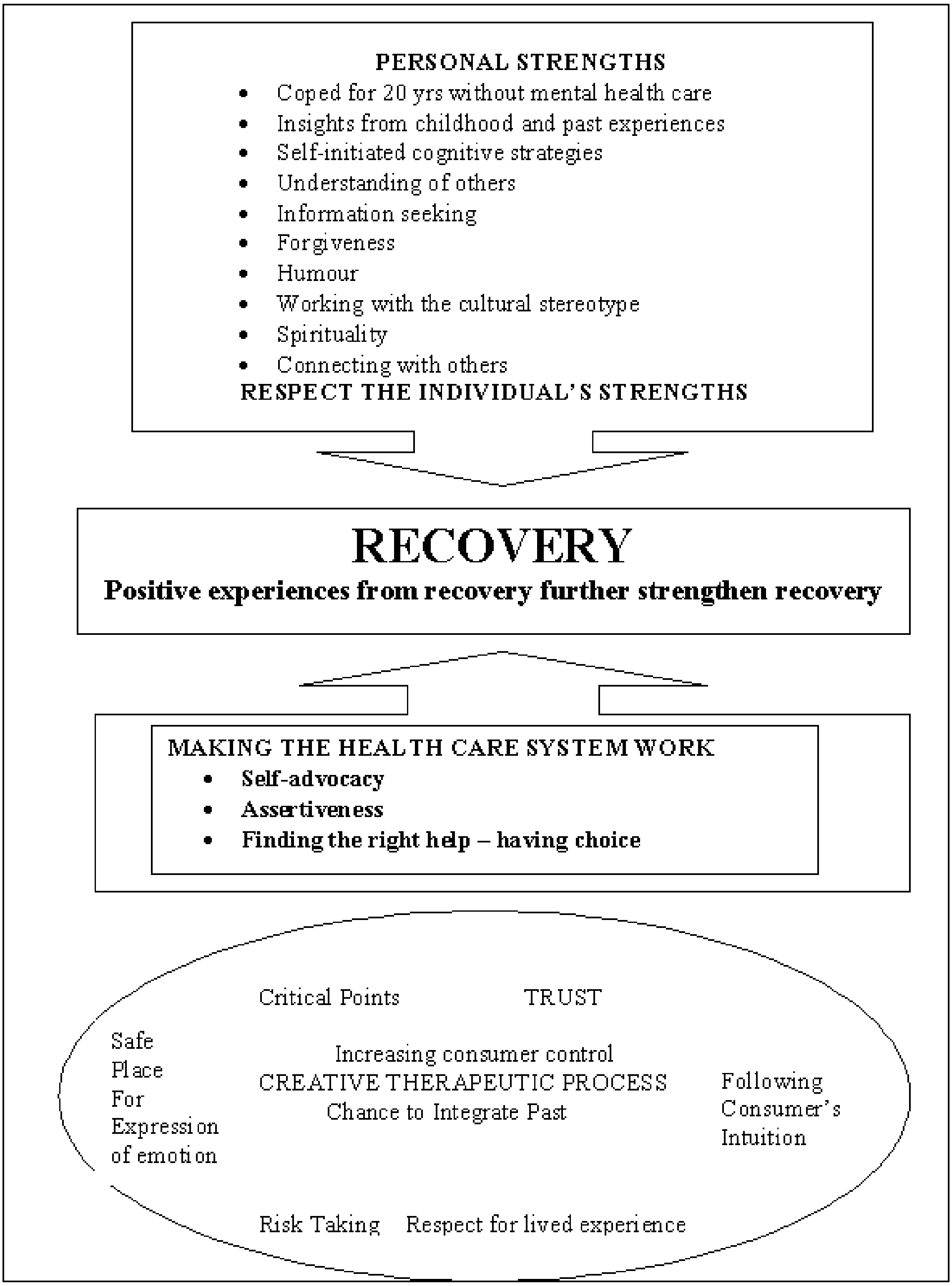
The process of recovery within the mental health system as outlined in this article is eloquently summed up by the participant's metaphor of the slab,

> - I would often describe the mental health system as a slab over my head. I would feel that it was so solid and so concrete that at any point in time it could fall and crush me to death. Then I saw my psychiatrist in the therapy process as a chain that held this slab off my head and I would say, 'please hold the slab don't let it fall' I know I am standing here but I trust you to hold it because I need you to. I realised that he could not do that forever for me. I knew the slab would eventually fall on me and so I needed to do something with it. I've got to say that in doing my psychology degree. I am above the slab. I have built a couple of walls. From where I am now it is really good. The slab turned into the ground floor for the next level.

Discussion

Recovery is now understood to be a 'unique process' (17, p. 160). This case history of recovery provides a clear demonstration of the importance of respecting the strengths within individuals with a mental illness to drive their own recovery. As such, it echoes Deegan's (12) argument that people who experience a diagnosable psychiatric illness are much more resilient than myths about mental illness would suggest. As outlined in Figure 1, the person in this case study brought a wealth of personal strengths combined with an assertive self-advocacy to a mental health care system unresponsive to her needs. In doing so she avoided the more usual process of engulfment in the role of passive recipient of care, a treatment effect that contributes to chronicity (1, 20). Through assertiveness and serendipity she manages to find a therapeutic alliance within the system through which she explored her intuitive ideas about what was needed for her recovery. It is the combination of her personal strengths and a supportive psychiatric relationship that allowed her to deal with difficult issues from the past and refine present coping strategies. Kotake Smith's research (21) also affirms the importance for the consumer of finding the right psychiatrist.

Figure 1. Flow Chart of Ideas



The essential ingredients of the therapeutic process are that it came at a crucial turning point in her life, and that the relationship was built on trust and respect. Corring and Cook (22) argue that at the core of an effective 'client-centred' approach to practice is the professional view of the person with the mental illness as a valuable human being.

Another key central feature of the therapeutic relationship reported here is that it gave priority for responsible risk taking over the need to control. Taking responsibility for one's recovery is documented as a core component of recovery (1, 23, 24). As Deegan (25) states part of that responsibility includes self-management of wellness and medication, autonomy in one's life choices, and the willingness to take informed risks in order to grow. She argues,
Professionals must embrace the concept of the dignity of risk, and the right to failure if they are to be supportive of us.' (25, p. 97)

The literature on recovery is emphatic about the centrality of the notion of choice (4,17). As Anthony (17, p. 160) outlines one of the core assumptions about recovery is that it demands that a person has choices, 'The notion that one has options from which to choose is often more important than the particular option one initially selects.'

The case study documents the pressure within the mental health system to respond to consumers primarily through the prescription of medication. The limits to medication both in terms of distressing side effects and blocking therapeutic progress were noted along with evidence of a medication free recovery. Elsewhere there are description of the problematic use of medications, sometimes described as being worse than the disease and blocking recovery (24, 26, 27, 28). The work of Carpenter (29) points to the detrimental effect of the hegemony of the biomedical model in mental health policy and service provision and argues for a consumer-survivor recovery movement. Similarly Watson (30) points to the lack of consistent evidence to support the use of neuroleptic medications and their problematic side-effects. He argues for a post-modern psychiatry that dispenses with the biomedical model. McGruder (31) echoes these ideas with anthropological arguments that demonstrate that the medical paradigm of disease strips away the meaning of the illness experience. The findings concur with Deegan's (32) concerns about the spirit breaking practices that are documented as a destructive potential of mental health professionals within the system.

A full discussion of the findings on spirituality will be dealt with elsewhere, so it will suffice here to note its importance. Although spirituality is marginalised in the mental health literature (33), there is evidence that this dimension is starting to be recognised as central to recovery (21).

Of the several models of recovery in the literature, the one that is the closest fit with the findings in this article is that of Jacobson's (34) four component processes: recognizing the problem, transforming the self, reconciling the system, and reaching out to others. The participant's extensive signs of recovery, which include taking effective control of her own life and finding the creative energy to make a difference to the lives of others, is a testament to Spaniol's (35) argument that people do recover and go on to fulfilling and contributing lives. The suggestion for the way forward coming from such findings would echo the Australian work of Shanley and associates (36) that identifies a new system of mental health called the Partnership in Coping (PinC) system. The PinC system uses a positive, holistic perspective that focuses on the strengths in clients.

Conclusions

The participant's metaphorical description of the mental health care as a concrete slab capable of killing her which is held up only by the slender chain of a therapeutic psychiatric relationship is a sobering reminder of the power within the system. Recovery for this participant symbolises the removal of the fear of being crushed and progress from the dependency on the slender chain that keeps the slab from falling. The benefits of recovery bring further strengths: metaphorically speaking the building of a room above the slab. It is the hope and expectation that by sharing the metaphor of the slab and the insights that go with it, that the information will go some way to strengthening the chain of recovery for other consumers negotiating their own journey of recovery through the mental health care system.

Acknowledgement: The authors would like to thank Mr Hamish Holewa for his work as Project Officer and Mrs Elaine Phillips for her transcription of the interview for the study.

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The International Journal of Psychosocial Rehabilitation
Volume 9, Number 1
July 2004– June 2005

Effectiveness of Assertive Community Treatment for Patients Referred under Kendra's Law: Proximal and Distal Outcomes

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Citation:
Perese, E.F. , Wu, Y.-W. B., & Ranganathan R. (2004). Effectiveness of Assertive Community Treatment for Patients Referred under Kendra's Law: Proximal and Distal Outcomes **International Journal of Psychosocial Rehabilitation. 9,** 75-98

Acknowledgment: The authors gratefully acknowledge the assistance and support of Lake Shore Behavioral Health Incorporated and the help of the Assertive Community Treatment team. They wish to express their appreciation to Cathleen Curtin, MSN for data management and to nursing students, Earl Adams and Cheryl Putnam, for assistance in reviewing the records. The study was supported by funds from the Research and Development Fund of the School of Nursing of the University at Buffalo, The State University of New York.

Key words: Assertive Community Treatment, involuntary outpatient commitment, Kendra's Law, proximal and distal outcomes

Abstract

This study examined proximal and distal outcomes achieved by 37 patients referred under New York's Kendra's Law (Group I) and 19 voluntary patients (Group II) in Assertive Community Treatment. Group I had greater age diversity and less social support on admission. The groups did not differ significantly on admission in rates of hospitalizations, homelessness, dangerousness and arrest/incarcerations. Face-to-face interviews were conducted at baseline, 6 months and 12 months. Among proximal outcomes, psychiatric symptoms, distress, stress and dangerousness to self improved; dangerousness to others did not. There was a trend toward improvement of unmet needs. Among distal outcomes, health, life satisfaction, psychiatric and medical emergency room visits, medical hospitalizations, homelessness and police contacts/arrests improved. Social support, psychiatric hospitalizations, incarcerations and employment did not. Global functioning improved but specific role functioning did not. Group I was less satisfied with treatment. Group outcomes differed only on psychiatric hospitalizations, with fewer admissions among Group I.

Introduction

Among patients with severe mental illness (SMI), there is a group—the "Revolving Door" patients (Hiday & Scheid-Cook, 1991, p. 83)—who are non-adherent to medications and treatment and high users of psychiatric services (Hafemeister & Banks, 1996; Cuffel, 1997). They also have frequent contact with other community services and agencies such as the police, courts, jails, prisons and emergency medical facilities around episodes of dangerousness and victimization (Swartz & Monahan, 2001). In the past, these patients might have been referred for involuntary admission to a psychiatric hospital but now they are likely to be referred for involuntary outpatient treatment (Torrey & Kaplan, 1995).

Although some mental health professionals consider involuntary outpatient commitment to be helpful in engaging in treatment persons with SMI who are at risk for danger to themselves or others but who are unable or unwilling to accept on-going treatment (Muentz, Grande, Kleist & Peterson, 1996; Swartz, et al., 2001; Torrey & Zdanowicz, 2001), others believe that court ordered treatment is the extreme end of a continuum of coercion (Diamond, 1995). Family members of the National Alliance for the Mentally Ill (NAMI) see involuntary outpatient treatment as a way of getting help for family members before they become so ill that they are a danger to themselves or others ("AOT Update", 2000). Consumers of mental health services have a wide range of opinions with one consumer, Frese, (1997) saying that involuntary outpatient treatment

helped him when he was unable to realize that he was ill, but with others expressing concern that involuntary treatment will create fear, destroy trust between consumer and clinician, and cause people to avoid seeking help (Mad Nation, 1999). Geller (1995, p. 233) views involuntary treatment as a compassionate measure, a compensatory therapeutic intervention for individuals who have biological, psychological and social deficits due to their mental illness or to the residual effects of the illness--a "form of prosthesis for a biopsychosocial deficit". Policy makers view involuntary outpatient commitment as a solution for many problems associated with severe mental illness-- homelessness, frequent use of emergency health services, contact with the police/arrests, and violent behaviors (Swartz, et al., 1999; Applebaum, 2001).

According to Muentz, Grande, Kleist and Peterson (1996) and Appelbaum (2001),
involuntary outpatient commitment is associated with a reduction of hospitalizations, increase in time in treatment, increase in ability to remain in the community and a reduction of episodes of violence (Torrey & Zdanowicz, 2001). On the other hand, there are those who

believe that availability and provision of appropriate mental health care services would make involuntary outpatient treatment unnecessary (Diamond, 1995). There have been two large studies that have examined the effect of outpatient commitment on outcome-- the Duke North Carolina Study (Swartz, et al., 2001) and the Bellevue pilot study (Steadman, et al., 2001). The Duke study did not find any difference in hospitalization between the patients committed for outpatient treatment and the controls at one year but the authors suggest that outpatient commitment is effective in reducing hospital stays and violence as long as the intervention is sustained and combined with a high intensity of community services. The Bellevue study compared outcomes of patients mandated to receive community treatment and a control group. Both groups received enhanced community services. There was no significant difference in hospitalization and arrests and other outcomes .

With the passage of Kendra’s Law, Assisted Outpatient Treatment (AOT), in 1999, New York joined the 40 states and the District of Columbia that have some form of involuntary outpatient commitment laws (Applebaum, 2001).The New York State Office of Mental Health assumed responsibility for AOT and delegated implementation to the counties. Across the state, from the cosmopolitan New York City area to the dormant steel towns of Western New York, counties with varying resources faced the task of providing treatment with limited information about the effectiveness of different treatment modalities under usual practice conditions to guide them (Holloway, Szmukler & Sullivan, 2000). Counties often used existing programs such as Assertive Community Treatment (ACT) (Swanson, et al., 1997). Extensive studies of ACT for voluntary patients have shown that ACT reduces hospital readmissions, use of emergency services, legal problems, and homelessness and improves global functioning and clinical symptoms (Scott & Dixon, 1995; Lehman, et al., 1999). There is less evidence that ACT improves social functioning and employment (Mueser et al., 1998). ACT programs are widely accepted as the “gold-standard” of treatment for persons with SMI who are frequent users of inpatient psychiatric care and emergency psychiatric services (Burns & Santos, 1995; Lehman, et al., 1999; Phillips et al., 2001) but there is little information about effectiveness of ACT in providing care for patients who have been court-ordered to receive treatment or as a “jail diversion program” (Phillips, et al., 2001, p.772). Arboleda-Florez (1999, p. 4) writes that ACT “is not better than standard community care on imprisonment, arrests or police contacts”. Mays (1995) questions the effectiveness of ACT for those high users of emergency psychiatric services who deny their need for on-going care and reject efforts of ACT staff to develop a trusting, cooperative relationship with them. Mueser, et al. (1998) raise the question of the need to modify ACT to meet the needs of patients with SMI who have high rates of illegal behaviors.

This study examines the effectiveness of ACT in providing care for patients referred for treatment under Kendra’s Law. Because severe mental illness affects many aspects of a person’s life, Lehman (1999, p.

30) recommends that measures of treatment effectiveness include a broad range of outcomes—" clinical, rehabilitative, humanitarian and public welfare domains"; and, that both proximal and distal outcomes be considered. Based on Lehman's suggestions, the following research questions were posed: 1. Was there improvement of proximal outcomes –basic needs, psychiatric symptoms, psychological distress, stress, and dangerousness to self and to others---after six months of ACT? 2. Was there improvement of distal outcomes –health, functioning, social support, life satisfaction, employment, homelessness, police contacts, arrests/incarcerations and use of psychiatric and non-psychiatric emergency rooms and hospitals-- after one year of ACT? 3. How satisfied were the patients with treatment? 4. Was there a relationship between patients' status—voluntary or referred for involuntary outpatient treatment-- on admission to ACT and outcomes and satisfaction with treatment?

Proximal and Distal Outcomes

The terms proximal and distal outcomes carry the meaning of cause and time relationships to the treatment intervention. In comparison to distal outcomes that are broad and tend to be evidenced at a greater distance of time, the effect of the intervention is more likely to be stronger or more direct on proximal outcomes and to occur close in time to the intervention (Lehman, 1996). Because of the course of severe mental illness, psychiatric symptoms and residual disabilities, persons with SMI often have impaired functioning, inability to tolerate stress, limited social skills and compromised judgment (National Institute of Mental Health, 1991) that result in unmet needs (Arvidsson, 2003), poor health (Massaro, 1992), poverty, homelessness and victimization (Steinwachs, Kaspser & Skinner, 1992), increased contact with the police, arrests and incarcerations (Schellenberg, Wasylenki, Webster & Goering, 1992), high rates of unemployment (Anthony & Blanch, 1987; Mueser, Drake & Bond, 1997), lack of social support (Cohen & Farkas, 1986; Estroff, Zimmer, Lachicotte & Benoit, 1994; Shankar & Collyer, 2002) and diminished quality of life, (Mueser, Drake & Bond, 1997). In addition to having increased rates of medical problems, persons with SMI often lack the ability to access health care, including preventive care, and the ability to modify unhealthy life-style practices (NIMH, 1991; Felker, 1996; Hutchinson, 1996; Getty, Perese & Knab, 1998; Berren, 1999; Brown, 1999). Evaluation of effectiveness of treatment for persons with SMI must consider the intervention's ability to bring about change for these multiple problems

Proximal outcomes

In this study, proximal outcomes include perceived basic needs, psychiatric symptoms, psychological distress, stress, and dangerousness to self or others. Basic needs. Malm, May and Dencken (1981) identified the needs of persons with SMI as: medical care, human relationships, material supplies (housing, clothing food), work and employment opportunities, safety, leisure activities, communication and transportation, and inner experiences such as a sense of purpose. In

Buffalo, New York, located in the western part of New York State and the setting of this study, when 73 members of a chapter of (NAMI) who had SMI were surveyed about basic needs, the needs identified as unmet by more than half of the respondents were: a friend (62%), a role-in-life [a job] (60%), a group to belong to (56%), a sense of self-identity (55%), and information about mental illness for others [experienced stigma] (53%) (Perese, 1997).

In another Buffalo study, among 34 patients with SMI who were psychosocial club members, the most frequently identified unmet needs were: role in life (job), self-identity, financial resources, a friend and a group to belong to (Perese, Getty & Wooldridge, unpublished). A Swedish five-year study of 377 persons with SMI receiving treatment in the community found similar unmet needs. The overall unmet needs improved over a five year period but there was no change in unmet needs for work and social contact with friends and relatives (Arvidsson, 2003). Psychiatric symptoms and Psychological distress. Even when receiving treatment, many persons with SMI continue to experience psychiatric symptoms (Clinton, Lunney, Edwards, Weir & Barr, 1998; Mueser, Bond, Drake & Resnick, 1998). In studying subjective distress of patients with SMI, Bradshaw and Brekke (1999) found that distress was influenced not only by high levels of psychiatric symptoms but also by patients' perception that people were angry with them. Stress.

In a study of 34 persons with SMI, the stress level was found to be 6.67 on a scale of 1 to 10 with nearly half (42%) reporting high levels (8, 9 or 10). The subjects identified daily hassles as: being criticized, problems getting along with others, family relations, physical health problems and financial worries; and major events as: acute episodes of physical illness, surgery, death of a family member or friend, homelessness, being robbed, and problems with housing (Perese, Getty & Wooldridge, 2003). Dangerousness. In comparison to the general population, there is an increased risk of violent behavior among a subgroup of persons with SMI who have a prior history of violence and substance abuse disorder or antisocial personality disorder (Eronen, Angermeyer & Schulze, 1998). The risk is further increased when these patients are non-compliant with medication (Swartz, et al., 1998). Hiday and Wales (2003) say that, if violence is defined broadly to include being in a fight, the proportion of persons with SMI who are violent is about 50%.

Distal outcomes

Health - Over all, persons with SMI have poorer health than the general population (Lehman, 1996). The effects of their illness and the residual disabilities further compromise their health by limiting their ability to maintain health and prevent health problems from occurring (Hutchinson, 1996). In addition, high rates of unhealthy lifestyle practices, poverty, victimization and stigma negatively affect their health (Felker, Yazel & Short, 1996; Berren, Hill, Merikle, Gonzalez & Santiago, 1999; Brown, Birtwistle, Roe & Thompson, 1999). Although about 70% of people with SMI who report health problems receive treatment, only half of those with dental problems receive treatment (Dixon, Postrado, Delahanty, Fischer & Lehman, 1999). Use of health care services by persons with SMI has been found to be inefficient and costly (Felker, 1996; Berren, et al., 1999), with high rates of non-urgent use of emergency services linked to perceived unavailability of other sources of care and psychosocial factors such as lack of social support (Padgett & Brodskky, 1992) and limited knowledge and capacity for self-care (Getty, Perese & Knab, 1998).

Functioning - Among persons with SMI, impaired functioning often results in problems in carrying out a role in life such as a worker, homemaker or student; problems with relationships; problems with leisure or social activities and problems with caring for oneself including managing mental and physical health problems (Pratt & Mueser, 2002).

Social Support - In 1988, House, Landis and Umberson described a link between lack of social support and higher mortality rates and higher rates of physical and psychiatric illnesses in the general population; and, in 1994, Berren et al. reported similar findings among persons with SMI. In addition to social support's influence on health, Clinton et al., 1998, found that social support plays an important role in helping persons with SMI adjust to living in the community. Among the general population, social support was 5.4 when measured with the Social Support Index that has a range of 0-8 (Bell, LeRoy & Stephenson, 1982). In Buffalo, among 34 persons with SMI, social support was 4.6 (Perese, et al., 2003). Lack of treatment effect on social support among patients with SMI was found by Walsh (1996) and Getty, Perese and Wooldridge (unpublished).

Life satisfaction - In the general population, the mean life satisfaction score as measured with Lehman's (1988) General Life Satisfaction Scale (GLSS) was 5.4. That is between mostly satisfied and pleased (Sullivan, Wells & Leake, 1991). Among persons with SMI living in the community, life satisfaction was 4.4 (Lehman, Ward & Linn, 1982). A similar rate (4.2) was found among persons with SMI who were NAMI members (Perese, 1997) but a lower rate (3.8) was found among psychosocial club members, (Perese, et al., 2003).

Homelessness - Approximately one-third of the homeless population has severe mental illness; and, among this population there is a high rate of co-existing medical problems, substance abuse, relationship problems, contact with law enforcement agencies and limited education (Shern, et al., (2000). In Buffalo, the two year rate of homelessness or "on-the –streets" varied dramatically from 17.8% among NAMI members (Perese, 1997) to 26.5% among psychosocial club members (Perese, et al., 2003).

Psychiatric emergency room visits - Psychiatric emergency rooms are the first line of care for many persons with severe mental illness in crisis; and for some, the only source of mental health care (Arfken, Zeman, Yeagaer, Mischel & Amirsadri, 2002). About one-third of the visits are accounted for by repeat visitors (Ellison, Blum & Barsky, 1986). In an early study, Munves (1983) reported that the rate of repeat emergency room visits among persons with chronic mental illness was 20% in one year. In Buffalo, the two-year rates were 45% (Perese, 1997) and 39% (Perese, et al., 2003).

Readmission to psychiatric hospital - Hafemeister and Banks (1996), who examined re-hospitalization rates in six New York State hospitals, predicted that 32-57% would be readmitted at one year and 43-64% at two years. In Buffalo, two-year readmission rate was 64% (Perese, 1997) and one-year rate was 32% (Perese, et al., 2003). Interestingly, reduction of hospitalizations is believed by clinicians to be related to decreased substance use and, by consumers, to be related to improvement in social support and finances (Lang, et al., 1999). Police contact, arrests and incarceration. Because of diminished ability to manage crises and limited skills for surviving in the community, persons with SMI are likely to have more encounters with the police than the general population (Lamb, Weinberger & DeCuir, 2002). With a duty to protect both the welfare of the community and individuals with disabilities who cannot manage on their own, police often try to settle crises, for non-mentally ill as well as for mentally ill, by defusing the situation. If they are not able to resolve the crisis, they decide whether the person will be arrested or taken to a psychiatric evaluation setting (Hiday & Wales, 2003). According to Schellenberg et al., (1992), between 33% and 50% of psychiatric patients have a history of being arrested; and, they say that, even after engagement in treatment, one in thirteen patients will be arrested. Factors that predict increased risk of arrest are: being young, male, nonwhite, homeless, substance abusing and having a history of prior arrests. Persons with SMI who are arrested tend to be charged with nuisance crimes such as trespassing, failure to pay for meals, vandalism, loitering and disorderly conduct; or with shoplifting and theft. They are more likely to threaten harm than to use weapons or to cause injury.

Employment - Anthony and Blanch (1987) report that less than 15% of patients with severe mental illness are competitively employed. Barriers to employment include the residual disabilities of mental illness (Mueser, et al., 1997; McGurk & Mueser, 2003), lack of economic incentives, such as fear of losing social insurance program benefits and treatment programs that emphasize prevocational goals rather than competitive employment (Drake, McHugo, Becker, Anthony & Clark, 1996).

Satisfaction with Treatment - Howard, et al., (2001) emphasize the need for consumers' evaluation of their satisfaction with service, quality of care and effectiveness of treatment as a vital part of evaluating the effectiveness of a treatment option. In measuring client satisfaction with Assertive Community Treatment, Gerber and Prince (1999) found that 80% of the clients indicated overall satisfaction with the treatment.

They were less satisfied in the areas of medications and their ability to influence treatment choices.

Method

Setting and Subjects

The setting was an ACT program provided by a not-for-profit Behavioral Health Services Organization. After obtaining approval from the University at Buffalo's Institutional Review Board and the agency's clinical director, the 71 patients in the ACT program were invited to join the study. Fifty-six (79%) agreed to participate and signed consent forms. There was no significant difference in age, race, marital status, living situation, employment, dangerousness, arrests/incarcerations, hospital readmissions, and functioning between patients who agreed to participate and those who refused. They differed significantly on three items. Women were more likely to refuse, as were patients with higher levels of educational achievement and patients with lower rates of alcohol and substance abuse.

Study Design

This comparative study was conducted between November 2000 and March 2002. Data were obtained using record review, face-to-face interviews and staff observations. Record review carried out by trained research assistants provided information about demographic characteristics and about hospital admissions, arrests, incarcerations, employment and homelessness for the year prior to admission to the ACT program and for the year following admission to the program. Proximal outcomes and distal outcomes were obtained in face-to-face interviews conducted by the PI and, for three patients, by a Spanish speaking agency member. ACT staff completed standard scales that related to severity of psychiatric symptoms and level of functioning based on their observations. At the end of the study, patients completed a questionnaire that measured their degree of satisfaction with the program in an interview with research assistants or on their own if they preferred.

Intervention

The ACT program provides 24-hour, 7 day a week services by a multidisciplinary team that includes a psychiatrist, a nurse, case managers, substance abuse and vocational specialists and peer counselors. It collaborates with other agencies such as housing, transportation and social services and has an agreement with a primary care clinician to provide medical care. In a study that used The Dartmouth Asssertive Community Treatment Scale (DACTS) (Winter & Calsyn, 2000) to evaluate the fidelity to the ACT model of 28 ACT programs in New York State, the Buffalo ACT program had the highest rating of fidelity, a score of 3.81 out of a possible 5 (Laughlin, C., personal communication, March 21, 2002). Priority for admission to ACT is given to patients who are non-responsive to treatment, homeless, recently incarcerated, at risk of danger to themselves or others, frequent users of psychiatric emergency services and to patients with repeated hospital admissions. Patients are admitted to ACT voluntarily, often upon discharge from the hospital; or, as referrals from the AOT committee for enhanced outpatient treatment. If patients are found by the AOT committee to be in need of AOT, they are given the choice of agreeing to a voluntary enhanced outpatient treatment plan, the AOT diversion agreement, or facing a court order to follow a recommended treatment plan. In Erie County, the proportion of people who accepted the diversion agreement from passage of Kendra' Law in the fall of 1999 through February 2003 is much higher (83%) than the rate for all of New York State (39%) ("Western New York Assisted Outpatient Treatment Report", 2003). In Erie County, during the time of the study, 90% of individuals referred to AOT chose the diversion agreement (The Challenger, 2000).

Instrumentation

The Buffalo Client Assessment Inventory (BCAI), developed by the authors and used to obtain data, includes structured questions and research instruments—10 brief self-report instruments and 3 instruments that used observation- based ratings. For this study, psychiatric diagnosis was the diagnosis entered in the patient's record by the ACT team psychiatrist on enrollment in ACT and was based on longitudinal data, an extensive psychiatric evaluation and data available from collateral sources. Data relating to readmissions to a psychiatric hospital, police contact, arrests, and incarcerations during the year preceding admission to ACT were obtained from the record. Legal status was obtained from the record review and, for the purpose of this study, is represented by AOT status and includes AOT diversion agreement and court petitions, the Group I patients, and voluntary status, the Group II patients. Among proximal outcomes, basic needs (food, clothing, transportation, medical care, dental care, housing and finances) were measured using the Meeting Basic Needs scale, a subscale of The Colorado Client Assessment Record (Ellis, Wilson & Foster, 1984), that was modified to include medical and dental needs. The scale has a range of 7 to 28 with higher scores indicating more unmet needs. Psychiatric symptoms were assessed with the Brief Psychiatric Rating Scale (BPRS) (Overall & Gorham, 1962), score range of 18 to 126 with higher scores indicating greater severity of symptoms. Psychological distress was measured with the Six-Item Indexes of Psychological Distress (Rosen, Drescher, Moos, Finney & Murphy, 2000), score range of 6 to 30 with higher scores indicating more psychological distress. The scale asks the patients to indicate on a scale of 1 (not at all) to 5 (extremely distressed) how distressed they are by certain feelings or ideas. Stress was measured with the Modified Stress Ladder (Duffy et al., 1992), score range of 1 to 10 with higher scores indicating more stress. Dangerousness was measured with the Violent Behavior Scale (Neale & Rosenheck, 2000) that elicits patients' history of dangerous behaviors. The scale consists of eight questions about thoughts, discussions, threats or actions, four relating to self and four to others. The patient responds with a yes or no. Each yes response counts as one. Score range is 0 to 8 for the total scale or 0 to 4 for danger to self and 0-4 for danger to others with higher scores indicating greater risk for dangerous behavior.

Distal outcomes--health, social support and life satisfaction--were measured respectively with the

Self-rated Health Scale (Stewart, Hays & Ware, 1992), an eight item scale that has a score range 1-5, lower score indicates better health (not reported in this article) and the Self-reported Health scale (Idler & Angel, 1990), a one-item scale that has a score range of 1-5 with lower score indicating better health; the Social Support Index (SSI) (Bell, et al., 1982) that has a score range of 0-8 with higher scores indicating greater support and the General Life Satisfaction Scale (GLSS) (Lehman, 1988), that has a score range of 1, terrible, to 7, delighted. Functioning was measured with two instruments, the Role Functioning Scale (RFS) (Goodman, Sewell, Cooley & Leavitt, 1993) and the Global Assessment of Functioning (GAF) (DSM-IV, 1994). The Role Functioning Scale (RFS) was used to measure overall level of functioning and functioning in four domains-- working/productivity; independent living/self-care; immediate social relationships and extended social relationships. The RFS is considered to be a reliable scale for measuring functioning among persons with SMI (Green & Gracely, 1987). The RFS score range for individual domains is 1 to 7 and for overall functioning, 7 to 28. Higher score indicates better functioning. The GAF (DSM-IV, 1994) has a score range from 0 to 100. Higher scores reflect better functioning, with scores of 50 to 41 indicating serious distress and dysfunction, 40 to 31, severe distress and dysfunction, 30-21, inability to function in most areas, and 20-11, danger to self or others (Rosse & Deutsch, 2000). All members of the ACT team received training in use of the GAF before the research study was initiated. Satisfaction with treatment was measured with the Client Evaluation of Services (CSQ-8) (Nguyen, Attkisson & Stegner, 1983), an eight-item scale with a score range of 8 to 32. Higher scores indicated greater satisfaction.

Analysis of data

A repeated measures analytical approach was used to answer our research questions. Descriptive statistics were used to present demographic characteristics. Chi-square analysis was used to examine demographic characteristics between patients referred by AOT and voluntary patients. Paired t-tests were used to compare the effectiveness of the intervention between prior year or baseline and 6 months for proximal outcomes. For distal outcomes, paired t-tests were used to compare the effectiveness of the intervention between prior year or baseline and 12 months. To manage missing data, existing time one data was used to create a regression equation. Based on the parameters estimated by these regression equations, we substituted the missing values. Chi-square and independent t-tests were also used to compare outcomes of Group I and Group II. Statistical significance level was set at .05 level and 1-tailed test was used.

Results

Demographic characteristics

As shown in Table 1, the majority of the 56 participants were male (77%) and African-American (59%). Twenty-four (44%) had not completed high school. Most common clinical diagnosis was schizophrenia. According to admission data in the record, 30 (54%) had a diagnosis of alcohol abuse and 32 (57%), drug abuse; 51 (91%) had been hospitalized at least once in the prior year; and 13 (31%) of the 41 participants with available data had exhibited dangerousness to others. Nineteen (34%) lived in unstable situations (emergency housing, shelters or "staying with friends") and nineteen (34%) had been homeless at least once during the prior year. Thirty-seven had been referred by AOT. Nineteen were voluntary admissions to ACT.

Table 1. Demographic, Clinical and Community Adaptation Characteristics of Patients on Admission to ACT
N=56

Demographic Characteristics		
	n	%
Gender		
Male	43	77.0
Female	13	23.0
Age		
18-29	9	16.1
30-49	39	69.6
50-69	8	14.3
Race		
Caucasian	19	34.0
African American	33	59.0
Latino	3	5.0
Pacific Rim	1	2.0
Marital Status		
Divorced	11	20.0
Single	45	80.0
Education		
Less than high school	24	44.0
High school	22	41.0
Some college	5	9.0
College degree	3	6.0
Employment		
Unemployed	18	32.0

Employed	5	9.0
Total disability	33	60.0
Living situation (n=50)		
Stable housing	31	55.4
(house, apartment,		
room, group home,		
board and care)		
Unstable housing	25	44.6
(shelter, motel, friend, homeless)		
Legal status		
AOT	37	66.1
Non-AOT	19	33.9
Clinical Characteristics		
Psychiatric diagnosis		
Schizophrenia	40	71.4
Schizoaffective	7	12.5
Unipolar disorder	2	3.6
Bipolar disorder	3	5.4
Anxiety Disorder	1	1.8
Alcohol abuse alone	7	12.5
Drug abuse alone	8	14.2
Alcohol & drug abuse	22	39.2
Psychosis NOS	2	3.6
Borderline Personality Disorder	2	3.6
Antisocial Personality Disorder	7	12.5
Personality Disorder NOS	3	5.4

Danger to self (n=43)		
(year prior to ACT enrollment)		
0	39	91
1-3 times	4	9
Danger to others (n=41)		
(year prior to ACT enrollment)		
0	29	69
1-3 times	9	21
more than 3 times	4	10
Hospital admissions		
(year prior to ACT enrollment)		
0	5	9
1-3 times	36	65
more than 3 times	14	26
Community Adaptation Characteristics		
(year prior to ACT enrollment)		
Contact with police (n=34)		
0	14	41
1-3 times	14	41
more than 3 times	6	18
Arrests (n=48)		
	30	63
1-3 times	13	27
more than 3 times	5	10

Incarcerations (n=40)		
0	29	73
1-3 times	11	27
more than 3 times	0	

Chi square analysis indicated that there was no significant difference in gender, race, marital status, education, housing, diagnosis, alcohol and substance abuse, arrest/incarcerations, dangerousness or hospital admissions between Group I and Group II on admission. There was a difference in age ($\chi 2=6.28$, df=2, p=.043). Among 37 patients in Group I, 22 (59.5%) were 30 to 49 years old and there were nearly equal numbers of younger patients (7 or 18.9%) and older patients (8 or 21.6%). Among 19 patients in Group II, 17 (89.5%) were in 30 to 49 years old and two younger than 30. The statistical difference in employment status ($\chi 2=7.73$, df=2, p=.02) was of little clinical importance; e.g. four (10.8%) Group I patients employed and one (5.3%) in Group II.. Social support (score range 0-8) among Group I patients (3.35, s.d.=2.1) was significantly lower than among Group II patients, (4.77 , s.d.=2.1, df=2, p=.021). (Test result is t (54)=1.71, p=.046.)

Research question 1: Was there improvement of proximal outcomes?

Table 2 summarizes the pre-post comparisons of proximal outcomes. Basic needs.
The overall rating of needs at the initial assessment was 12.68; e.g., the patients perceived their needs as met between "most of the time" and "some of the time". (Data obtained by asking patients about their unmet needs for the year prior to admission to ACT are not included in the measurement of the effect of treatment from baseline to 6 months; however, the total rating of needs for the prior year was 14.0, significantly more unmet needs than at the initial assessment.) At initial assessment, the three needs most frequently rated as unmet were transportation, housing and dental care. There was no significant change in patients' perception of needs met between initial assessment and six months. Patients' comments included: "If I want to go somewhere, I still have to walk"; " I have a place to stay but it is not what I want; and, "I am afraid to go to the dentist".

Table 2. Proximal Outcomes of Patients in ACT

	Initial Assessment			**6 month Assessment**		
	M	sd	n	M	sd	n
Total Basic Needs^a	12.68	5.39	50	11.74		

					3.21	50
Psychiatric Symptoms						
BPRS [b]	40.80	16.35	50	32.7*	10.47	50
Psychological Distress	**12.21**	**5.54**	**56**	**10.86***	**5.27**	**56**
SCL-6[c]						
Stress	4.98	2.37	53	3.94*	2.27	53
Stress Ladder[d]						
Dangerousness						
Violent Behavior Scale[e]						
Toward self	.25	.76	43	.07*	.46	43
(score range 4-8)						
Toward others	.21	.66	39	.21	.52	3

(score range 4-8 *significant at .05 (one-tail)

[a] Meeting Basic Needs scale (Ellis, Wilson & Foster, 1984) score range 7-28, higher score indicates more *unmet* needs
[b] Brief Psychiatric Rating Scale (Overall & Gorham, 1962), score range 18-126, higher score indicates greater severity
[c] Six-Item Indexes of Psychological Distress (Rosen, Drescher, Moos, Finney & Murphy, 2000), score range 6-30, higher score indicates greater psychological distress
[d] Modified Stress Ladder, (Duffy et al. 1992), score range 1-10, higher score indicates greater stress
[e] Violent Behavior Scale (Neale & Rosenheck, 2000), score range 8-24, higher score indicates greater violence. Subscale danger to self, score 4-12; danger to others, score 4-.

Psychiatric symptoms, Psychological distress, Stress and Dangerousness.

There was a significant improvement of psychiatric symptoms that were rated by the ACT team and also a significant improvement of psychological distress that was rated by the patients. On initial assessment of distress, feelings such as depression, fear, anxiety, hopelessness and thoughts such as there is something wrong with your mind were rated in the moderately distressful range and at one year they were rated in the range of little distress. Perceived stress showed significant improvement, decreasing one point. There was a dramatic decrease in dangerousness toward self; but there was no significant change in dangerousness toward others. In responding affirmatively to the questions of whether they talked about hurting or striking someone or threatened to do so, patients often added comments indicating that those actions were required to protect themselves in the community. Of the six proximal outcomes, five (86%) showed significant improvement.

Research question 2: Was there improvement of distal outcomes?

Table 3 summarizes the results from pre-post comparisons of distal outcomes. Health. There was a significant positive change in perception of general health; e.g., patients perceived their health as improved from time of admission. Functioning. There was significant improvement of one measure of functioning, the GAF that includes psychiatric symptoms but no improvement in functioning as measured by the RFS that does not include psychiatric symptoms. Social support. There was no significant change in perceived social support. Data obtained by asking the patients about their perceived social support for the year prior to admission to ACT showed that social support was 3.69 s.d. 2.1, considerably lower than the score obtained on the initial assessment, with patients referred for Assisted Outpatient Treatment having significantly lower social support, (3.4, s.d. 2.1) than voluntary patients (4.4, s.d. 2.1). Life satisfaction. There was significant improvement in life satisfaction. Employment. There was no significant increase in employment. Arrests/incarcerations. There was significant decrease in police contacts and arrests but no significant decrease in incarcerations. Use of medical and psychiatric emergency rooms and hospitals. There was significant decrease in medical emergency room visits, medical hospital admissions and psychiatric emergency room visits. The change was striking with the rates cut nearly in half. There was no decrease in psychiatric hospital admissions. Of the 13 distal outcomes examined, 8 (62%) showed improvement.

Table 3. One-year distal outcomes of patients in ACT

	1 year prior			Initial Interview			12 month Interview		
	M	sd	n	M	sd	n	M	sd	n
Health									
Self-rated Health[a]				**2.98**	**1.12**	**40**	**2.63***	**1.21**	**40**
Functioning									
1) RFS[b]				13.35	4.59	53	13.67	3.31	53
2) GAF[c]				29.35	4.25	56	31.72*	3.96	56

Social				4.13	2.12	40	4.30	1.80	40			
SSI^d												
Life												
Satisfaction				4.43	1.27	40	4.97*	1.27	40			
GLSS^e												
Medical	.47	.84	32				.19*	.54	32			
Hospital												
Admissions												
Medical	.86	1.3	36				.47*	.91	36			
Emergency												
Room visits												
Psychiatric	1.33	7.98	40							1.10	1.84	40
Hospital												
Admissions												
Psychiatric	1.91	1.90	32							.81*	2.22	32

Emergency Room						
Visits						
Police contact	.84	.75	25	.40*	.58	25
Arrests	.59	.80	32	.34*	.55	32
Jail	.40	.71	25	.28	46	25
Number						
Employed	5 [9%]		56			
Number Homelessness						
	19 [38%]		**50**	**5 [9%]**		**56**
Patient Satisfaction						
With treatment				28.71	4.09	35
(CES score range 8-32)						

[a] Self-rated Health, Idler & Angel, 1990), score range 1-5. Higher score indicates better health.

[b] Role Functioning Scale (RFS), (Goodman, Sewell, Cooley & Leavitt, 1993), score range 4 to 28. Higher score indicates more positive functioning.

[c] Global Assessment of functioning (GAF), DSM_IV based on GAS (Endicott, Spitzer, Fleiss & Cohen, 1977), score range 1-100. Higher score indicates more positive functioning.

[d] Social Support Index (SSI), (Bell, LeRoy & Stephenson, 1982), score range 0-8. Higher score indicates greater social support.

[e] General Life Satisfactioin Scale, (Lehman, 1988), score range 1 (terrible) to 7 (delighted).

[f] Client Evaluation of Services (CSQ-I), (Nguyen, Aattkisson & Stegner, 1983), score range 8 to 32. Higher score indicates greater satisfaction.

Research question 3: Were the patients satisfied with treatment?

The majority of the patients, 88%, were satisfied with treatment. There was a significant difference in satisfaction between those referred by AOT (Group I) (mean= 27.78, s.d.= 4.72) and voluntary patients (Group II) (mean=30.50, s.d.=1.38).

Research question 4:

Was there a relationship between status on admission to ACT; e.g., being referred by AOT (Group I) or being a voluntary patient (Group II) and outcomes? Table 4 summarizes the differences between distal outcomes of Group I and Group II patients. There were no significant differences of outcomes with one exception. There was a significant difference in readmissions to psychiatric hospitals with Group I having fewer psychiatric hospital readmissions.

Table 4. Distal Outcomes of Group I and Group II

	Group I			**Group II**			**t**
	M	sd	n	M	sd	n	
Health [a]							
Baseline	2.9	1.2	37	2.8	1.4	19	- .29
12-months	2.6	1.2	27	2.7	1.3	13	.24
RFS[b]							
Baseline	13.1	4.6	37	13.3	4.7	19	.20
12-months	12.0	4.3	30	14.2	4.3	14	.92
GAF[c]							
Baseline	29.3	3.8	37	29.0	4.6	19	-.28
12-months	31.0	4.7	20	33.5	6.6	10	1.23 SSI[d]
Baseline	3.62	2.24	37	4.74	2.02	19	1.82*
12-months	4.2	1.8	26	4.5	1.9	13	.50
GLSS[e]							
Baseline	4.5	1.5	37	4.2	1.4	19	-.80 12-

months	4.9	1.4	27	5.3	1.6	13	.79
CSQ-8^f	28	4.7	23	30.5	1.4	12	2.6*
	Group I			**Group II**			**z**
Hospital admissions							
Year prior	34/37 [.91]			16/18 [.89]			.24
12-months	17/30 [.57]			15/16 [.94]			-3.42*
Arrests							
Year prior	15/33 (.45)			3/15 (.20)			1.85
12-months	8/30 (.27)			8/16 (.50)			-1.54
Incarcerations							
Year prior	9/27 (.33)			2/13 (.15)			1.34
12-months	9/30 (.30)			6/16 (.38)			-.54
Employment							
Year prior	4/36 (.11)			1/19 (.05)			.83
12-months	5/30 (.17)			2/16 (.13)			.3

*significant at .05

a Self-rated Health, Idler & Angel, 1990), score range 1-5. Higher score indicates better health.
b Role Functioning Scale (RFS), (Goodman, Sewell, Cooley & Leavitt, 1993), score range 4 to 28. Higher score indicates more positive functioning.
cGlobal Assessment of functioning (GAF), DSM_IV based on GAS (Endicott, Spitzer, Fleiss & Cohen, 1977), score range 1-100. Higher score indicates more positive functioning.
dSocial Support Index (SSI), (Bell, LeRoy & Stephenson, 1982), score range 0-8. Higher score indicates greater social support.
eGeneral Life Satisfaction Scale, (Lehman, 1988), score range 1 (terrible) to 7 (delighted.
fClient Evaluation of Services (CSQ-I), (Nguyen, Attkisson & Stegner, 1983), score range 8 to 32. Higher score indicates greater satisfaction.

Discussion

The ability to generalize the findings of the study is limited by the small sample size and the characteristics of the setting--a poor, close-knit community with few entry level jobs but with available low-cost housing and established informal networks between the ACT team, other care providers and community agencies. That there were few significant differences between demographic characteristics of Group I and Group II indicates that both groups came from the same pool of patients—frequent users of psychiatric and community services with high levels of psychiatric symptoms, substance abuse, dangerousness to others and impaired functioning and low levels of social support, employment, and education. The fact that Group I had more younger and older patients may reflect the community's acceptance of AOT as a vehicle for obtaining treatment for younger patients who might otherwise not access treatment or who, without needed treatment, might be incarcerated and for older patients who have fallen through the cracks and are no longer receiving needed care. The lower initial assessment of social support among Group I suggests that these patients may lack people in their lives who could provide assistance or urge them to seek treatment. Without such help, the likelihood of referral to AOT may have been increased.

It is likely that within the intervention, Assertive Community Treatment (ACT), the ACT team's ability to: 1) develop a strong alliance with the patients; 2) engage them in treatment that often included monitoring their medications, counseling and substance abuse group interventions; 3) reduce their unmet needs from the status prior to admission to ACT (even though improvement did not continue) and 4) resolve conflicts with families, landlords, police and entitlement programs contributed directly to improvement of proximal outcomes e.g., reduction of psychiatric symptoms, distress, stress and self-harm. Because the measurement of dangerousness to others was broad, including thinking about hurting someone, talking about it, threatening it as well as actually striking or injuring someone, lack of improvement of dangerousness may represent continuing use of threats as a community survival strategy as well as actual acts of dangerousness toward others.

ACT team's expertise in mobilizing community resources and strong community networking skills likely influenced the evolvement of certain distal outcomes. For example, the ACT team's ability to access health care for patients undoubtedly influenced their perception of improved health and also led to the striking reduction of the number of visits to medical and psychiatric emergency rooms and medical hospitalizations. In addition to influencing proximal outcomes such as stress and distress, ACT team's involvement in helping patients resolve conflicts likely contributed to the reduction of homelessness, police contacts and arrests. Improvement of functioning when measured with the GAF scale that includes psychiatric symptoms suggests that ACT team's influence on functioning may have been due, at least in part, to their emphasis on adherence to medication. Lack of improvement of role functioning in specific domains, of social support and of employment may be related to short exposure to Assertive Community Treatment, insufficient intensity of treatment or lack of treatment activities targeted to these specific outcomes. It may also be related to patient attributes such as limited education, lack of previous work experience and co-occurring substance abuse.

Conclusion

ACT is effective in providing treatment for patients referred for Assisted Outpatient Treatment. The findings suggest that Kendra's Law did not add to outcomes. The findings do suggest that Kendra's Law served as a compensatory intervention for patients who lacked social support that might otherwise have prompted them to seek treatment and stay in treatment. Lack of a decrease of incarcerations may be related to lack of improvement of dangerousness to others and also to some patients' being sent directly to jail when they violated the diversion agreement. That there was no reduction of psychiatric hospitalizations may be due to patient attributes such as substance use, non-adherence to medications, unmet needs and lack of social support. However, it may paradoxically, indicate ACT effectiveness. That is, the ACT team sought hospitalization for patients at high risk of becoming a danger to themselves or others. The lack of effectiveness of ACT in improving certain outcomes-- role functioning, social support and employment—is consistent with findings of other studies. The only treatment outcome difference between the groups, fewer psychiatric hospitalizations among Group I, is difficult to interpret. Because of their greater lack of natural occurring social support, they may have been more responsive to the support and assistance provided by the ACT team. Further study is needed to examine the influence of patient attributes, length of exposure to ACT and intensity and specificity of components within ACT on patient outcomes.

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The International Journal of Psychosocial Rehabilitation
Volume 9, Number 1
July 2004– June 2005

In the Midst of Winter there was an Eternal Summer: Finding Spirituality and Hope in Suffering, the Case of Antisocial-Narcissistic Personality.

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Citation:
Singer, O. (2004). In the Midst of Winter there was an Eternal Summer: Finding Spirituality and Hope in Suffering, the Case of Antisocial-Narcissistic Personality. **International Journal of Psychosocial Rehabilitation. 9** (1) 99-106.

Abstract

The only living organism that fails of being genuine with his own nature is man (Camus, 1956). An animal is fixed to its here-and-now by the senses, but man manages to detach himself, to remember, to sympathize with others, to visualize their states of mind and feelings. However Humans capacity to grasp their selves is only achieved darkly and imperfectly. Suffering is created, until every single atom in men's feeling becomes a 'howling of anguish' (Lem, 1984). Within every men there is a tormented martyr nailed to a cross, said Hesse (Hesse, 1965). Each individual must carry his own burden in the most unique way. Realizing it, is coming from afar, closer to fulfillment, closer to friendships closer to hope, and closer to peace (Camus, 1966; Walsh, 1999; Frankl, 1984). This is a look into Dread, Suffering, struggle and it's relationship to the spiritual life.

Existential Psychotherapy: Etiological Views and Pathology and the Human Condition

"Midway the journey of this life I was aware that I had strayed into the dark forest, and the right path appeared not anywhere"(Dante, 1947, pp.3). Such journey is the journey of men. Born to the cradle thrown with fear and dread into life of confusion and uncertainty, knowing the only certain factor is death (Kiekegaard, 1944, 1958; Heidegger, 1962). The cause of happiness comes rarely, says the bodhisattva, while stating that the seeds of sufferings are many (Lama, 1994). However he leaves the scholar with a sense of optimism:" yet if I have no pain, I'll never long for freedom" (Shantideva, 1997, pp.78). The Rabbi followed his eastern sage, lamenting:" the whole heart is a broken heart" (Kotzker Rebbe cited in Wolpe, 1999, pp.7).

The sages valued suffering, pain and illnesses and saw them as communication vessel between the human being and the divine, as well as between individuals and their inner selves (Walsh, 1997; Cooper, 1997; Rumi, 1994). Suffering was another opportunity for men to investigate his life, and his behavior (Walsh, 1999).
In contrast therapists and counselors since the time of Freud over emphasized individual self- interest

(Doherty, 1995). Contemporary trends, both psychological and economical highlighted pursuit of happiness and comfort as the main goals of life, overlooking the moral-philosophical arena, in which avoidance of discomfort and narcissism will prevail (Fromm, 1976; Doherty, 1995).

These is an investigation into the world of dread, fear, and negative emotions in general, as arising out of the existential conflict between the ontological and the epistemological, between human beings and the absurdity of life's unpleasant occurrences (Shoham, 1987).
A systemic approach will examine the historical-philosophical existentialism, moving towards the practical phenomenology with two anti-social/narcissistic clients and their unique journey towards healing. This is and qualitative attempt to capture the despair, revolt and eventually divine acceptance and surrender by the human spirit.

The Human Condition: the void and the absurd

Existentialism is the title of the set of philosophical ideals that emphasizes the existence of the human being, the lack of meaning and purpose in life, and the solitude of human existence (Kaufmann, 1956; Frankl, 1984) Existentialism maintains existence precedes essence: This implies that the human being has no essence, no essential self, and is no more that what he is (Frankl, 1984; Hesse, 1965; Camus, 1956).

According the existential thought existence is always particular, unique and individual (Hesse, 1965; Camus, 1956). Existentialists are opposed to the view laws explaining human freedom and activity can be formulated. Existence is essential and fundamental: Being cannot be made a topic of objective study. Being is revealed to and felt by the human being through his own experience and his situation (Laing, 1967; Camus, 1956; Frankl, 1984).

Existentialism stresses the risk, the voidness of human reality and admits that the human being is thrown into the world, the world in which pain, frustration, sickness, contempt, malaise and death dominates (Camus, 1956; Kierkegaard, 1944,1958; Kaufmann, 1956). Life has no absolute meaning. In spite of the human's irrational "nostalgia" for unity, for absolutes, for a definite order and meaning to the "not me" of the universe, no such meaning exists in the silent, indifferent universe (Camus, 1956, 1966).

Between this yearning for meaning and eternal verities and the actual condition of the universe there is a gap that can never be filled. The void is a living void. Lack of meaning is elastic by nature all that is relieving, all that helps alleviate the pain, drugs, food, gambling, sex, and possessions. The confrontation of the irrational, longing human heart and the indifferent universe brings about the notion of the absurd (Camus, 1966; Frankl, 1984).

Thrown into the world, the human being is condemned to be free. The human being must take this freedom of being and the responsibility and guilt of his actions (Kiekegaard, 1944, 1958; Camus, 1956; Sartre, 1958; Heidegger, 1962). Humanity's primary distinction, in the view of most existentialists, is the freedom to choose. Existentialists have held that human beings do not have a fixed nature, or essence, as other animals and plants do; each human being makes choices that create his or her own nature (Sartre, 1958; Camus, 1966). Freedom of choice entails commitment and responsibility. Because individuals are free to choose their own path, existentialists have argued, they must accept the risk and responsibility of following their commitment wherever it leads (Camus, 1956, 1966; Sartre, 1958; Comer, 1998).

Where the absurd starts and agony takes over

Existence is of two types: authentic and inauthentic forms of existence. Authentic existence is contrasted with dynamic and is the being-for-itself, rising from the human being's bad faith, by which the human being moves away from the burden of responsibility (Kiekegaard, 1944,1958; Comer, 1998). The inauthentic being-in-itself is characteristically distinctive of things; it is what the human being is diseased with for his failure to see himself as and act according as a free agent and his impotency to reject bad faith. Things are only what they are (Camus, 1956; Sartre, 1958).

The human being hides himself from freedom by self-deception, acting like a thing, as if he is a passive subject, instead of realizing the authentic being for the human being (Comer, 1998). This self-deception is the root of man's dysfunctions (Kierkegaard, 1985; Comer, 1998). By trying to avoid, hide, misplace, and blame, individuals moves beyond anxieties into the realms of anger, depression, resentments and guilt (May& Yalom, 1995 1989; May, 1987).

The Defiant nature of man's Spirit

The defiant power of the human spirit (Frankl, 1965) refers to the human capacity to tap into the spiritual part of the self and rise about the negative effects of situations, illness or the past. Camus referred to the defiant behavior of man towards crises, as the rebellion, which may produces Ill emotions or, if done creatively, may establish a new meaning for the sufferer (Camus, 1956, 1966).

The revolt against the universe, situations, events, traumas, creates more than just ill emotions. It may also produce stress on the value system (Camus, 1956). Virtue and vice are mixed when man lies in the pit of despair (Camus, 1956). As that happens and the client becomes a victim of outside forces, since he fails to be accountable, all is permitted. Deviant behavior may be the outcome of failure to cope with the anxieties, anger, blame or even suicide (Camus, 1956, 1966).

The need for control of the outcomes is another cause for neurotic existence (Hayes, 1997). The client who becomes helpless, since he/she neither has nor control over the trauma or bad circumstances, he or she has no significance in this world. The human being cannot find any purpose in life; his existence is only a contingent fact (Frankl, 1984; Hayes, 1997). His being does not emerge from necessity. If a human being rejects the false pretensions, the illusions of his existence having a meaning, he encounters the absurdity, the futility of life.

The Cry for Meaning: Dread and Anxiety

In a world stripped of its illusions and false pretensions, the human being is an outside, who lives without any meaning. The human being is placed in a hopeless and void situation (Camus, 1966; Frankl, 1984). This limiting reality leads the human being to encounter the absurd in every aspect of being, ranging from routine activities in life to unusual and unconventional circumstances (Camus, 1956, 1966).

All human actions and thoughts develop in the void, in the midst of weariness and frustrations, irrelevancies, the bizarre, unconformities, illusions, and evasions, which make those actions and thoughts absurd. The human attempt to grasp the mechanism and the dynamics of the universe also turns into an absurd confrontation between the human being and his surroundings (Camus, 1956; Sartre, 1958).

Out of the cry for meaning, man's becomes hopeless, helpless, and meaningless. Those introverted ones may turn the anger and frustration towards self, may become alienated from self and other fall into the world of psychosis (Laing, 1965, 1967). Extroverted beings may revolt outwardly by anti social behavior, or by any others aggressive means (Shoham, 1987; May, 1972).

The client may also feel completely alone. A break in attachment or a conflict in relationship is created. The client now realizes he must depend on self. In this state of aloneness the client starts wondering how will he/she live (Corey, 1996). Aloneness and isolation may result as lack of affective rottenness and interactions of the individual with his environment (Fromm, 1973).

Hope, Courage, and Healing: The Case of antisocial personality

Facing the absurdity of illness, life and trauma, men becomes helpless and hopeless and may resort extreme measures (Camus, 1965, 1966; May, 1972; Fromm, 1973). Without emotional ties with the world, the extroverted rebel may be in a state of lostness, relationship will become evolved around self only (narcissism), the individual might also try to control, aggressively others in a sadistic way (Fromm, 1973).

Doesn't this make a futile pessimistic chaos of life? Wouldn't suicide, or self-injurious behavior as in addiction be a legitimate way out of a meaningless life? As the individual face the absurd he rebels cognitively and emotionally against God and the world, the options remain open for the rebel: suicide (hurt self)/homicide (hurt others) (Camus, 1966).

In the following section emotional-existential focused therapy will examine beneficial outcomes for 2 individual who chose life long rebellion with alcohol, drugs and aggression which brought about incarceration and grief. Though the absurd cancels all chances of eternal freedom it magnifies freedom of action (Camus, 1965, 1966).

Brief Literature review of Anti-social personality treatment shows a gloomy, pessimistic view (Comer, 1998).

Approximately quarter of people diagnosed with antisocial personality disorder actually receive treatment for it (Reiger, et al., 1993). Generally most of today’s treatments approaches have a little or no impact of individuals with antisocial personality disorder (Comer, 1998).

The Emotional Life of a Narcissist

Narcissism is an effort to contain the ominous onslaught of stale emotions, repressed rage, a child's injuries. Narcissism Isolates the Narcissist from the pain, and dread of facing reality and allows him to inhabit the fantasyland of ideal God like perfection and brilliance (Vaknin, 2003).

APD affect lacks subtlety, depth, and modulation. Individuals with severe APD appear to live in a pre-socialized emotional world; feelings are experienced in relation to self but not to others (Cleckley, 1982). Such individuals are unable to experience emotions such as gratitude, empathy, sympathy, affection, guilt, or mutual eroticism that depend on the perception of others as whole, real, and meaningful (Cleckley, 1982; Comer, 1998).

Clinical investigations confirm previously discussed reactions to negative emotions of life’s absurdity. Individuals with APD are frequently described as irritable. This irritability is defined as a disposition toward anger and aggression. Here, aggression is the APD behavior intended to inflict discomfort, hurt, harm, injury, or destruction on others (Comer, 1998). Oldham suggests that even if individuals with APD improve later in life, they remain irritable, angry, and tense (Oldham, 1990). The narcissist's positive emotions come bundled with very negative ones. This is the outcome of frustration and the consequent transformations of aggression. This frustration is connected to the primary caregivers of the narcissist's childhood (Vaknin, 2003). Bundling, and stuffing is far easier than unbundling. The narcissist is unable to evoke his positive feelings without provoking his negative ones. Gradually, he becomes phobic: afraid to feel anything, lest it be accompanied by the fearsome, guilt inducing, anxiety provoking, out of control emotional complements (Vaknin, 2003).

Here are the stories in which courage to feel, opened a new path, a new meaning. The counselors attempts were to move emotions from cognitive schema into an experiential one, allowing the detached individual to become one with the totality of the “the kingdom within”.

The void, the hunger, the destruction, and the hope: The Case of Joe

Joe was born in a barrio, to a father who was in prison and mother whom was a pusher and a drug addict (O.S., Field Notes, May, 2003). Joe adolescents and early adulthood was characterized by anger and hostility toward mother, whom he tried to befriend and love numerous of times, finding himself beat and humiliated. Joe turned his aggression toward self and women in general (O.S., Field Notes, June, 2003)

Joe described his life as a chase after money, women and material possessions, and as long as he was satisfied, he was falsely happy. Joe reported his suffering growing as the void got filled but none in essence existed: relationship with women, turned into a tale of abuse, and then a conflict, Money ran down along with his growing habit to assassinate the self (O.S., Field Notes, May, 2003). The security Joe found in possessions faded away as his addiction ran deeper and deeper into oblivion. “Nothing could satisfy”, said Joe. “I was angry at everybody” (O.S., Field Notes, May, 2003).

Out of desperation and aloneness, Joe turned again to mother, but “she turned me away”, sending him coldly into the street. “When she was desperate, I allowed her to stay with me, she didn’t have to do a thing”, stating with bitter morose (O.S., Field Notes, June, 2003).

After two month of looking at the creation of the void down the passages of childhood, sitting tied to a chair hungry, going to school with wet socks and torn pants, yearning for love, Joe came to realize that he was aimlessly seeking the love, growing up and unable to fulfill his own essence with care towards self, unconditional care (O.S., Field Notes, August, 2003). Client realized that all his life he was living in a wheel chair, using a crutch whether it was alcohol, drugs, women, or possessions. But these did not satisfy the void (O.S., Field Notes, June, 2003).

Throughout the also month of treatment, Joe turn all the efforts and motivations towards self. In the past he was ashamed he couldn’t read, now he decided to engage with school (O.S., Field Notes, May, 2003). Joe came from evening schooling and with tears of joy said:” I’m sitting with older folks, I don’t feel ashamed, I feel good, I felt belonged” (O.S., Field Notes, June, 2003)

Client left treatment and started filling his time with volunteering, helping in hospitals. Joe started working (O.S., Field Notes, September, 2003). Calling me few months later, Joe said:” Thank you, I do today everything I haven’t done, I did not read no I started reading poetry, I went to the show Cats, I always ran to relationship and sex, I don’t even look for it now, I know that if God will allow it will come, today I am somebody, thank you” (O.S., Field Notes, February, 2004).

From Brokenness to Arrogance: Georges’ search for significance

This was his seventh or eighth treatment center. Desperate he entered the session stating his diagnosis clearly:” I’m anti social with narcissistic traits (O.S., Field Notes, September 2002).

George discussed his journey into darkness, reflecting on a conquest. George was summarizing his rise and fall. Snorting cocaine with the rich and famous. Having his own band, touring, and women all around tapping on his shoulder boosting up his ego (O.S., Field Notes, September 2002).

“Can you feel?” I asked at one point. “ You talk greatly and intellectualize your life, but can you live it, love it, and feel it, don’t answer, write in your journal, think about it” (O.S., Field Notes, October 2002). George left my office and returned a day later quietly with sadness saying:” I can’t cry I can’t feel I don’t know how too”. “Tell me about your childhood”, I said (O.S., Field Notes, October 2002).

George started with vivid descriptions of childhood memories, sleeping scared at night, his father, a raging alcoholic, beating up his mother (O.S., Field Notes, October 2002). “One night we heard the anguish screams of my mom, my brother woke me saying:” lets kill him”.” How do you feel I said, don’t think feel, I urged him. Georges’ eyes were red, the closest I saw him in two month to feeling empathy. “I am sad”, he said.” I am angry too” (O.S., Field Notes, October 2002).
Not long after that, George started getting into the childhood he never had, feeling alienated by parents, feeling lonely and sad. Going into description of adolescent and adulthood, George realized that he his anger and rage were developed into a more sophisticated beast: arrogance. “Everything I wanted I got. Money women, power”. “I did not feel empty and lonely no more” (O.S., Field Notes, October/November 2002).

“Now I have nothing”, said George in a mourning tone of voice. The show is over, the crowd is gone, women aren’t clapping, and I’m alone again” (O.S., Field Notes, October 2002). I could see now, three month after, George was tearing. “I am feeling again”, he said.” I don’t like what I feel, but I feel it”. Thank you (O.S., Field Notes, November 2002).

George left treatment successfully after 4 month. He changes his occupation and now he helps transporting the mentally retarded. He called me few months after:” This is king baby”, he said. “I feel humble, the residents teach me to be humble again, I feel like a kid again, all fresh all new, it feels good not to feel good Oudi”, he said (O.S., Field Notes, February 2003).

Discussion

Emotional wisdom is defines by Greenberg (Greenberg, 2001), as the ability to be aware and express one’s own difficult emotions. Such process can open new doors for the sufferer, such as: greater capacity to make sense of self, improved emotion regulation and the ability to develop better empathy toward others’ feelings. In both cases, patterns of avoidance and escape were created by living hedonistic life. Chasing women, money, and drugs. Avoidance of pain as suggested by scholars will create further grief and pain, and will perpetuate the cycle of maladaptive behaviors (Hayes, 1997; Greenberg, 2001; Walsh, 1999).

Growth and change, as a process, are attained through the mirror of relationships, through the understanding of the contents of his/her own mind, and through observation and not through intellectual analysis or introspective dissection. Man has built in himself images as a fence of security - religious, political, personal. These manifest as symbols, ideas, and beliefs. The burden of these images dominates man's thinking, his relationships, and his daily life. These images are the causes of our problems for they divide man from man (Krishnamurti, 2000).

In This dyad of the therapeutic dialogue, conditions of deep empathetic and compassionate care are authentically embraced and applied by health practitioners; a climate of change and self-actualization will eventually be created (Laing, 1965, 1967; Rogers, 1951, 1961). By building trust and love, and by encouraging the client to feel and express negative emotions (fear, anger, guilt, shame est.…), the chain of self medicaiding and avoidance in broken (Hayes, 1997; Greenberg, 2001; Walsh, 1999).

Clinical literature shows a high recidivism and high drop out of anti- social clients from treatment (Comer, 1998). However, even due to the limitation of small sample casework analysis, the hope of helping individuals who suffer from emotional frozenness is still somewhat evident. Only through loving relationship, the therapist can help his recipient actualize his lost potential (Frankl, 1984).

Blake's hope of living in joys'- 'eternity's sunrise' is promised only to those sufferers who break the binds to Joy Itself (Rinpoche, 1994). To embrace and feel the dread, the depression and anger of life is not a curse for the Sufi teacher but a blessing. The old mystic teacher, Jalaluddin Rumi, chose to embrace the ill emotions, seeing negative emotions as a bridge to better life. The supreme style of coping is best illustrated in the guesthouse poem:

> *"This being human is a guesthouse every morning a new arrival a joy, a depression, a meanness Some momentary awareness comes as an unexpected visitor welcome and entertain them all! Even if they're a crowd of sorrows who violently sweep your house Empty of its furniture Still treat each guest honorably, He may be cleaning you out for some new delight! The dark thought, the shame, the malice meet them at the door laughing and invite them in, be grateful for whoever comes Because each has been sent as a guide from the beyond". (Rumi, 1995 cited in Zokav, 2001,pp.47).*

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The International Journal of Psychosocial Rehabilitation
Volume 9, Number 1
July 2004– June 2005

Mental Health and Palliative Care: Exploring the Ideological Interface

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Citation:
McGrath, P. & Holewa, H. (2004). Mental Health and Palliative Care: Exploring the Ideological Interface. **International Journal of Psychosocial Rehabilitation. 9,** 107-119.

Abstract

People with a mental illness have an excess mortality, a reduced life expectancy and die from ten to fifteen years earlier than the general population In the face of such sobering facts about the difficult end-of-life issues in relation to mental illness, there is a 'loud silence' in the literature on palliative care and hospice services for individuals in the mental health system. This paper seeks to address this hiatus by presenting findings from a qualitative research project on end-of-life care for patients in a mental health institution called The Park, Centre for Mental Health, located in Brisbane, Queensland, Australia. In particular, this discussion will focus on the findings from the project which highlight the similarity in philosophy between palliative care and mental health practice. The similarity which includes a person centred practice, relationship- based connectedness, a belief in compassionate, holistic care, respect for autonomy and choice, quality of life issues, family as the unit of care and need for a democratic and multi- discipline work team , will be described. It will be argued that the common philosophical meeting ground is an excellent foundation for integrating palliative care, now recognised as best-practice end-of-life care, into mental health service delivery. In short, the shared practice values and vision between these two disciplines provide an optimistic starting point from which to plan to address the lack of hospice and palliative care service delivery in mental health.

Keywords: mental health, palliative care, qualitative research.

Introduction

The mental health literature indicates that there are many factors that point to the need for serious consideration of end-of-life issues for psychiatric patients. Foremost of these concerns is the excess mortality and higher case fatality rate for patients within the mental health system with cancer. By way of example, the West Australian work of Lawrence and associates (1) demonstrates that despite scant differences in overall cancer incidence rates between psychiatric patients and the general community, cancer mortality within the mental health system was 39% higher in males and 24% higher in females. Indeed, the evidence indicates that high rates of medical co- morbidity and premature death are now considered normative health outcomes for individuals with mental illness (2). Mortality among psychiatric patients not only remains high, but there is evidence that it is increasing (3).

The second concern is that mortality concerns in mental health are not just associated with traditional palliative care diagnostic categories, but extend to the equally serious incidence of death by suicide (4,5). Studies of psychiatric patients indicate that the highest cause-specific mortality rate is for deaths due to suicide (3). Of considerable worry is the fact that excess mortality risk is concentrated in the first few years after first contact with mental health services (3). In summary, then, statistical information demonstrates that people with a mental illness have an excess mortality, a reduced life expectancy and die from ten to fifteen years earlier than the general population (2,6,7,8).

In the face of such sobering facts about the difficult end-of-life issues in relation to mental illness, there is a 'loud silence' in the literature on palliative care and hospice services for individuals in the mental health system. The only work that exists is about liaison psychiatry working with patients with stress and depression in mainstream hospice services (9,10). There is neither research nor commentary on end-of-life services for patients within the mental health system. Thus, this paper seeks to address this hiatus by presenting findings from a qualitative research project on end-of-life care for patients in a mental health institution called The Park, Centre for Mental Health, located in Brisbane, Queensland, Australia. In particular, this discussion will focus on the findings from the project which highlight the similarity in philosophy between palliative care and mental health practice. The similarity will be described and it will be argued that the common philosophical meeting ground is an excellent foundation for integrating palliative care, now recognised as best-practice end-of-life care (11,12), into mental health service delivery. In short, the shared practice values and vision between these two disciplines provide an optimistic starting point from which to plan to address the lack of hospice and palliative care service delivery in mental health.

The Park, Centre for Mental Health

Situated in the Brisbane suburb of Wacol, The Park, Centre for Mental Health (TPCMH) provides mental health and psychiatric services to the people of Queensland and was one of the largest psychiatric facilities in Australia (13). Established in 1865, TPCMH has recently decentralized its extended care services as provisioned by the Ten Year Mental Health Plan for Queensland (14) through adopting a paradigm focused towards rehabilitation and recovery. Currently, TPCMH provides five clinical and rehabilitation services programs to 192 clients from central and southern Queensland, including, Extended Treatment and Rehabilitation, Dual Diagnosis services, Extended Secure Services, High Security/ Forensic Care Services and Adolescent Rehabilitation Services. Support Services available at TPCMH include General Health Services, School of Mental Health and Library, Centre Management and Research

Services.

The Research

Mindful of the lack of research on palliative care in a mental health setting, the principal aim of the research project was to document the experience of providing end-of-life care to patients for health care workers in an institutional mental health setting at TPCMH. The work was carried out by a Central Queensland University post-doctoral research fellow with a background in palliative care research and infrastructure links to TPCMH.
Ethical consent to conduct the study was obtained from the West Moreton Health Service District Human Research Ethics Committee. Participants were verbally informed of their rights in research and written consent was obtained for participation in the research.

Methodology

The theoretical framework for the research is situated in descriptive phenomenology, defined by Spiegelberg (15) as "direct exploration, analysis, and description of particular phenomena, as free as possible from unexamined presuppositions, aiming at maximum intuitive presentation". The phenomenon in this case is the experience of providing terminal care for patients with a physical illness in an institutional mental health setting. Descriptive phenomenology is particularly appropriate where little is known about a group of people (16,17) and so is well suited to the study of palliative care in a mental health facility where there is no previous research literature.
The experience of providing terminal care is documented through qualitative research using open-ended interviews conducted with health care workers at TPCMH by a post-doctoral fellow experienced in palliative care research.

Sample population

The two qualitative strategies of purposive sampling and snowballing enrolments guided the selection of participants. Because of the legal issues associated with end-of-life care, research discussions with regards to any death at The Park is highly sensitive, or taboo in the case of a death presently under coronary inquiry. For this reason participants had to be purposively sampled through those directly involved in the care of two patients who had died in the last year but who were no longer under legal consideration in relation to either police or coronary inquiry. Those involved in these two death were enrolled by snowballing techniques of targeting key people involved in the care of those patients and asking those participants of others who they would consider should be interview because of their significant role during the dying trajectory. The result was eight (n=8) interviews which covered a sample representing key people involved in the care during the dying trajectory of the two (n=2) specified patients.

It is important to note that although a sample of eight is small, it is considered substantial in terms of the qualitative literature. The small number is directly related to the fact that there have been few recent deaths at The Park and so the overall target population is small and further reduced by the fact that only those deaths not under legal consideration can be targeted. In view of such restrictions and the seminal nature of the work being undertaken, it was considered satisfying to be able to obtain a sample of eight. As there is no other work completed on palliative care and mental health, these interviews provide a unique opportunity to begin to place important end-of-life issues on the agenda.
Demographics
Because of the sensitive nature of the topic under investigation and the fact that the interviews were completed in a closed institutional setting, extra precautions needed to be taken and promised to participants during informed consent procedures. Such procedures were important in

order to build a sufficiently safe environment where the interviewees could participate with confidence. Thus, it is an ethical imperative that the information provided for demographics will need to be provided in generalities so that participants cannot be identified.

There were eight (n=8) participants with both males and females interviewed. All of the participants had worked at The Park for a number of years, and some of the participants had very long work history at the institution, so all were well placed to understand the fullness of the issues in relation to their work place. The participants were involved in nursing, care co-ordination, education and advocacy roles at the institution and were directly involved in the care of the two patients who had died within the last year and were no longer under coronary inquiry.

Data collection and analysis

The time and location of the interviews were of the participants choosing. The interviews lasted for approximately one hour, and the interviews were conducted in interviewing rooms in the hospital. Participants were encouraged to tell their experience with caring for a terminally ill patient with the initial question of "Could you tell me in your own words and in your own way of your experience as a health professional caring
for a patient in a mental health facility with a terminal illness?" Of particular interest was an exploration of factors that the participant believed either facilitated or hindered the provision of optimal end-of-life care. The momentum of the interviews was maintained by the descriptive phenomenological method of 'imaginative listening' (18). The challenge in descriptive phenomenology is for the researcher to follow the ideas of participants rather than impose preformed assumptions on data collection (19).

The interviews were audio-recorded and transcribed verbatim. The language texts were then entered into the NUD*IST (Nonnumerical Unstructured Data Indexing Searching and Theorizing) computer program, computer software available to facilitate cutting and pasting interview transcripts into codes (17,20), and analysed thematically. As descriptive phenomenology is an inductive process which seeks to record experiences from the viewpoint of the individual who had them without imposing a conceptual framework, the thematic analysis was driven entirely by the participants' insights (17). The coder read all of the transcripts, then created codes from every statement made by the participants. The title of each code was usually from the exact words of the participant. As Grbich (21) explains, such coding practices use minimal underpinnings to avoid data being forced into predetermined frames and to encourage uncontaminated themes to emerge from the data. There were thirty five (n=35) free nodes created. Once all of the participants' comments were coded into free nodes, the list of nodes were then organised under thematic headings.

As phenomenological description can never encompass the whole of the phenomenon but shows only particular aspects (19), only the findings from the free nodes directly related to the impact of the legal framework on terminal care service provision are presented here. In relation to the common problem for the qualitative researcher of summarising the sheer volume of data (17), the findings section will follow the usual format of presentation (20) of detailed descriptive commentary accompanied by sequences from the original data (segments of the interview texts). The interpretation of the findings, set in the context of available literature, will follow in the Discussion section.

Findings

Knowledge of palliative care

With the exception of one person who had previously worked in oncology, the participants had little experience with, or knowledge of, palliative care. Thus, when asked about their knowledge of the discipline most responded with an unqualified "No": they knew very little. The following is typical of such responses,

- No. What is it called again?

The reasons given for this unfamiliarity were, firstly, to do with the lack of involvement of palliative care at the institution,

- We (at The Park institution) have had so little to do with palliative care across time

Second, it was noted that, although many were nurses, they did not have practitioner experience in palliative care. For example,

- I never really understood what that means, never been to a palliative care unit.

However, for some, there was familiarity with the general concept through the mass media or through conversations with others in their intimate circle,

- Never been to a palliative care ward, just sort read in the papers, friends commented on their relative had to have palliative care

Definitions – Educated guesses

Although the participants indicated they had no formal professional knowledge or experience, they demonstrated an excellent understanding of many of the basic criteria in their educated guesses about the nature of palliative care. These guesses covered central concepts such as a focus on the individual in the context of their family,

- And so not just for the individual but for their family members as well, to make sure the best possible outcome.

The priority given to a concern about quality of life,

- Be as comfortable and enjoy, it seems ludicrous to use that word and I am trying to think of a more appropriate word. Why should the last days be your worst days? So quality of life.
- Making life for a person who is dying as much comfortable as possible

The centrality of the patient-centred notion of choice and autonomy,

- And that might mean that person is managed at home or in an inpatient facility with services delivered not as assessed by the palliative care team but as the individual would have thought would be the ideal arrangement.

The provision of effective pain management,

- I would say a respectful way of letting a person be pain free in the end stages of their life.

The provision of psycho-social-spiritual support,

- The role of palliative care is to ensure that appropriate medical and psychological and spiritual support are brought to bear for that person at that point in time, at that point of need,

An understanding of clinical skill,

- Palliative care in a hospice setting where experts who deal with it every day know how to do it.

And lastly, an awareness that it involved care of patients during the terminal stage of their disease,

- I get the impression that it is somewhere you can go for management of your illness or pain relief just general management, overall care; you are not doing any magic cures.

Similarity to mental health philosophy and practice

In view of the participants clearly stated lack of knowledge of palliative care practice which rested solely on educated guesses, it is interesting to note that descriptions of the mental health work resonated clearly with the ideology and practice of palliative care. As will be seen by the following descriptions, there is a close affinity between the attitudes, values and practice of mental health and palliative care.

A person-centred practice

As with palliative care, connecting with the person is the central focus in the work of the mental health staff interviewed.

- Our whole model of service delivery is about making contact with people.

It was noted that this can be very challenging in practice in a situation where the person's mental illness can impact strongly on their ability to make relationships. As one participant sums up,

- Our focus is connecting with that person. Connecting with the person and forgetting the illness. Connecting with the person and we are trying very hard to do that. And it is not easy.

However, participants pointed to their person-centred mental health training and skill that prepares and assists them in the difficult task of making the connection.

- We should be skilled people. We are supposed to be able to go to that person and take cues from the person about how they can handle it.

Some of the staff interviewed spoke of their individual strategies for connecting with mentally ill patients.

- One thing that I've been taught in nursing when you are not quite sure what they think is to put yourself in their position and what would you want if you were them.

Descriptions were provided of situations where with training, perseverance and a strong person-centred philosophy, connections were even made with floridly psychotic patients.

- I try to talk to them and open up something… a lot of people believe that it doesn't make a difference to patients because they are floridly psychotic.. I don't believe that... because I have had conversations with totally psychotic persons…

Relationship- based connectedness

As with palliative care practice, the modus operandi for connecting with clients is through the establishment of nurturing relationships. As one participant summed up,

- On an individual level that connectedness is there, (our work is concerned with) forming relationship with our clients

Similar to palliative care, the relationship is formed through daily interaction attending to patients needs.

- To talk to them and try to help them with their needs – (if they) need shower, need change of bed, helping them clean their clothes, just to talk to them.

There was evidence of work satisfaction as reward for the energy invested in the relationship-based connection.

- I am this person who is constantly with them. You hardly see me sitting in the nursing station only if I have to document something. I love to be there even if they are in a psychotic state; I really believe that I can make a difference.

One participant expressed strongly the similarity between mental health and palliative care on this aspect of care,

- (Pointing to the similarity of palliative care and mental health) because you try to get closer to the patients no matter what. You try to get closer as much as you can. We try to make them comfortable as much as you can. If totally psychotic give medication and just start talking to them. Do you think this will help? I feel that you are not very well today? Do you want to talk to me about it? And then try to talk

As the following example demonstrates, where the patient has been in the facility for years many staff will have established significant relationships with them,

- The memorial service was made for the entire facility. Everyone who knew him. We took photos and posted them.

However, a caveat to the discussion was given by the reference to the fact that some in the institution may not agree with the desire to form nurturing relationships.

- (Talking about the problem of locked doors and observation through window) A lot of people are not close to patients and they are not in contact with them because they chose to.

Compassionate and Holistic Care

The participants also emphasised that the person-centred mental health philosophy was based on compassionate and humanistic principles of holistic care. The references to humanistic and holistic care were direct, not inferred.

- Working in mental health we are supposed to be holistic practitioners.
- It is humanistic

The focus is not restricted to the mental illness, but rather is concerned with the whole person and how best to rehabilitate them from both a psychological and social perspective.

- You are just trying to rehabilitate them, treat them as best you can. Try to get them back to the community. Or get them back into social life again without crimes or whatever they committed to come in here.

Again, the strong similarity on this point between mental health and general nursing was drawn,

- It is unfortunate that there is this (difference between) general nursing and psyche nursing because I believe in holistic nursing and I don’t see the big difference.

The point was also made that during the end-of-life trajectory of the patient the mental health staff felt a heightened inclination towards compassionate, humanistic and holistic care.

- You can be compassionate. I would go there towards the end - I would make more effort to actually go and be with him. And I would open his fridge and pour him drinks which was not kind of what I do because I am away from that area. So I made more of an effort to go and do those humanistic things than I would ordinarily have done.

Because of the psychological orientation of the holistic mental health practice, handling the end-of-life issues of grief was not a difficulty.

- I think we really do try to do the appropriate thing and of course our thing is psychological. So we knew about the grief issues.

As with palliative care, the holistic motivation involved a desire to make a difference,

- I just felt that I make a little bit of difference.

Respect for autonomy and choice

Although legal notions of informed consent in mental health are complicated by the concept of cognitive capacity, there is evidence in participants' statements of a commitment to foster autonomous choice. Such sensitivity to respecting autonomy strengthened the development of trusting relationships.

- I would never push the issues… if I thought he was uncomfortable you wouldn't go further. I didn't push it unless I could help his total consent with that. We had a very good understanding. He trusted me completely.

Concern for quality of life as defined by the client

As with palliative care practice, the mental health staff not only posited the importance of quality of life but also emphasised that it must be defined by the patient's frame of reference.

- From the subjective viewpoint, quality of life is a term that is totally subjective because your quality of life is different to mine.

Focus on family as unit of care

Although in mental health there are complex obstacles to maintaining family connections (findings on this issue will be published separately), the staff indicated that they valued and in invested energy into affirming the importance of family context.

- To me it is totally the same - the family issue is most important for these patients as well.
- When she first arrive the staff were 'thank God family is here'

Multi-disciplinary team work

A further similarity to palliative care is the participants' stated belief in the importance of a democratic, multi-disciplinary organisational structure.

- Team work… flat structure… doctor supported decisions made
- The whole philosophy is multidisciplinary and the team ... has to do with that structure

Ability to face and deal with dying

As the interview focus was on end-of-life issues, there were many statements to indicate that (as with palliative care professionals) the mental health participants had an ability to accept and work comfortably with the notion of death.

- (Some people prefer not to be on shift when someone dies) I prefer to be on, (as it provides) closure.

Death with dignity

Accompanying the comfort with death is the priority given to ensuring that patients have the opportunity to die with dignity.

- I really wanted to make sure he had the opportunity to die with dignity really important

Concern to keep patient in familiar environment

As will be published elsewhere, the participants indicated that in the mental health setting patients' contacts with their families were often lost or problematic. Where the patient had been in the institutional setting for many years the staff become substitute family. Taking into account this idea of 'institutional family', there is extensive evidence in the data to show that, similar to palliative care, the mental health staff prioritised the importance of the patient dying within the comfort of the familiar net work of relationships and in the physical place that had been the individual's home.

- Most of my colleagues were pleased that he had his last few days with us rather than send him off to hospital for that time.

Special attribute of staff

Although there is a great similarity in the insights of all participants interviewed for this study, there are also indications of difference to other mental health workers on issues of compassion and involvement with patients. Thus, it is important to posit the caveat that the interviewees may mirror a self-selection process that reflects the attitudes of mental health staff prepared to become involved with patients during the dying trajectory. As noted in the Discussion section, a similar self-selection process operates in the discipline of hospice and palliative care.

- I don't think we can teach people to be compassionate if it is not in their personality. .. It may even be a self selection process..

Participants indicated awareness that the foundation for effective work with the dying may be related to personal as much as professional qualities of staff.

- Not everyone can do it. People have not dealt with their own issues their own mortality and understanding the meaning of life if you have not come to grips with the meaning of life, it is pretty hard to sit down with someone … you probably need dealing with your own feelings

Summary statement

In summary, the similarity between the palliative care and mental health philosophies was noted by the participants.

- I am not very familiar with the palliative care stuff because I've never been there but if the philosophy sounds like that then that would fit in here.

The ideological concern at the core of both disciplines is reflected in one participant's summary statement,

- We were trying our damnedest to do the right thing.

Discussion

The findings strongly indicate a lack of knowledge of, an affinity with, and a need for, palliative care in the mental health setting.

This group of mental health practitioners directly involved in caring for the terminally ill did not have a professional understanding of palliative care and had not been exposed to education or training on best practice end-of-life care. However, they were able to make educated guesses about the discipline because of their informal exposure to either the media or familial experiences with dying. Such guesses addressed core issues documented as central to palliative care including notions of quality of life (22), family involvement (23), patient-centre care (24), respect for choice and autonomy (25), effective pain management (26), psycho-social-spiritual support (27), the importance of clinical skill (28), and the focus on palliation rather than cure (29).

In their discussions of end-of-life care in a mental health institution, the participants articulated many commonalities between the mental health and palliative care philosophies and practice. The first issue of similarity is the idea of person-centred practice. Issues of concern to the client form the starting point for planning interventions within the person-centred approach to health care (30,31). Particularly in relation to recovery, there are now models of care available in mental health, such as The Tidal Model by Barker (32), that emphasis the centrality of an empowering, person-centred approach.

The participants indicated that in mental health connecting with the individual can be challenging and requires skill and training. As noted in the literature, a repertoire of knowledge is essential to the mental health worker as they require highly developed interpersonal skills and strategies for providing help in a way that preserves the dignity and pride of the client (33,34). As Cleary (35) explains; training, experience and aptitude are necessary to acquire such skills.

The second link of commonality between the disciplines was stated as a focus on a relationship-based connectedness. The relationship between the health professional and the patient is now considered the essence of mental health nursing and the most basic principle taught to mental health nurses (33,36,37). Similar to palliative care, in mental health the therapeutic essence of relationship building dates back to the origins of the movement. In the case of mental health it is traced to the work of Peplau (38) who emphasised the importance of interpersonal relationships, with most of the subsequent mental health nursing literature drawing on Peplau's conceptualisation (39,40,41,42,43).

The third point of comparison is the belief in compassionate, holistic care. The support for holistic care is strengthening in mental health with many authors warning against reductionist treatments as bound to fail (44). The holistic paradigm emerging in mental health is one concerned with a commitment to care and a dedication to understanding the meaning of illness experience from the patient's perspective (45,46). As Raingruber (47) argues, the holistic and egalitarian focus is consistent with the value base of mental health nursing.

The participants' fifth parallel in practice and ideology is that of respect for autonomy and choice. Engendering respect for a person's autonomy is recorded as a key aspect of mental health service delivery (48). As Atikinson (49) explains, fostering autonomy in mental health can be regarded as manifesting respect therapeutically for a client's own goals and ways of pursuing them. As with palliative care, information giving is seen as a key process in fostering autonomy and choice in mental health (49).

The sixth point of similarity noted is a concern for quality of life as defined by the client. Although described as a difficult concept to define (50), the notion of 'Quality of life' has grown in influence in the broad arena of health care in recent years (30). The concept of quality of life posited by the mental health participants in the present study echoes the palliative care concern that it can only be defined by the client in terms of their own life space. For as Verri and associates (51) clearly state, Quality of Life 'encompasses both the objective circumstances of living and the degree of positive feelings which people have about their lives'.

The seventh practice resemblance is the focus on the family as the unit of care. As Raingruber (47) notes in regards to mental health patients, people live in webs of relationships including families, communities and cultures. Although the intimate network of relationships are often problematic because of the negative sequelae of mental illness, psychiatric staff, like palliative care workers, value and try to work within the framework of the familiar unit of care. As will be described elsewhere, the staff indicated that where patients are long-term and family network are absent the staff become a substitute or 'institutional family'. There was considerable angst voiced by the staff interviewed about the need to send patients away from the 'institutional family' during the dying trajectory because of the lack of in-patient palliative care facilities. As with palliative care praxis, the concern for the mental health staff was to try to keep the patient within their familiar environment during the distressing time of the dying trajectory.

The eighth professional similarity was in relation to the valuing of democratic, multi-disciplinary team work. As Cleary's research (33) documents, mental health staff priorities the notion of the flat structure of the multidisciplinary team and believe the complementary skills and expertise of different health professionals are required to deliver appropriate and competent holistic care.

The ninth, and last, point of similarity is the reference to the need for special attributes for staff. As Sand (52) clearly states, the personalities and qualities of nursing staff are now thought to be of considerable significance in their interactions and nursing relationships with patients. The need for special attributes for staff is noted both for working within the mental health system and with those facing the dying trajectory. The findings indicate that for palliative care in a mental health institution staff will require the attributes of an effective psychiatric health carer and the ability to deal with the facts of death and dying.

In summary, then, the findings indicate that there are many positive similarities between mental health and palliative care practice. The commonalities provide an excellent foundation from which to build the much needed transfer of palliative care ideology and practice into the mental health arena where the profound difficulties associated with the dying trajectory need addressing.

Conclusion

This article has outlined the insights from a group of mental health practitioners who have recorded their struggled with providing end-of-life care in a system where concepts of hospice and palliation are not presently integrated. It is the hope and expectation that the sharing of these insights will not only put palliative care in mental health on the research agenda, but will also establish the beginning of a productive collaboration between two disciplines with a common value and practice base.

Acknowledgement: I would like to thank Mrs Elaine Phillips for her excellent work transcribing the tapes for this project.

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The International Journal of Psychosocial Rehabilitation
Volume 9, Number 1
July 2004– June 2005

Participants' Reported Experiences of an Irish Psychiatric Residential Rehabilitation Programme

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Citation:
Price B. & Western B. (2004). Participants' Reported Experiences of anIrish Psychiatric Residential Rehabilitation Programme. **International Journal of Psychosocial Rehabilitation. 9**, 121-134.

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Abstract

Individuals currently participating in the high, medium and low support components of the Cluain Mhuire Residential Rehabilitation Programme (RRP) in Dublin, Ireland were asked to give an account of their experiences of the programme and their evaluation. Participants completed two questionnaires containing qualitative and quantitative questions. Demographic information was sought on age, marital status and cultural identity as well as information on their current living and employment status. A qualitative section at the end of this questionnaire gave participants the opportunity to state their own understanding of the reasons for being in the programme and their expectations of the programme. Secondly, participants completed a standardised questionnaire called Measuring Psychosocial Rehabilitation Outcomes (MPRO) that provided them with the opportunity for self-evaluation. The MPRO assesses quality of life issues, beliefs around empowerment and the ability to influence and control one's life using a rated scale that provides scores on four main outcomes: 1) Subjective Quality of Life (SQOL); 2) Mastery (M); 3) Empowerment (EMP); and 4) Programme Satisfaction (PROG). A qualitative section at the end of this questionnaire gave participants the opportunity to evaluate what are the most and/or least satisfactory aspects of their time within the RRP.

The data was statistically analysed to evaluate whether there are correlations between a participants' living status and the four outcome measures on the MPRO – Subjective Quality of Life, Mastery, Empowerment, and Programme Satisfaction- and if there are any positive or negative correlations between these four outcome measures.

The results indicate that a participants' level of residential support can be statistically significant in correlation to their self-evaluation, with those in high support scoring the lowest on PROG ($p=0.01$) and those in medium support scoring higher and more consistently. There were also significant correlations within the four outcome measures on the MPRO ($p=0.01$ to $p=0.05$).

Keywords: psychosocial rehabilitation; evaluation; programme satisfaction

Introduction

"The main tasks of psychiatric rehabilitation are: (1) to assist in reintegrating psychiatrically disabled persons into the community and (2) to maintain their ability to function independently…in other words, psychiatric rehabilitation practitioners attempt either to reduce the patient's dependence on the mental health system of people and facilities, or to reinforce whatever level of independence from the system the patient has been able to achieve." (Anthony Cohen and Vitalo, 1978, p.365)

The term psychosocial rehabilitation is currently most often used to describe those programmes with a focus on providing the least restrictive setting, avoiding hospitalisation and providing skills training. Fields (1990) criticizes a lack of discernment and definition with regard to residential programmes, and claims the same term is often applied to very different programmes. He provides a definition: "the purpose of residential treatment programmes is twofold: (1) to provide treatment alternatives for those individuals who would otherwise be left in acute and longterm hospitals or other institutional settings, including jails, due to the severity and seriousness of their disabilities; (2) to utilize a range of residential settings to transition the mental health system from an institutional dependency to a community based services perspective"(p.107).

Fields (1990) explains that "on a programmatic level, residential treatment programmes are therapeutic communities designed to assist clients to stabilise from a crisis, to develop and implement a community support plan, and to interact with other people, staff members and clients, in order to strengthen interpersonal skills and identify individual goals….the programmes should be active in the life of their communities and not isolated facilities" (p.109).

Research studies into the measurement of rehabilitation outcomes have found that there is a need for baseline analysis in this area, as programme evaluation is contingent on continuous assessment of the delivery of rehabilitation programmes (Hawthorne et al., 1994, p. 152). Gathering this data will hopefully provide an opportunity for researchers in years to come to obtain information on the programmes offered within the Cluain Mhuire Residential Rehabilitation Programme (RRP) and to measure the improvements, or need for change, within the programme. Indeed there is much to be said for creating a culture of research and ongoing programme evaluation within the RRP, bearing in mind that "assessment of rehabilitation outcome must be more than a research activity. It should be an ongoing responsibility of each practitioner "(Anthony et al., 1978, p.379). Issues such as quality of care, the cost effectiveness of programmes and, most importantly, the benefit to the client can be dramatically and positively affected by this kind of research.

Such evaluations have been encouraged by researchers who posit that "the main tasks of rehabilitation are to assist clients in re-integrating into the community and to maintain their ability to function independently" (Anthony et al., 1978, p.365). A key to comprehensive evaluation must include the participants' satisfaction of the services. An evaluation model that includes a self - evaluation component is preferable to an evaluation conducted by non - treatment personnel". (Anthony et al., 1978, p. 379).

The Cluain Mhuire Residential Rehabilitation Programme

The Cluain Mhuire Residential Rehabilitation Programme (RRP) addresses differing levels of need and provides a transition from institutional dependency to a community- based services perspective such as that advocated by Fields (1990, p.107). However, there has not yet been an evaluation provided by residents nor a compilation of information gathered on their current circumstances. To date, there has been substantial movement through the programme, with an average of about seven people making a transition each year. Occasionally, those who have made such a transition to a lower level of support discover that they need to return to a higher level once again.

The RRP is a component of the Cluain Mhuire Mental Health Service and run under the auspices of the Hospitaller Order of St. John of God. The emphasis is on helping participants to move through the different phases of the programme with a focus on rehabilitative possibilities based on individualised assessment. The ultimate aim is for re-integration into the community where appropriate.

Previously named the Community Living Programme, the RRP was so named after a review in 2000, which recognised the increased need to focus on rehabilitation and the attainment of skills in helping people, re-integrate into the community. Largely, the programme encompasses many different elements, examples of which are: residential, educational, medical, the teaching of social and domestic living skills and recreation. All participants maintain outpatient contact with their psychiatrist. Participants are required to pay a weekly rent and are encouraged to maintain regular payment. Rent covers all domestic expenses and the programme funds group recreational activities.

The three phases of the RRP are 1) High Support, 2) Medium Support and 3) Low Support.

Those individuals residing in Oropesa[1], the high support component of the RRP, are in most cases referred by their medical team from St John of God Hospital. Oropesa is a 20-bed hostel in the community and the level of support is designed for those individuals who have been identified and assessed as being most suitable to participate in the skills training offered within the Residential Rehabilitation Programme. Participants of the programme are usually expected to engage in outside activities that are either provided by the service - for example, day centres or workshops - or other agencies accessed by participants themselves. Staff encourage maintenance of self-care. Meals are prepared by kitchen staff and participants are requested to help in maintaining cleanliness in the building. Medication is either supervised or unsupervised depending on the needs and capabilities of the individual participants. There are a minimum of two staff members on duty at all times (24 hrs).

The participant is assigned two keyworkers who will over a period of time, work with them in formulating and actualising personal goals, the achievement of which are necessary for transition through the programme. A link worker is on duty to facilitate keyworkers with such goals as improving self care, budgeting and initiating daily activity as well as management of anxiety/stress and support in coping with current life issues.

A medium support environment, Avila[2], is provided elsewhere in the community, and caters for fifteen people. There are alternately one or two staff members on duty on a twenty-four hour basis. Each participant at Avila is assigned a keyworker who will help to build upon the goals that have been met within the high support component and to continue programme plans adapted to a medium support environment. This is usually based on the improvement/attainment of daily living skills such as cooking and shopping, budgeting and self care i.e. hygiene. There is also support in managing anxiety, stress, grief or any current issues in participants' lives. Participants are expected to engage in the routine activities of the hostel and to maintain room hygiene.

The main theme is self-governance with participants' meetings held weekly, where menus are planned and shopping duties allocated. Participants take turns to cook and to shop while observing budgetary limits. All necessities are met by the hostel budget including food and cleaning materials. Group recreational activities are funded by the hostel and participants are encouraged to access activities in the community that are conducive to their goals and may be funded where appropriate. Most participants take unsupervised medication where appropriate.

Those who have successfully completed the other modules move to one of the low support hostels[3] with the eventual aim of moving to private or local authority housing. This comprises three houses on housing estates in the Stillorgan/Blackrock area. Each house contains four/five residents, each with their own room. Two staff members are available within flexible working hours. Rent relief can be claimed, unlike in the other hostels. Staff inspect the homes and ensure that they are kept to a good standard in terms of hygiene. Group activities are funded by the service and are facilitated by staff. Residents are expected to have a daily activity where possible. Since this research was initiated there has been an added component to low support in the provision of a unit specifically for those who will imminently make the transition from supported living to independence with an outreach service.

The aim of this study is to provide an overview of the current circumstances of those participating in the RRP, which we hope will help to identify and meet their needs to the maximum level, and will help in assessing outcomes. Overall we hope that information gleaned would provide valuable knowledge for future planning and an information base for future studies. We also hope to promote a greater awareness of the issues in psychosocial rehabilitation today.

This study will address the hypothesis that:

The Residential Rehabilitation Programme benefits the participant in terms of quality of care, employment, empowerment and independence. The benefits of the programme are related to progressive movement through the Residential Rehabilitation Programme.

1. Oropesa is the place name of an area in Spain where St John of God spent his childhood. He lived and worked here as a shepherd until adulthood, when he left to join the Spanish army.
2. Avila is a reference to Father John de Avila who was a minister living in Grenada whom John looked up to as a mentor. He became a very good friend of John's and was instrumental in guiding John through his spiritual conversion.
3. Ardmeen, Allen Park and Leopardstown Avenue are the names of the three houses , or low support hostels, that are nestled in the communites of Blackrock and Stillorgan.

Method

Demographic questionnaire:

An adapted questionnaire produced by the US based Human Services Research Institute (HSRI) was used to seek demographic information such as living status, age, marital status, income, employment status, time spent in the RRP and readmissions to hospital. Two qualitative questions at the end of the questionnaire asked for people's expectations of the programme and their reasons for being part of the programme, in their opinion.

Measuring Psychosocial Rehabilitation Outcomes (MPRO)

The MPRO is a scale devised by the research committee of the International Association of Psychosocial Rehabilitation Services in cooperation with the Evaluation Center at the Human Services Research Institute (HSRI) in the US. It is specifically designed to measure the perspective of programme users in a number of areas that are relevant to the goals of psychosocial rehabilitation programmes. The four areas focused on were:

1) Subjective Quality of Life (SQOL) - assesses overall perception of well-being.
2) Empowerment (EMP) - assesses the individual's sense of his/her rights and opportunities to control his/her life and services received.
3) Mastery (MAST) - assesses the individual's beliefs around ability to control and influence his/her own life.
4) Programme Satisfaction (PROG) - assesses satisfaction with the programme.

The questionnaire contains 20 questions, with five questions for each variable. Participants rated their answers on a scale, which measured the extent to which they agreed or disagreed with the statements made. Questions were scored and added with an average figure taken for each individual for all four variables and an average overall score for each variable.

Lower scores indicated less satisfaction with the programme, or a lower sense of well being, while higher scores indicated the opposite. At first glance the lowest overall average score was for Mastery, followed by Subjective Quality of Life, and then Empowerment and the highest score was Programme Satisfaction. The use of a computer statistical package (SPSS) helped to analyse the data for differences between the four variables and their relation to the three levels of support.

After securing the Hospitaller Order of St. John of God Ethics Committee approval, individual programme participants were posted a letter of information and a letter of consent along with a stamped addressed envelope and a return date prior to commencement of the project. Letters of consent were to be posted or dropped into sealed boxes in Avila and Oropesa. After the return date, the MPRO, demographic questionnaire and stamped addressed envelope were posted individually. Again, participants were asked to either return the questionnaire by post or to leave them in sealed boxes located securely in the offices of Avila and Oropesa by a certain date. Other staff members were briefed on the ethical concerns. The researchers were contactable in the event of any queries. Estimated time to complete the questionnaires was approximately 20 minutes and participants were given four weeks to return the completed questionnaires. The study related to the RRP only and not to the service as a whole. All consultants' permission was sought and any opinions/concerns regarding individual residents were invited. No funding was requested or obtained for the purpose of this project.

Subjects

Fifty participants of the Cluain Mhuire Residential Rehabilitation Programme were provided with the demographic questionnaire and the MPRO. Twenty-four RRP participants responded (48%). The age range of the 24 participants was 19 to 65 years old (mean = 42, median = 44). Sixteen were male and eight were female.

Results

Demographic questionnaire:

48% of RRP programme participants took part in the study. The average age was 42. Only two respondents had been married and one was divorced/separated. All other respondents were single (92%).

22 responded that they are Irish with two failing to answer that question.

7 (29.16%) of the study participants were residing in Low Support, 5 (20.8%) were in Avila, the medium support setting, and 12 (50%) were residing in Oropesa, the high support component of the RRP.

When asked about their current employment status, 8 (33.3%) cited that they were in a sheltered workshop. 4 (16%) said they were currently unemployed. 3 (12.5%) were on a training course such as Roslyn Park, a service provided by the Rehab group, and another 4 (16%) classified themselves as actively seeking employment. 3 (12.5%) said they were employed outside of St John of God services. One person said they were studying and another said they were starting their own business.

16(66%) had been previously employed, with occupations being or having been; library assistant, real estate apprentice, gardener, secretarial work, cashier, commis chef, maintenance technician/ production, advertising copywriter, babysitter, data input, accounts assistant

The hours of those currently engaged in outside activities ranged from 9 to 40 hours a week. Income ranged from €17 to €335.75 per week of those who were earning a salary. Of three people employed independently, two were permanent and one was temporary.

19 (79.16%) had some kind of educational qualification. 3(12.5%) were educated to degree level, 13 (54.16%) to cert level and 3(12.5%) to diploma level. 7 (29.16%) had attended third level institutions, a further 7 (29.16%) had attended technical/ vocational colleges and 3 (12.5%) had attended community courses.

14(58%) cited the disability allowance as their main source of income.

The average age at first hospitalisation was 23 yrs. The average time spent in the RRP was 6.5 yrs and the average number of self-reported readmissions to hospital since being admitted to the RRP was 2. The lowest rate of self reported readmission to hospital was in medium support with the rate of re-admission from medium support being one third that of high support and a quarter of that of low support.

Table 1.

	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		F ratio	P value
					Lower Bound	Upper Bound		
firsthosp 1.00	11	21.09	4.989	1.504	17.74	24.44	1.104	.352
2.00	4	24.35	3.594	1.797	18.53	29.97		
3.00	7	25.57	9.199	3.477	17.06	34.08		
Total	22	23.09	6.502	1.386	20.21	25.97		
timerrp 1.00	11	6.21	6.322	1.906	1.96	10.46	.444	.648
2.00	5	5.20	3.701	1.655	.60	9.80		
3.00	7	7.86	2.795	1.056	5.27	10.44		
Total	23	6.49	4.878	1.017	4.38	8.60		
readhosp 1.00	11	2.55	3.205	.966	.39	4.70	1.136	.341
2.00	5	.60	.894	.400	-.51	1.71		
3.00	7	1.86	1.215	.459	.73	2.98		
Total	23	1.91	2.410	.503	.87	2.96		

firsthosp = first hospitalization; timerrp = length of years in RRP; readhosp = number of readmissions to hospital while in the RRP

Qualitative Questionnaire

Four qualitative questions were asked. The first question asked respondents **what were the reasons for their referral to the RRP.** Overall six out of twenty four people cited diagnostic criteria alone for their admission to the RRP such as anxiety/depression and schizophrenia. Two others used more general terms such as "*I have an illness*" or "*mental health*". The majority of the above eight were in the High support component. Seven reported that they were in the RRP in order to live independently/learn new skills. All but one of these seven was in Med/Low support. Three cited accommodation needs as being their main reason for admittance to the RRP. Two of these respondents were in the high support component. Three others cited conflict with family or inability to function alone. Three did not answer.

The second question asked **what are your expectations of your time in the RRP?**
In answering this question, the majority of respondents reported that they expected a supportive and stable environment from which they could gain the confidence to live independently. One respondent wrote; "*to build up my self confidence as I learn to cope again in the 'real' world – every day you take a step forward and sometimes it can be two backwards. Taking responsibility for oneself and living with the consequences of your actions, something one has to learn again. Living in a group home, one has to learn to live and let live.*" Another wrote, *"my chief expectations are time and support. Time to readjust to life outside and the support to enable me do that."* Another, *"to be mentally strong enough to live independently and practically".*

The third question was: **What are the most satisfactory aspects of your time in the RRP?** Again many focused on the learning of new skills and the availability of staff support, while some were very appreciative of the material comforts available such as regular meals, the provision of washing machines/dryers, and the economical advantages. The majority of those who cited practical/ material concerns were those in the high support component. One person in the low support component wrote;

"being challenged to 'go for it' - feeling at home with my housemates – a sense of belonging which does not exist to the same extent in the high support hostels – a real sense of independence and being able to use my own initiative". Another from medium support wrote; *"social rehabilitation, independence, budgetary management, access to training. Personal freedom, self reliance, tolerance, increasing maturity and assertiveness"* another from medium support – *"The RRP allows me to have time to think and this to me is very important. but I think there should be more intervention from the staff, attitude reconstruction, personal development"* etc. Another from medium support wrote: *"My experience of the service has in general been very positive. I have felt supported, well cared for, and have benefited from living with others in my position. The environment is one of healing."*

The fourth question was: **What are the least satisfactory aspects of your time in the RRP?** This was the least answered question of the four qualitative questions, with seven people not answering. Five people cited problems in their relations with staff. Two referred to confrontations they had had with individual staff members and others gave more general comments such as *"too strict – the staff are"* and *"sometimes I don't think that staff understand how ill I feel". Or "staff have too much control." One person said: "Institutionalisation – even the medium support is so regimented, one loses the ability to make any decisions – totally reliant on the staff. Resentment that a well educated person can be treated in the same manner as others less intelligent, taking no account of the person's age or life experience and a perceived level of patronisation."* Environmental concerns ranged from an uncomfortable bed to smoke and dirty surroundings to irritation with other clients. One person answered *"medication".*

Measuring Psychosocial Rehabilitation Outcomes (MPRO)

The results showed that across the three levels of support, clients' perception of **subjective quality of life** was similar when analysed using the Oneway Analysis of Variance (ANOVA). Those in medium support were more consistent with each other and scored higher than the other groups on this variable than those in high or low support, with those in low support being less sure of things.

Table 2.

	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		F ratio	P Value
					Lower Bound	Upper Bound		
SQOL 1.00	12	2.852	.5246	.1514	2.518	3.185	.874	.432
2.00	5	3.200	.3742	.1673	2.735	3.665		
3.00	7	2.743	.8384	.3169	1.967	3.518		
Total	24	2.893	.6063	.1238	2.636	3.149		
EMP 1.00	12	2.97	.584	.168	2.60	3.34	.523	.601

2.00	5	3.24	.410	.183	2.73	3.75		
3.00	7	3.03	.390	.148	2.67	3.39		
Total	24	3.04	.493	.101	2.83	3.25		
MAST 1.00	12	2.813	.6238	.1801	2.416	3.209	1.121	.345
2.00	5	3.040	.5550	.2482	2.351	3.729		
3.00	7	2.514	.6309	.2385	1.931	3.098		
Total	24	2.773	.6166	.1259	2.513	3.033		

Oneway ANOVA – Subjective Quality of Life (SQOL), Empowerment (EMP), Mastery (MAST), Program (PROG)
Level of Support – 1.00 = High Support, 2.00 = Medium Support, 3.00 = Low Support

On **empowerment,** although not statistically significant, it is worth mentioning that those in medium support scored noticeably higher on this variable. It is also important to mention that there was a less than 50% response rate (33%) from those in medium support, which suggests a possible difference between those who responded and those who did not and may explain this increased level.

Scores on **mastery**, although again not statistically significant, were higher for those in medium support. The overall score for this variable was the lowest of the four variables.

When it came to **programme satisfaction,** there was a statistically significant lower evaluation from those in high support than from those in the other levels whose evaluations were the same. Those in medium and low support had similar levels of satisfaction with the programme.

There were positive correlations between **subjective quality of life** and **empowerment,** between **empowerment** and **mastery,** and between **programme satisfaction** and **empowerment**, which was the strongest correlation. All of the above were moderate to high positive correlations at p= 0.01 significance. There was a low positive correlation between **programme satisfaction** and **subjective quality of life.**

Table 3.

	SQOL	EMP	MAST	PROG
SQOL Pearson Correlation	1	.668**	.307	.440*
Sig. (2 Tailed)	.	.000	.145	.032
N	24	24	24	24
EMP Pearson Correlation	.668**	1	.594**	.681**
Sig. (2 Tailed)	.000	.	.002	.000
N	24	24	24	24
MAST Pearson	.307	.594**	1	.310

Correlation				
Sig. (2 Tailed)	.145	.002	.	.141
N	24	24	24	24
PROG Pearson Correlation	.440*	.681**	.310	1
Sig. (2 Tailed)	.032	.000	.141	.
N	24	24	24	24

**. Correlation is significant at the 0.01 level (2-tailed)
*. Correlation is significant at the 0.05 level (2-tailed)

Discussion

In general, it would appear that the RRP is achieving much of what it sets out to do, and that it is evaluated quite highly by those who have participated in this study.

Although the response rate of 48% was fairly typical of such studies, it leaves a large portion of those residing in the programme that did not respond. This may be due to the fact that many residents would simply find it difficult to concentrate on such a task as filling out a questionnaire. Many of those who did respond informally indicated to staff their satisfaction at the opportunity to express themselves, however one or two wanted to satisfy themselves as to the anonymity of the project before participating.

The majority (92%) of respondents are single. Many would have come straight to the Cluain Mhuire RRP from their family homes. As the average age of first hospitalisation fell between 20 to 25 for all respondents, it may be assumed that their illness has disrupted the formation of long term relationships for many.

A large number of respondents (33%) are attending a sheltered workshop provided by the service of the with 12.5% employed outside of the St. John of God Services. This may indicate a reliance on the agency to provide long-term daily activities. This result may pose a question as to why such a number are not accessing jobs in the community? It may be that they are just not well enough or they are not accessing a job coach/placement supervisor. Perhaps we need to be accessing more employers who are capable of providing a supportive and independent work environment for programme participants. An approach such as this - where there is an opportunity for people to try out work related skills in a safe and independent environment – would have greater overall economic and societal benefits. With 66% of participants having been previously employed it is obvious that their illnesses have been disruptive and seem to be the main reason for inability to re enter the work force. Is there anything more we as a service could be doing? It is of course an inappropriate and sometimes unrealistic goal for some to contemplate unsupported employment and economic independence. Of those who responded that they were employed outside of the St. John of God Services (12.5%), it is unclear if they accessed these jobs alone or with the help of the service.

It would appear that the overall policy of the RRP, that of imparting independence skills to residents in order to achieve optimum self-reliance and appropriate movement through the programme, is effective. This is evident in the responses elicited from the first qualitative question: **what are your reasons for referral to the RRP?** Those in high support tended to be more concrete in their answers, such as citing their illnesses alone as the reason for their admittance. Generally, it appears that those in medium and low support were more likely to be future orientated and focussed on eventual independent living and to cite this as their reason for referral. The emphasis for these people was not their illness but their coping skills.

The overall high scores related to programme satisfaction suggests that most respondents believe that their expectations of the programme are being met and are thus satisfied with the services they receive. However the significantly lower programme satisfaction from those in high support is interesting. This may be a reflection of what individuals expect of themselves when they are first admitted to the RRP, as high support would usually be their introduction to the programme. Individuals at Oropesa may have a notion of having skills deficits and their self-confidence and self-esteem may be negatively affected by this self-perception. As part of their individual programme plans they would be given goals and objectives. If they do not achieve these goals, this could reflect on their evaluation of the programme as a whole. Their responses overall were more concrete with regard to their reasons for being on the programme, and most viewed their satisfaction with the programme in terms of material and economic concerns. Those in medium and low support described their satisfaction and expectations of the programme in terms of their relations with, and support from, staff and the skills they are acquiring. Generally, there is an obvious trend of people gaining more of an understanding of the role of the RRP for them as they move through. This finding is consistent with our hypothesis that the *Residential Rehabilitation Programme benefits the participant in terms of quality of care, employment, empowerment and independence. The benefits of the programme are related to progressive movement through the Residential Rehabilitation Programme.*

It is interesting to note that participants in Oropesa (high support) scored lowest on **programme satisfaction**, and on **empowerment**, yet rated much the same as residents of Avila (medium support) and the low support homes on **subjective quality of life**. So, being less satisfied with the programme and feeling less empowered than those in other components does not seem to have affected the evaluation of subjective quality of life for those in high support despite the overall positive correlations as outlined above. In addition to scoring lower on these variables, those in high support as already mentioned above, were more inclined to view their placement in concrete terms, seeing the programme as a place of refuge with material and economic benefits. However as people progress through the programme they are less likely to view their placement in those terms and evaluate the programme more highly in addition to feeling more empowered.

Overall, the lowest score for all respondents was for **mastery** - the individuals' beliefs around ability to control and influence one's own life. This implies that although people are satisfied with the programme and understand the objectives of the programme, they feel less confident about going out and interacting with the wider world. This would suggest that a focused approach on building confidence and self-esteem may be worthwhile. An increased focus on helping participants to acquire skills, other than domestic management skills, such as interview skills and knowledge of basic rights and resources in relation to statutory bodies may also have an important effect on scores of mastery. Perhaps workshops on self esteem or anxiety management aimed specifically at users of this programme would be beneficial in helping those who make the transition through the programme to maintain their progress. This could ensure that there is an emphasis on the value of progress and psychological change, rather than solely on movement and the acquisition of skills.

An overall trend that emerges is that there is a greater consistency and higher scores in medium support. Once again it is worth bearing in mind that the level of response (33%) from medium support could skew results. It may appear that there are two distinct levels of functioning in medium support, if level of functioning is a factor in the response rate. Perhaps this greater consistency and higher scores indicate a need for further investigation as to the reasons behind such a marked difference in scores across the groups. The higher scores within the medium support respondents would also be borne out by the significantly lower rate of readmission to hospital of this group – measuring at one third of the rate for low support and one quarter of the rate of high support (see Table 1).

In comparison to the results here, a Canadian review of the MPRO using factor analysis suggested the two concepts of mastery and empowerment were less conceptually distinct than first thought, resulting in a questionnaire based on three factors: programme satisfaction, quality of life and mastery. In addition, empowerment seemed to be related to programme satisfaction. The Canadian study also said that some items developed to measure empowerment appeared to be measuring programme satisfaction. Programme satisfaction and empowerment were the most strongly correlated in our study. So it may be that feelings of empowerment are related to the programme and not necessarily to their lives in general, as supported by the low mastery scores.

In conclusion, the Cluain Mhuire Residential Rehabilitation Programme was rated highly by all participants with those in medium support scoring the highest and most consistently across the variables. Although the response rate was lower for this group, the scores suggest different levels of functioning in the medium support setting. The overall lower scores in mastery for all three levels of support may be a result of too much emphasis on movement rather than confidence building and psychological change. Further investigation may give a clearer picture of whether medium support differs in a significant way that could inevitably benefit those in high and low support. Suggestions for further areas of study include: a detailed initial assessment of self-esteem and anxiety levels for individuals being admitted to the Cluain Mhuire Residential Rehabilitation Programme and specifically designed workshops on self-esteem and coping with anxiety that are specially tailored for RRP participants. Many of the Cluain Mhuire Service Users who attend workshops such as the above are functioning at a higher level in terms of social skills, independence and self-esteem in comparison with the RRP participants. In addition, administering the MPRO at follow up intervals may yield interesting results when compared with programme change and enhancement.

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The International Journal of Psychosocial Rehabilitation
Volume 9, Number 1
July 2004– June 2005

Quality of Life of People with Long-Term Psychiatric Illness Living in Residential Home

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Citation:
Young, KW. (2004). Quality of Life of People with Long-Term Psychiatric Illness Living in a Residential Home. **International Journal of Psychosocial Rehabilitation. 9**, 133-145.

Key words: Quality of Life, Residential care, Mental Illness

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Abstract

This study aims at exploring the impact of residential home on the quality of life of people with long-term mental illness after their discharge from mental hospitals. Research sample included 88 subjects, coming from mental hospitals and a large residential home in Hong Kong. This research adopted a combined research methodology and QoL data were obtained from both quantitative and qualitative analysis. Results showed that residential home residents had better QoL, including overall life satisfaction, than that of hospital in-patients. In sum, this study demonstrates that residential care could lead to a better QoL for people with long-term psychiatric illness.

Introduction

People with long-term psychiatric illness are so disabled and impaired that they are difficult to be placed in the community [1]. In the past few decades, several models of community care program for these people have been developed in the Western countries, especially in United Kingdom and United State, including: staffed community house [2], hospital hostels [3-4], "Training in community living" model [5] and fostering care homes [6]. However, these community care models are not widely developed in the community. In fact, the majority of people with long-term psychiatric illness live in rather different settings such as hostels and residential homes.

In the past, residential homes, such as nursing homes, hostels as well as board and care homes are often being criticized as “institutional like” and becoming another kind of “asylum” in the community [7-8]. In fact, institutional care does not depend on the type of residence nor residents’ mental state, but on the care giver’s management [9]. So not all residential services should be identified as “institution” as characterized by Knuze and Lamb [7-8]. Research studies often report different or even contradictory results in this area. For example, In U.S.A., Linn et al. [10], in a randomized control study on nursing home care for people with long-term psychiatric illness, reported that nursing home residents deteriorated significantly in self-care, behavioral problems, mental confusion, and depression. However, Timko et al. [11], in another randomized control study of nursing home care, reported that, as compared with the hospital in-patients, nursing home residents had better choice, control in policies, more social and recreational activities while their subjective life satisfactions remained positive and unchanged. Similarly, in Australia, Burdekin [12]described hostels and boarding houses as the "new institutions", while Horan et al. [13] reported that residents of hostels and boarding houses were satisfied with their quality of life although they had negligible participation in daily activities, few family contacts and limited finances. So whether or not residential care has positive impacts on the life conditions of people with long-term psychiatric illness remained unanswered. Moreover, Thronicroft et al. [14] have pointed out that the success of some community care programs may not be generalized to elsewhere due to a lot of reasons including cultural difference, and suggested the importance of exploring local experience of implementing community care programs.

In Hong Kong, the government has adopted a policy of community care since 1970s [15]. However, after the incident of severe violent act of a psychotic outpatient on a public estate in 1982, there was a strong "Anti-half way house movement" among local community residents who showed low acceptance towards people with mental illness [16]. Since then, due to the strong community opposition, the progress of the development of community-based rehabilitation services was largely limited. On the other hand, in order to protect people with psychiatric illness from social stigmatization, community-based supportive services have become segregated and tended to be confined in large and institution-like [16]. In 1990s, several large residential homes, named long stay care home (below referred as LSCH), with each LSCH has about two hundred beds, have been established to support people with long-term psychiatric illness living in the community. Despite the Hong Kong Government's keen interest in expanding this kind of residential home rapidly, it is important to ensure that the life conditions of its residents are well maintained or even get improvement in the community. This study attempts to explore the impact of residential home on the quality of life of people with long-term mental illness after they have discharged from mental hospitals and lived in the community.

In evaluating community care program, quality of life (below referred as QoL) is increasingly identified as a key outcome for evaluating community mental health services [17]. However, there is a disagreement on how quality of life should be defined [18]. The lack of agreement on its definition is due to a number of reasons [19]. In this study, quality of life is defined as individual's subjective feeling of overall life satisfaction, as determined by the mentally alert individual whose life is being evaluated.

Aims and research hypothesizes

The aim of this research study is to explore the QoL of people with long-term psychiatric illness after their discharge from mental hospitals and live in residential home (i.e. LSCH) in Hong King context.

The research hypothesis is that people with long-term psychiatric illness would have a better QoL after they have discharged from hospital to LSCH.

Research Design

Settings

In this study, two groups of people with long-term psychiatric illness were included in the studied sample. One studied group came from a newly built LSCH with two hundreds beds which has been opened in 1996 in Hong Kong. Four to five residents lived in the same bedroom. It had a large occupational unit. Various kinds of professional and non-professional staff had been employed to provide 24-hour personal care services for its residents. Staff to resident ratio was about 1:3. .

Another studied group came from two traditional large mental hospitals in Hong Kong, which have been built in 1970s and 1980s respectively.

Studied Sample

As the research objective is to examine the QoL of people with long-term psychiatric illness after their discharge from mental hospitals, the studied subjects were restricted to those who were discharged from mental hospitals and admitted into LSCH. So only those LSCH residents, who were being assessed by registered psychiatric nurses and the author as mentally stable, had suitable cognitive and communicative skills for interview, had discharged from mental hospitals and then lived at LSCH for more than one year, were eligible for being selected and invited to join in the research project. Finally 45 residents had given their written consent and were interviewed by the author successfully. This group of people constituted the experimental group (below referred as LSCH group).

Similarly, those hospital in-patients, who were identified by the hospital psychiatrists as suitable and ready for discharge into LSCH; assessed by hospital psychiatric nurses and the author as mentally stable, had appropriate cognitive and communicative skills for interview, were eligible for being selected and invited to join in the research project. Finally 43 hospital in-patients had given their written consent and were interviewed by the author successfully. This group of people constituted the control group (below referred as hospital group).

This study adopted a quasi-experiment research design, and the QoL of the experimental as well as the control group were compared. The QoL data of both studied groups were collected between April, 96 and December, 1997.

Data Collection

A) Quantitative Analysis

Quality of Life Interview

Lehman’s Quality of Life Interview [20] is adopted and modified in this study. The reliability and validity of the scale are well established [20-21] and the scale has been widely used. In this study, there is no modification in the sub-scales of overall life satisfaction and subjective QoL in various life domains. The only modification is the modification of the objective QoL indicators of living environment so as to suit the special living environment in mental hospitals and residential setting in Hong Kong. In these settings, all basic facilities such as bed, food, electricity, air-conditioning, water-heater, etc, are provided by the residential home and mental hospitals with good conditions.. Thus the availability of these facilities is not respondents’ concern. Rather whether or not these living places are crowded and too restrictive are their main concerns. So items measuring the crowdedness and restriction were included in the objective QoL indicators of living environment. The scale has 56 items, and contains objective QoL indicators, subjective QoL indicators as well as overall life satisfaction.

In this study, the reliabilities of the subscales of the Quality of Life scale, as measured by means of internal consistency Cronbach’s alpha, are found to rank from 0.62 to 0.93. It shows that the reliabilities of these subscales have reached acceptable levels for statistical analyses purpose, and are comparable to that of original Quality of Life Interview [20].

B) Qualitative Interview

In addition to the above quantitative data, some qualitative data are also collected to supplement the quantitative QoL data. Eight respondents were randomly selected from a group of people who had appropriate communicative skills and going to be discharged to LSCH from mental hospitals. These people were followed up for more than one year before and after they had discharged from mental hospitals. Sixteen semi-structured individual interviews were carried out for these eight persons. Eight interviews were carried out when respondents still lived in mental hospital several months before their discharge, while another eight interviews were carried out when they had lived in LSCH for about one year. The conversations of these sixteen interviews were tape-recorded and transcribed. The content of these scripts were then coded and analyzed.

In this study, qualitative data obtaining through semi-structural interview served two main functions. Firstly, qualitative QoL data could complement the quantitative QoL data obtained from the measuring scale so as to increases the understanding about respondents' life situations in both mental hospitals and LSCH settings. Secondly, qualitative QoL data was used to cross check the QoL data found by the quantitative analysis, and seek for convergence of research results. To achieve these purposes, during qualitative interview, respondents were asked some open-end questions including: respondents' own evaluation of their overall life conditions at current living places; comparing their overall life conditions between long stay care home and mental hospitals; describing those life domains they concerned; describing whether they were satisfied or dis-satisfied with various life domains; and the reasons why they were satisfied or not satisfied in that life domain.

Characteristics of the research sample

Below describes the characteristics of the studied sample: LSCH group (n=45) and hospital group (n=43). Results showed that these two groups of respondents did not differ in almost all demographic factors, except in sex ratio. The Hospital group was predominately male while LSCH group was predominated female.

Table 1 Demographic characteristic of the samples.

	Hospital group (N =43)	**LSCH group (N=45)**	**Test**	**significance**
Gender (%male)	72	38	Chi-square	.001*
Age (mean year)	48	49	Student t-test	.701
Education % none % primary school % secondary school % higher education	 10 52 34 5	 11 56 27 6	Chi-square	.864
Marital status (% single, divorced or widow)	83	87	Chi-square	.562
Religion (% none)	69	71	Chi-square	.053
Financial Situation % rely on governmental assistance	93	91	Chi-square	.740
Diagnosis (% schizophrenic)	91	91	Chi-square	.946
Period of Illness (mean year)	19	21	Student t-test	.348

Number of hospitalizations (mean)	5	5	Student t-test	.755
Period of latest Hospital stay (mean year)	6	8	Student t-test	.158

* <.01 **<.05

Overall, the people with long-term psychiatric illness were predominately male, schizophrenic and single. All of them were under 65 years of age (mean 48-49 years). Most of them had reached primary school level or above, and did not have any religious affiliation. Just over half of them have at least one physical illness. Almost all of them suffered from schizophrenia. Their illnesses were so chronic that most of them had been ill for more than 20 years. One half of patients had a latest continuous hospital stay for 1-4 year, while the other half 5 year and more. Most were single or divorced, and had few contacts with their families. They did not have any friends outside the hospitals and LSCH. Most of them were lack of employable skills and attended some forms of vocational training. Almost all of them had to rely on governmental social security schemes to support their lives.

Research Results

As quality of life is a multi-dimensional concept, three kinds of quality of life indicators, including: traditional indicators, objective quality of life indicators and the subjective quality of life indicators, are used in this study in order to get a holistic picture about the life conditions of the studied subjects.

A) Quantitative Analysis

Traditional Indicators

Basic information on the numbers of suicides, deaths, homeless patients, number of patients being charged for criminal offences and number of hospital re-admission rate between 1-4-96 and 31-12-97 were collected and supplied by the superintendent of the LSCH.

During the 21 months period, none committed suicide, 2 out of 204 LSCH residents died because of physical illness (producing a mortality rate of 0.56% annually), none of them became homelessness, and none was arrested. In addition, 21 out of 204 LSCH residents had been re-admitted to hospital at least once during the 21 months period, producing a hospital re-admission rate of 10.3% annually.

Objective Quality of life Indicators

Table 2 Objective quality of life indicators of the studied groups

Objective QoL (Mean Score)	Hospital gp (N=43)	LSCH gp (N=45)	Student t-test Significance (2-tailed)
Living Situation (Score between 1-4, with 1 have the best outcome)	1.9	1.9	.971
Daily Activities & Functioning (Score between 0-1, with 1 have the best outcome)	0.6	0.8	.000 *
Family	4.1	3.8	.726

(Score between 1-5, with 1 have the best outcome)			
Social Relationship (Score between 1-5, with 1 have the best outcome)	3.9	3.4	.056
Finance (Score between 0-1, with 1 the best outcome)	0.8	0.9	.415
Health (Score between 1-5, with 1 have the best outcome)	2.5	2.3	.271

* significance <.01 ** significance <.05

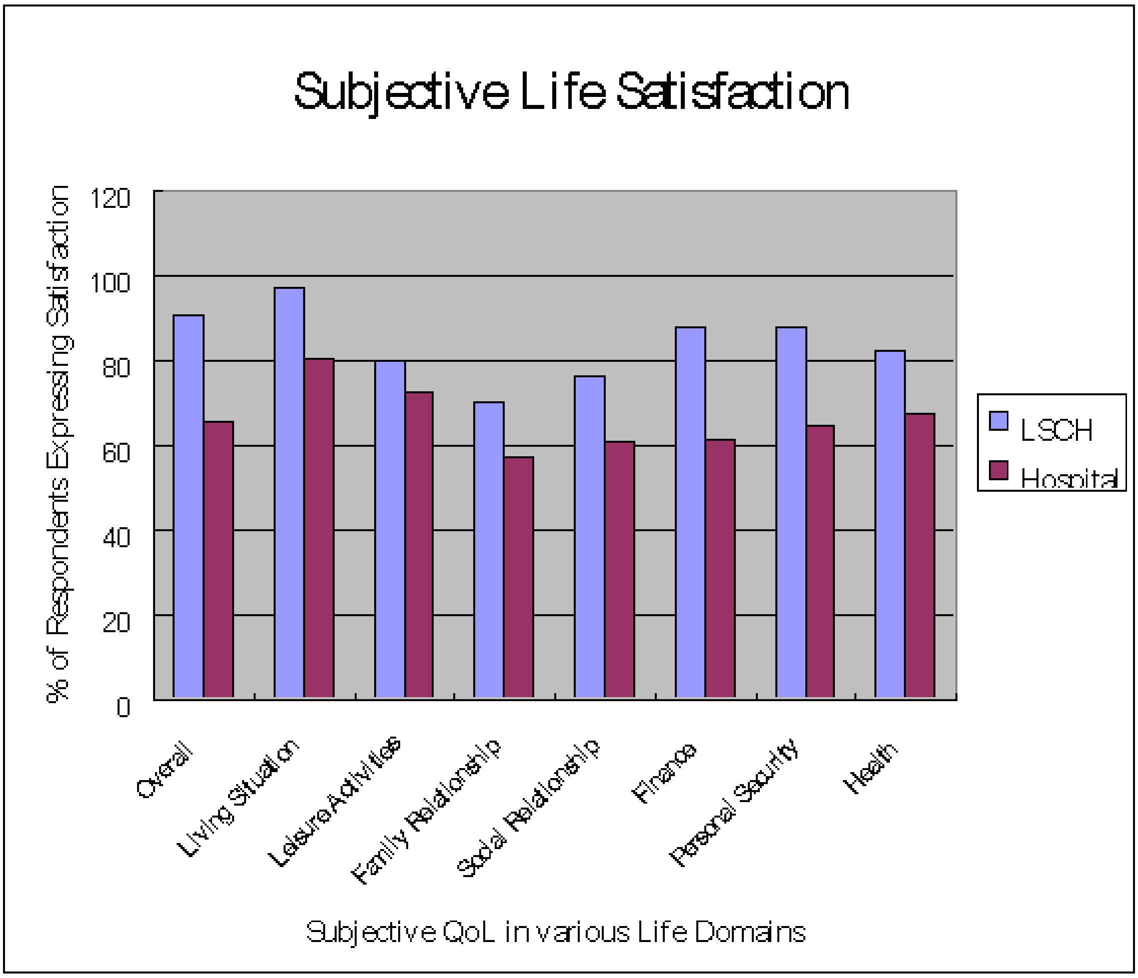
When comparing the objective QoL of LSCH group with that of hospital group, the following findings were found (data please refer to Table 2):

> LSCH group had better objective QoL in daily activities & functioning (t-test =-4.221, d.f. =86, p<.000). As compared with hospital group, LSCH group used public transportation, went out for tea and shopping more frequently.
>
> LSCH group and hospital group did not differ in objective QoL in many life domains including: living environment, family relationships, social relationship, financial situation and personal safety etc.

Subjective Quality of Life

Both LSCH and Hospital group regarded most of their life domains as average to satisfactory, and more than two thirds of these two studied groups expressed satisfaction in each life domains. In particular, they were most satisfied with living situation, while least satisfied with family and social relationships (please refer to Figure 1 for reference).

Figure 1 Subjective Life Satisfaction



When comparing the subjective QoL of LSCH and hospital group, the following findings were found (data please refer to Table 3 for reference):

> LSCH group were more satisfied with their overall life satisfaction (t-test=-2.756, d.f.=86, p=.007<.01), personal safety (t-test=-2.842, d.f.=86, p=.006<.01) and health (t-test=-3.046, d.f.=86, p=.003<.01) as compared with that of hospital group.
> LSCH and hospital group were equally satisfied in most life domains, including: living situation, daily activities and functioning, family relationships, social relationship, and financial situation.

Table 3 Subjective Life Satisfaction of LSCH and hospital group

Subjective QoL in various life domains (Score between 1-7 with 7 means most satisfactory)	Hospital gp (N=43)	LSCH gp (N=45)	Student t-test Significance (2-tailed)
Average subjective satisfaction in living condition	5.442 (3.365)	5.417 (0.867)	.961
Average satisfaction in leisure	5.070 (1.442)	5.389 (1.027)	.233
Average satisfaction in family relationship	4.756 (1.894)	5.000 (1.739)	.530
Average satisfaction in social relationship	4.767 (1.315)	5.506 (1.226)	.291
Average satisfaction in financial situation	4.616 (1.683)	5.133 (1.375)	.117
Average satisfaction in personal safety	4.733 (1.841)	5.489 (0.997)	.006*
Average satisfaction in health condition	4.458 (1.461)	5.344 (0.910)	.003*
Global Subjective QoL	4.791 (1.604)	5.567 (0.975)	.008*

* significance < .01   * *significance < .05   ( )—standard deviation

B) Qualitative Analysis

Data from qualitative interview also showed that most respondents were more satisfied with their lives at LSCH than at hospital. Below were some respondents' accounts for their overall lives at LSCH as compared with that at hospital. Due to confidentiality, the names of the respondents and hospitals have changed to other labels.

Better Overall Life

> "*Long stay care home is better than hospital because here provide better meal and more activities. Also residents here are better than hospital*" (Ah Wing).

> "*Long stay care home is better than hospital…When I lived at hospital, I did not have any money. Also I was not allowed to go out of hospital. I felt boring at hospital. Here, I have more freedom and can go out to have food and tea…After finishing I can have bath and then go to sleep whenever I want to*" (Ah Fai).
>
> "*I prefer to live at long stay care home. It has better living environment and more entertainment. The patients here are better. The staff here is better*" (Ah Fun).
>
> "*Here (LSCH) is better than Hospital B. It has a better living environment, better entertainment, better staff, better work environment, better personal safety, ….Living here, I can have a better health…… Here offer me more freedom*" (Ah Ngan).
>
> "*Last year, I have $100 per week. Now (at LSCH) I can have $200 per week. Now I have enough money to spend ... Here (LSCH) is good! It is better than Hospital A. Living here, my pocket money is being controlled. Apart from it, everything seems alright*" (Ah Chong).
>
> "*When comparing my life here with that at Hospital B, they are the same.…Both places are good. These two places have their own advantages and disadvantages. It was more convenient to see the doctor at hospital. Also if there is any problem, staff will take action quickly….Here (LSCH), I can enjoy more freedom. I can put on my own clothes. Also O.T. is not a hard job for me*" (Ah Too).
>
> "*Both settings are good. At hospital, I was allowed to walk around the garden. Here, I can go out (to nearby community) on Saturday and Sunday. However, here I am required to pack my own belongs all the time, and clean the floor, etc. These are difficult tasks. At hospital, I did not need to do any cleaning*" (Ah Chung).

On the other hand, data from qualitative interview also showed that respondents appreciated some life domains at LSCH including : residents behaving more properly, better staff attitude; and less restriction and more freedom, which were not reflected in the quantitative analysis. Below are some of the respondents' personal accounts:

Residents behaved more properly at LSCH

> *"Hospital residents had complex social background. They always had quarrel, fighting and gambling. They also stole money and things from others…LSCH has better residents…. Here (LSCH), we don't have any fighting,...If resident do something wrong, that resident will be sent back to hospital…They seldom have any conflict" (Ah Chong);*
>
> *"Here (LSCH), residents are better…….No one take advantages from me. No one ask me to give them money and cigarettes. No one steal my belongings…. It was difficult to get along with other patients of Hospital A…. These patients liked gambling, smoking, taking advantages from others" (Ah Wing).*
>
> *"Other patients are quite nice. They do not blame at me nor punch me…. No patients take advantage on me…. I like them" (Ah Too).*

Better Staff Attitude

> *"Staff of LSCH is better. …They offer assistance such as escorting client to go out, buying things for us, and drawing money from the bank etc. Also they are more polite... Hospital patients were being shouted at, punched, restrained, given injection by staff. The staff of LSCH does not shout at residents" (Ah Chong).*
>
> *"Here (LSCH), staff treats me good. When I lost temper, they do not restrain me. Rather they just ignore me and let me clam down. Moreover, they listened to my unhappiness, which make me feel better" (Ah Chung).*
>
> *"Staff here is better than hospital staff. They offer me help. For example, before going to picnic, they remind me whether I have got enough money. Also when I am sick, they show concern to me. Also they give*

> *me encouragement and support. They praise me whenever I have good performance in doing household duties, and in my work" (Ah Ngan).*

Less Restriction and More Freedom at LSCH

> *"To me, restriction is loose (at LSCH). However, restriction is tight for others… The management of daily routine of Hospital A was more strict than here (LSCH). For example, the bathing time is more flexible here…Also, I can go out to have tea and shopping from 4:30pm to 5:30pm from Monday to Friday, and from 8:30 am to 5:30 pm on Saturday and Sunday….. LSCH provides more freedom." (Ah Wing).*
>
> *"Other than going out, I can have freedom here…. the management of daily routine is not strict here (LSCH)" (Ah Too).*
>
> *"I have more freedom here (LSCH)…. I don't think the management is strict here. Some resident refuse to have bath, or refuse to do O.T.. Staff just let them and do not punish them" (Ah Fai).*
>
> *"The management of basic routine is quite strict here (LSCH). Anyway Hospital B is more strict in the basic routine….. There is no restriction about the bathing time, but the water heater is opened between 5:00 p.m. to 9:30 p.m." (Ah Ngan).*
>
> *When I lived at hospital, I was allowed to go out once a month under the permission of my doctor… Here (LSCH), I am allowed to go out twice weekly, usually on Saturday and Sunday. So, at LSCH, I have more chance to go out" (Ah Ming).*

When comparing the QoL data from qualitative and quantitative analysis, data from qualitative interview supported the findings from quantitative analysis that: most LSCH residents viewed their overall life conditions as positive; and reported to have a better life at LSCH than that at mental hospitals. In addition, data from qualitative interview showed that LSCH residents appreciated and satisfied with some life domains at LSCH which were not identified in the quantitative analysis, including: other residents behaving more properly, better staff attitude, less restriction and more freedom.

Based on the above discussion, it is found that findings from both quantitative and qualitative analysis converged in a number of areas. This convergence supported the validity of finding that QoL at LSCH was better than that at mental hospitals. In sum, this research study demonstrated that LSCH yield a better quality of life by improving residents' overall life satisfaction, subjective QoL in health and personal safety, objective QoL in daily activities than that at mental hospital.

Discussion

Reflection on Methodology and Research Strategy

This study highlights the limitation in using of Quality of Life Interview scale to measure subjective QoL. It is found that this scale is not comprehensive enough and does not cover some QoL data mentioned and concerned by respondents during qualitative interview. These areas are: restrictions and freedom in daily routine, residents' behaviour, and staff attitude. On the other hand, data from qualitative interview is proven to provide valuable information complementing the data measured by Quality of Life Interview scale. Thus it would be useful to ask respondents some open-end questions including: respondents' own evaluation of their overall life conditions; comparing their overall life conditions between long stay care home and mental hospital; describing those life domains they concerned; describing whether they were satisfied or dis-satisfied with various life domains; and the reasons why they were satisfied or not satisfied in that life domain.

After acknowledging the limitation of Quality of Life Interview, it is recommended to use combined research methodology, i.e. the use of both qualitative and quantitative research methods in studying QoL. In this study, a combined research methodology, i.e. pre-eminence of the quantitative over qualitative research, is adopted and is shown to provide a more thorough picture about the QoL of respondents.

Residential Care is a Positive Choice

In the past few decades, there are a dualistic view of residential and community care---residential care is "bad" while community care is "good", which was regarded as an anti-residential care movement [25]. This anti-residential care bias was based on the influence of the "literature of dysfunction" in relation to residential care, which is both conceptually limited in its analysis and scientifically flawed in terms of methodology [25]. Research evidences tend to show that residential care has its own value and has numerous advantages [26]. So both residential service and other forms of community care facilities, such as family care, day care, etc, should be placed with equal weight of importance within an integrated network of community care system.

This research study has demonstrated that residential home care, as one kind of community care program, can lead to a better quality of life, including both subjective and objective quality of life for people with long-term psychiatric illness. This finding is supported by other research studies which have demonstrated that people with long-term psychiatric illness living a variety of community-based settings have positive and even better QoL after their discharge from mental hospitals [23, 24, 27-31]. Thus the research result in this study adds evidence to the fact that residential home care is a positive choice for its residents, as advocated by Wagner Report [32].

Conclusion

This research study has demonstrated that residential home care can lead to a better quality of life, including both subjective and objective quality of life for people with long-term psychiatric illness, and adds evidence to the fact that residential home care is an important component of the integrated network of community care system. The study is based on a quasi-experiment research strategy, so that the QoL of LSCH group was compared with that of hospital group which was acted as a control group. In future, a large-scale longitudinal study should be carried out in order to confirm the above research findings.

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The International Journal of Psychosocial Rehabilitation
Volume 9, Number 1
July 2004– June 2005

Burden of Caregivers of Mentally Ill Individuals in Israel: A Family Participatory Study

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Citation:
Rudnick, A R (2004). Burden of Caregivers of Mentally Ill Individuals in Israel: A Family Participatory Study. **International Journal of Psychosocial Rehabilitation. 9,** 147-152

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Acknowledgements
No conflict of interest nor financial support is involved in this study.
Many thanks are due to Otsma representatives Yochi Chibotero, Miri Dvir and Michal Gal, as well as to all the other Otsma family members who consulted on and participated in this study. Thanks are also due to Roni Dado-Harrari, MA, for assisting in data analyses.

Abstract

This study aimed at evaluating a caregiver burden questionnaire generated in collaboration with Israeli family members of mentally ill individuals, and assessed the burden of Israeli caregivers as well as its relation to their age, gender and kinship relationship to the mentally ill individual. 53 family members answered the questionnaire. Factor analysis was performed, as well as calculation of internal consistency and validity. Hypothesis testing included the Pearson correlation for association of caregiver age with burden, and the Mann-Whitney test for gender difference in burden. Association of caregiver burden with Kinship relationship could not be assessed as nearly all participants (94%) were parents of a mentally ill individual. The basic psychometric properties of the questionnaire were sound. Mean burden was moderate. Caregiver age was not associated with burden. Females were significantly more burdened than males. Further participatory study of caregiver burden is recommended. Mothers of mentally ill individuals may require particular assistance.

Key words: **Burden, Caregiver, Family, Mental illness, Participatory research**

Introduction

Care for severely mentally ill individuals, particularly in the community, may carry a heavy burden, more so than care for other disabled individuals such as mentally retarded people (1). While this is true for any person involved in such care, e.g., resulting in clinician burnout (2), it is particularly true for close family members such as parents, many of whom take care of their mentally ill children for long (3). Such burden manifests in reduced caregiver well-being (4), which admittedly depends in part on caregiver factors such as caregiving style (5). Moreover, such burden may manifest in reduced well-being of the mentally ill individuals themselves, e.g., due to impaired caregiver support (6).

Hence, caregiver burden, particularly that of closely involved family members such as parents, is important as an outcome measure in mental health care, so as to assess and reduce it for the well-being of both caregivers and the mentally ill. Indeed, the measurement of caregiver burden has been shown to enhance worker and administrator awareness of the need to reduce such burden in the health care field in general (7). This may be particularly important where reform is in the making, with a shift to the community, such as has been happening lately world-wide in the field of mental health care (8). This is so because with the shift to the community, caregivers such as families naturally take on a more central role. While the USA has only recently declared a need for additional reform in mental health care, particularly within the community (9), smaller localities have already moved ahead (10).

In 2000, Israel legislated the provision of psychiatric rehabilitation in the community, part of which is the support of caregiving families; yet adequate resources for such family support have not been provided. Furthermore, study of family burden in the mental health field is scant in Israel, although such study is central for rational service planning. In particular, there has been no use in Israel of a collaborative - participatory - framework, although such an approach could be helpful in that it addresses the concerns of the particular subjects being studied and hence is context-sensitive to socio-economic, cultural and personal conditions which differ across communities and individuals; admittedly, participatory study in this field has not commonly been attempted elsewhere (11).

The main purpose of this study is not necessarily to understand in-depth the burden of Israeli caregivers, nor to attempt to standardize a finalized tool to assess burden, but rather to explore the use of participatory research in the field of mental health care burden, so as to increase context-sensitivity. Thus, we wanted to develop, use and study a tool for measuring caregiver – mainly family – burden in collaboration with Israeli caregivers of mentally ill individuals, i.e., within a participatory research framework. In addition, we wanted to assess the extent and types of burden of Israeli family members of mentally ill individuals, and to examine the relation of such family burden to basic demographics.

We wanted to answer the following questions:

(a) What are the basic psychometric properties of a participatory research- generated questionnaire for measuring caregiver burden in the mental health care field?

(b) What is the burden of Israeli caregivers, i.e., family members, of mentally ill individuals, and how is it related to caregiver age, gender and kinship relationship to the mentally ill individual in care?

Method

During October to December of 2003, 53 family members (45, i.e., 85%, females; 7, i.e., 13%, males; and 1, i.e., 2%, unmarked gender) from the Israeli Forum of Families of Mental Health Clients (Otsma) anonymously answered at one point in time a caregiver burden questionnaire, as well as demographic questions of age, gender, race and kinship relation to the mentally ill individual in their care. No participants were related to each other, and all provided informed consent after receiving verbal and written information on the study.

During the first half of 2003 the principal investigator (AR) collaborated with 3 elected representatives of Otsma, who consulted with other Otsma members, to generate a caregiver burden self-report questionnaire. Questions were suggested by the principal investigator and Otsma representatives, and these were conceptualized as belonging either to practical burden or to emotional burden, according to an established framework of practical vs. emotional needs, as utilized in health care in general and in mental health care in particular (12). All questions dealt with burden, as a preliminary suggestion that the questionnaire deal with the broader experience of caregiving as measured in other countries, including also caregiver positive experience and contribution of the mentally ill individual to the caregiver (13,14), was firmly rejected by Otsma representatives. They argued that the caregiver situation in Israel is still too grim to realistically expect such positives to exist (although there is research from Israel that demonstrates some – albeit modest – caregiver rewards (15)), and therefore that such unrealistic positively-oriented questions might offend the participants and perhaps reduce collaboration. After eliminating overlapping questions, the final version of the questionnaire consisted of 28 questions, of which the first 13 address practical burden, the next 13 address emotional burden, and the last 2 address total burden and burden in the last month relative to the last year; the question of whether the caregiver actually lives with the mentally ill individual was not included, as questions reflecting various aspects of caregiver contact were considered more informative and as it is suggested that co-residence in itself does not have a major impact on burden (16). All questions refer to the last month, and are rated on a 4-point ordinal scale, ranging from 1 (no) to 4 (very much). Each numerical answer can be supplemented by written comments detailing the specific burden involved (e.g., the nature of the physical effort involved); this will not be analyzed here, due to the relatively small sample of the current study.

Univariate analysis (mean and standard deviation) was conducted for each item of the burden scale, as well as for the mean of the whole scale and for age. Factor analysis was performed. The internal consistency of the scale was calculated as the Cronbach's alpha; in accordance with the literature, we considered a Cronbach's alpha of 0.70 or higher as satisfactory (17), and a Cronbach's alpha > 0.50 as acceptable (18).

Pearson correlations were used to assess the association between total burden (item 27) and last month's burden relative to the last year (item 28), as well as the association between either of these and the mean of the rest of the scale. Pearson correlations were also used to assess the association between caregiver age and burden. The Mann-Whitney test was used to assess gender difference in burden. Analysis of race was not conducted as all participants were Jewish (even though roughly 20% of the Israeli population is Arab, with at least as much serious mental illness as in the Jewish population). Assessment of difference in burden according to kinship relation was not conducted due to nearly all assessed caregivers being parents of the mentally ill person taken care of (50, i.e., 94%).

Results

The mean age of the caregivers was 58.8 with a standard deviation of 9.3 and a range of 40-78 (years). The means and standard deviations of all burden questionnaire items are displayed in Table 1. Item 26 was eliminated from further analysis as it was the only question not answered by at least a third of the participants (18, i.e., 35%).

Table 1. *Means and standard deviations of the caregiver burden questionnaire scores*

Item (all referring to burden due to caregiver role)*	Mean	**SD**
1. I invest time in my mentally ill family member (MIFM)	3.44	0.66

2. I spend money on my MIFM	3.52	0.69
3. I invest physical effort in caring for my MIFM	2.69	1.03
4. I am busy caring for my MIFM	3.21	0.94
5. I am ill due to caring for my MIFM	2.07	0.95
6. I am in danger due to caring for my MIFM	1.66	0.77
7. I lack privacy due to caring for my MIFM	2.53	1.02
8. I lose work time due to caring for my MIFM	1.98	0.99
9. My leisure activities are reduced due to caring for my MIFM	2.51	1.12
10. I lack rest due to caring for my MIFM	2.69	1.05
11. I lack company due to caring for my MIFM	2.71	1.08
12. My plans are inhibited due to caring for my MIFM	2.92	1.05
13. I lack assistance in caring for my MIFM	2.63	0.99
14. I cannot share with others my concerns regarding my MIFM	2.67	1.05
15. I am angry about the care of my MIFM	2.80	1.04
16. I am desperate, related to my MIFM	2.82	1.01
17. I am ashamed, related to my MIFM	2.12	1.14
18. I am sad, related to my MIFM	3.43	0.77
19. I am worried, related to my MIFM	3.72	0.60
20. I am humiliated, related to my MIFM	1.86	1.14
21. I am exhausted, related to my MIFM	3.06	0.97
22. I am frightened, related to my MIFM	3.31	0.89
23. I feel guilty, related to my MIFM	1.84	0.89
24. I feel exploited, related to the care of my MIFM	1.81	1.05
25. I feel misunderstood, related to my MIFM	2.08	0.95
27. I generally suffer from burden, related to my MIFM	3.09	0.87
28. I suffered such burden the last month relative to the last year	2.27	0.90
Mean score	2.65	0.47

* range of score – 1 = no, to 4 = very much

Factor analysis did not reveal coherent factors. Therefore the scale was treated as a whole. Cronbach's alpha for the whole burden scale (excluding item 26) was 0.88.

Validity was assessed by separately correlating the 2 general burden items – which were also tested for correlation with each other – with the mean of the rest of the scale. The correlation between total burden (item 27) and last month's burden relative to last year (item 28) was 0.40, $p = 0.003$. The correlation between item 27 and the mean of the rest of the scale (items 1 to 25) was 0.57, $p < 0.001$. There was no significant correlation between item 28 and the mean of items 1 to 25 ($r = 0.23$, $p = 0.100$).

Age was not significantly correlated with mean burden of items 1 to 25 ($r = -0.20$, $p = 0.170$). On the mean burden score (items 1 to 25), females scored significantly higher than males ($U = 83.5$, $p = 0.046$).

Discussion

Basic psychometric properties of this participatory research-generated questionnaire for measuring burden of caregivers of mentally ill individuals were sound. No coherent factors were found, and the internal consistency of the whole scale was high. Validity was acceptable. The general burden reported by the family members was moderate, with danger being mildest and worry being most severe. Burden was not related to age of caregiver, while gender was (with females being more burdened).

Caregiver burden is relatively high in the field of mental health care in Israel, according to our findings. This is not surprising, as Israel has only recently started to systematically allocate resources for mental health care in the community, and the family support part of that is not yet well-established. Indeed, the highest burden was related to worry, which is particularly understandable if satisfactory services are not provided, and the second highest burden was related to financial costs, which again is understandable if sufficient public resources are not in place. Practical and emotional burden were not clearly distinguished among our subjects, perhaps because each type of burden may feed into the other (e.g., financial costs may augment worry, and worry, which is stressful, may augment physical illness). Overall burden severity may not differ across age in this group, nearly all of which were parents, as middle-aged parents may be troubled mainly by behavioral challenges of their son or daughter, in parallel to their work and other children, while elderly parents may be troubled mainly by the future of their disabled child, in parallel to their own failing health and dwindling social supports (19). Female caregivers may be more burdened than male caregivers due to taking more responsibility toward their mentally ill child, as is well-documented in other countries (20); this is a well-known fact regarding caregivers in general, e.g., with daughters – rather than sons – taking more of the caregiver responsibility for elderly ailing parents (21).

The limitations of this study are that it used a relatively small and selective sample, consisting mostly of middle-aged and elderly mothers of mentally ill individuals; moreover, all the subjects were members of a family association, and thus perhaps more aware of their caregiver burden. These limitations are also found in studies elsewhere, such as in an American study of family NAMI (National Alliance for the Mentally Ill) members (20). As all our participants were Jewish, racial variation could not be examined, although race (and ethnicity) have been shown to be related to caregiver burden elsewhere (22). Also, the Israeli situation may be sufficiently specific to restrict generalization to other localities, as suggested by the caregiver representatives who participated in constructing the questionnaire.

This study demonstrates that sound data can be produced by participatory research in the mental health field in general and regarding caregiver burden in particular. Additional participatory research studies in this field could be helpful, preferably addressing burden of a varied population of caregivers. Future research – both in Israel and elsewhere – should not necessarily use the questionnaire generated in this study, but rather a similar participatory methodology, so as to be as context-sensitive as possible. Following this, interventions may also be generated within a participatory framework so as to reduce burden, preferably focusing on specific needs of groups that may be at high risk for considerable caregiver burden, such as mothers of mentally ill individuals.

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The International Journal of Psychosocial Rehabilitation
Volume 9, Number 1
July 2004– June 2005

Quality of Life Correlates Among Individuals with a Spinal Cord Injury: Does Race Matter?

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Citation:
Rahman R.O., Forchheimer M., & Tate, D.G. (2004). Quality of Life Correlates Among Individuals with a Spinal Cord Injury: Does Race Matter? **International Journal of Psychosocial Rehabilitation. 9**, 153-165.

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Keywords: Quality of Life, Spinal Cord Injury, Race, Ethnicity

Abstract

The purpose of the present study was to investigate Quality of Life (QOL), and factors associated with QOL, in individuals with Spinal Cord Injury (SCI) in relation to race. The primary goal of this study was to examine the relationship between certain Physical / Injury-Related factors, Psychosocial factors, and Demographic factors with QOL in hopes of gaining understanding into which of these factors are most related to increased QOL. The secondary goal was to explore any potential differences in the associations between the aforementioned factors and QOL as related to race. For Caucasians, many of the factors examined within the aforementioned domains were found to be associated with the various instruments utilized in an effort to assess QOL. However, for African Americans, only one items (having a spouse or partner) had any such association.

Introduction

The concept of health, like many modern day perceptions, has demonstrated its dynamic nature in that it is no longer limited in scope to the absence of disease or pathology, be it physical or psychological; but rather has come to appreciate the merits of wellness and excellence within these realms. Though this broadened conceptualization was formally adopted by the World Health Organization in 1948 [25], only recently has this precept begun to pervade the present day culture of the western world's health care systems. As a resultant, of this change in perspective, recent years have seen an emerging effort to evaluate health from a more multidimensional, global perspective.

In light of efforts to appraise health across numerous domains (e.g. physical, psychological, social), there has been mounting attention placed on assessing subjective quality of life (QOL). QOL is a broadly-defined umbrella term that encompasses numerous themes, concepts, and factors such as self-perceptions of general physical health, similar perceptions of psychological health and emotional well-being, meaningful and worthwhile interpersonal relationships, active and satisfying sexual relationships, as well as spirituality to name a few.[29,33] As many of these QOL-related factors have entered into the conceptualization and definition of health, they have similarly become components of interest in the assessment and determination of success in the field of medical rehabilitation.[22] This is particularly so in relation to individuals with a spinal cord injury (SCI). Although the field of study addressing QOL is still in its infancy, there is an emerging literature exploring differences in QOL between minority and non-minority individuals with SCI, the primary interest of the present study.

There have been numerous and significant differences consistently documented between minority and non-minority individuals with SCI within the literature. For example, minorities have been observed to report lower levels of satisfaction on measures of career opportunities and finances.[13] Minorities are less likely to be gainfully employed post-injury, controlling for differences in education, age, and medical characteristics,[3,7,14,16,17,19-21] and they have been found to report elevated levels of post-injury depression, compared to their Caucasian counterparts.[12,18]

While prior studies have indicated that some of these factors are associated with QOL, these relationships have not been observed consistently. These factors may be cursorily divided into three general categories: Physical / Injury factors, Psychosocial factors, and Demographic factors. In terms of Physical / Injury Related Factors, differences in neurological level of injury have fairly consistently failed to yield any variations in QOL.[10,26,34] Time since injury has, however, produced mixed results, with some researchers suggesting that increased time since injury is associated with increased QOL[30,34] and others suggesting that no such relationship exists.[26] One study noted that QOL changes during the first two years post-injury but is stable thereafter.[6]

In terms of psychosocial factors, being employed, level of education, social integration and activity, as well as extent of community access have all been found to be associated with increased QOL.[8,30]

Demographic factors include variables such as marital status, age, and race. Findings regarding marital status have demonstrated that married individuals with SCI report greater QOL than those who are single.[11,27] Increased age has been associated with lower QOL.[26] In regards to race, however, the findings are inconsistent. Various studies suggest that any racial differences in QOL that may be observed are no longer discernible after controlling for various demographic variables (e.g. education, age, income), [4,8,9,28] while others suggest that race is indeed a noteworthy correlate of QOL in its own right.[15,30]

Hypotheses

The purpose of the present study is to investigate potential differences in factors associated with QOL, in individuals with SCI according to race. The underlying thesis is that differences in QOL should not be associated with race; factors that have been shown to be associated with QOL should do so similarly across races. Informed by the existing research discussed above the study's specific hypotheses are:

1) There are no significant differences ($p < .05$) in QOL between Caucasian and African American individuals with SCI.

2) There are no significant differences ($p < .05$) in QOL between individuals with paraplegia and those with tetraplegia amongst either Caucasians or African Americans.

3) Increased number of hours spent working or volunteering is associated with increased QOL in both Caucasians and African Americans, and should be significant at a level of $p < .05$ for both groups.

4) Greater time spent in recreational or self-improvement activities is associated with increased QOL in both Caucasians and African Americans, and should be significant at a level of $p < .05$ for both groups.

5) Having a spouse, or being involved in a romantic relationship, is associated with increased QOL in both Caucasians and African Americans, and should be significant at a level of $p < .05$ for both groups.

6) Increased age is associated with decreased QOL in both Caucasians and African Americans, and should be significant at a level of $p < .05$ for both groups.

Methods

This study utilizes data gathered via a collaborative, longitudinal project amongst five of the national Model Spinal Cord Injury Care Systems (MSCICS) entitled Lifetime Outcomes and Needs: Refining the Understand of Aging with Spinal Cord Injury (Longitudinal Study). It has been funded by the National Institute on Disability Rehabilitation Research since 1990. The data used for this study were collected during the period from 1995-2000.

Participants

Participants were selected from the data base according to the following criteria. All members of this study's sample frame had experienced a new, traumatic spinal cord injury, were first interviewed for the longitudinal study during the period between 1990 and 1995. They were all participants in the MSCICS and had been injured between ten and 25 years when interviewed. All subjects were at least 18 years of age and people were excluded if their neurological status upon discharge from initial rehabilitation was unknown or classified as minimal deficit. The racial composition of the data used for analyses was limited to Caucasian and African American as the numbers of participants in other racial/ethnic categories were too limited to be included in the analyses in terms of making any statistically valid comparisons. Furthermore, the inclusion of diminutive numbers of other racial and ethnic minority individuals, in order to create a "minority" group for comparison, would yield questionable results in terms of generalizability regarding any of the groups included under said "minority" designation. To this end the sample utilized for analyses did not included individuals of Hispanic ethnicity, be they Caucasian or African American.

In addition, those individuals meeting the International Standards for Neurological Classification of Spinal Cord Injury[2] Impairment Grade D were excluded, limiting the sample to individuals classified as either with paraplegia or tetraplegia. Though conceptually and scientifically, the inclusion of Grade D individuals was desirable, the sheer lack of sufficient individuals meeting this designation (Caucasian N = 37; African American N = 11) served as a prohibitive factor to inclusion in these analyses. Finally, only those individuals for whom complete data was available on the three primary outcome measures of interest, as described below, were included in this dataset.

Measures

<u>Physical / Injury-Related.</u> Data regarding subjects' neurological impairments was obtained from the Longitudinal Study's database.

Psychosocial. Participants were also asked to provide estimations regarding the numbers of hours spent per week in selected activities including working at a job, volunteering, recreation and self-improvement. These questions are components of the Craig Handicap Assessment and Reporting Technique.[35]

Demographics. In addition to age and race, participants were asked additional questions regarding whether they were married or in a romantic relationship.

QOL Outcomes. QOL was estimated using the Life Satisfaction Index – Z (LSI-Z),[24] an instrument composed of 13 Likert scale items aimed at assessing an individual's overall satisfaction with life. Higher scores on this index are representative of greater satisfaction with life. In addition, participants were administered the Perceived Stress Scale (PSS),[5] composed of ten Likert scale items, which is a measure of the degree to which situations in an individual's life are appraised as stressful. Lower scores on this measure are indicative of lower levels of perceived stress. Finally, participants were posed one face-valid item concerning their estimation of their current QOL. Responses were based upon a four point Likert scale consisting of the following responses: 0 = poor, 1 = fair, 2 = good, 3 = excellent.

Statistical Analyses

Initially, sample demographics were appraised by race. Each of the specific hypotheses was then examined by means of two-tailed independent samples t-tests to investigate between-group differences, as well as bivariate correlations to investigate relationship between factors. For the testing of all hypotheses, the criteria used for statistical significance was an alpha level of $p < .05$.

Results

Sample Characteristics

Data from 416 subjects were analyzed. Approximately 80% of the sample was male with a similar percentage of Caucasian participants. There was a near equal split in neurological level of injury in the sample between Para ABC (53.4%) and Tetra ABC (46.6%). The participants' average age was approximately 42 years, ranging from 20 to 78. The average numbers of years post injury for this sample was approximately fifteen years, with a range of ten to 25 years. Additional details regarding sample characteristics may be found in Table 1.

Table 1: Sample Demographics.

		Caucasian (N= 379)	African American (N = 88)	Total Sample (N = 416)
Neurological Status (%)	Para ABC	52.7	56.4	53.4
	Tetra ABC	47.3	43.6	46.6
Gender (%)	Male	80.2	85.9	81.3
	Female	19.8	14.1	18.8
Years Post Injury	Mean	14.67	15.51	14.83
	Standard Deviation	4.29	5.07	4.45
Age	Mean	41.16	43.31	41.56
	Standard Deviation	10.60	10.30	10.56

Hypotheses Examined
Hypothesis #1: *There are no significant differences (p < .05) in QOL between Caucasian and African American individuals with SCI.* This hypothesis was confirmed. Independent sample t-tests yielded no significant differences between the two groups on the LSI-Z, PSS, or the single QOL item. See Table 2 for results.

Table 2: Differences in QOL between Caucasians and African Americans

		N	Mean	SD	t	p - value
LSI-Z	Caucasian	338	11.28	4.49	1.318	.188
	African American	78	10.53	4.72		
PSS	Caucasian	338	12.08	7.33	.470	.639
	African American	78	11.65	6.72		
QOL item	Caucasian	338	2.11	.75	1.55	.123
	African American	78	1.96	.78		

Hypothesis #2: *There are no significant differences (p < .05) in QOL between individuals with paraplegia and those with tetraplegia amongst either Caucasians or African Americans.* Mixed results were obtained for this hypothesis. Among Caucasians, independent sample t-tests indicated that those with paraplegia had significantly higher levels of life satisfaction and lower levels of stress than did those with tetraplegia.

The two groups did not differ in terms of their responses to the single item QOL. In contrast, for the African American group, no differences were observed between individuals with paraplegia and those with tetraplegia in terms of any of these three indices of QOL. Results are available in Table 3.

Table 3: Differences in QOL between Para ABC and Tetra ABC by Race

Caucasian		N	Mean	SD	t	p - value
LSI-Z	Para	178	11.88	4.19	2.65	.009
	Tetra	160	10.60	4.72		
PSS	Para	178	11.28	6.96	-2.14	.033
	Tetra	160	12.98	7.63		
QOL item	Para	178	2.09	.72	-.504	.615
	Tetra	160	2.13	.79		
African American		**N**	**Mean**	**SD**	**t**	**p - value**
LSI-Z	Para	44	11.07	4.84	1.16	.250
	Tetra	34	9.82	4.52		
PSS	Para	44	11.86	7.60	.312	.756
	Tetra	34	11.38	5.48		
QOL item	Para	44	1.95	.81	-.088	.930
	Tetra	34	1.97	.78		

Hypothesis #3: *Increased number of hours spent working or volunteering is associated with increased QOL in both Caucasians and African Americans, and should be significant at a level of p < .05 for both groups.* This hypothesis was only partially confirmed. For Caucasians, increased hours per week spent working and / or volunteering was associated with lower PSS scores, increased LSI-Z scores, and increased QOL item ratings. However, none of the aforementioned relationships were found to be of significance amongst the African American group. These results are shown in Table 4. It is, however, of import to note that Caucasians (M = 16.75, SD = 21.10) spent significantly more hours per week working and/or volunteering than did African Americans (M = 6.32, SD = 14.32) (p < .0001).

Table 4: Correlations for work/volunteer hours and QOL measures, differential examination based upon race.

Caucasian		PSS	LSI-Z	QOL Item
Hours spent working and / or volunteering per week	Pearson Correlation	-.117	.330	.246
	p - value	. 039	.000	.000
	N*	313	313	313
African American		PSS	LSI-Z	QOL Item
Hours spent working and / or volunteering per week	Pearson Correlation	-.054	.078	.114
	p - value	.647	.509	.332
	N**	74	74	74

* 25 Caucasians were missing data regarding number of hours working/volunteering per week
** 4 African Americans were missing data regarding number of hours working/volunteering per week

Hypothesis #4: *Greater time spent in recreational or self-improvement activities is associated with increased QOL in both Caucasians and African Americans, and should be significant at a level of p < .05 for both groups.* Mixed results were obtained for this hypothesis. Increased hours spent in recreational activities was associated with higher QOL item ratings and greater hours spent in self improvement related activities was associated with lower levels of perceived stress for Caucasians. For African Americans, increased time spent in recreational activities was associated with lower levels of perceived stress, though no correlations were observed between time spent in self-improvement and any of the outcome measures. As with vocational activity, discussed above, the distribution of hours of self-improvement activity was highly abnormal among African Americans, See Table 5 for more details. Caucasians (M = 10.72, SD = 11.64) reported spending significantly more time in self improvement activities per week than did African Americans (M = 5.54, SD = 8.47) (p < .0001). Though a similar trend was observed with Caucasians (M = 7.21, SD = 8.24) spending more hours per week involved in recreational activities than African Americans (M = 5.28, SD = 5.85), it was not statistically significant (p < .06).

Table 5: Correlations for involvement in recreational and self improvement activities and QOL measures, differential examination based upon race.

Caucasian		PSS	LSI-Z	QOL Item
Recreation hours per week	Pearson Correlation	-.084	.082	.156
	p - value	.134	.145	.005

	N*	321	321	321
Self Improvement hours per week	Pearson Correlation	-.124	-.032	-.064
	p – value	.027	.575	.253
	N*	317	317	317
African American		PSS	LSI-Z	QOL Item
Recreation hours per week	Pearson Correlation	-.236	.185	-.019
	p – value	.042	.111	.870
	N**	75	75	75
Self Improvement hours per week	Pearson Correlation	-.059	-.146	.084
	p – value	.619	.215	.477
	N**	74	74	74

* 17 Caucasians were missing recreation data; 21 were missing self improvement data
** 3 African Americans were missing recreation data; 4 were missing self improvement data

Hypothesis #5: *Having a spouse, or being involved in a romantic relationship, is associated with increased QOL in both Caucasians and African Americans, and should be significant at a level of p < .05 for both groups.* This hypothesis was partially confirmed. Amongst Caucasians, having a spouse or romantic partner was associated with increased LSI-Z and QOL item scores, but yielded no relationship to PSS scores. For African Americans, however, having a spouse or romantic partner was associated with lower PSS scores, increased QOL item scores, and increased LSI-Z scores. Furthermore, the percentage of Caucasians (54.1%) reporting having a spouse/partner was similar to that reported by African Americans (55.4%). These results are provided in Table 6.

Table 6: Correlations for having a marital or romantic relationship and QOL, differential examination based upon race.

Caucasian		PSS	LSI-Z	QOL Item
Have a spouse or romantic partner	Pearson Correlation	-.093	.274	.168

	p - value	.110	.000	.004
	N*	296	296	296
African American		PSS	LSI-Z	QOL Item
Have a spouse or romantic partner	Pearson Correlation	-.380	.263	.268
	p – value	.002	.034	.031
	N**	65	65	65

* 42 Caucasians were missing data regarding having a spouse or romantic partner
** 13 African Americans were missing data regarding having spouse or romantic partner.

Hypothesis #6: *Increased age is associated with decreased QOL in both Caucasians and African Americans, and should be significant at a level of p < .05 for both groups.* The posited relationship was observed among Caucasians, with increased age associated with lower QOL item scores, though no relationship was observed between age and any of the outcome measures among African Americans. These results are available in Table 7. There were no significant differences (p < .106) in terms of age observed between Caucasians (M = 41.16, SD = 10.60) and African Americans (M = 43.31, SD = 10.30).

Table 7: Correlations for age and QOL, differential examination based upon race.

Caucasian		PSS	LSI-Z	QOL Item
Age	Pearson Correlation	-.076	-.095	-.157
	p - value	.163	.081	.004
	N	338	338	338
African American		PSS	LSI-Z	QOL Item
Age	Pearson Correlation	-.121	-.015	-.174
	p – value	.293	.897	.127
	N	78	78	78

Discussion

As the concept of QOL is in its relative infancy within mainstream healthcare, its definition remains dynamic and amorphous. The purpose of the present study was to investigate QOL, and factors associated with QOL, in individuals with SCI in relation to race. The primary goal of this study was to examine the relationship between certain Physical / Injury-Related factors, Psychosocial factors, and Demographic factors with QOL in hopes of gaining understanding into which of these factors are most related to increased QOL. The secondary goal was to explore any potential differences in the associations between the aforementioned factors and QOL as related to race.

It was posited that there would be no differences in QOL outcomes as a function of level of neurological level of impairment. While no association was observed among African American's, within the Caucasian sub-sample those with paraplegia reported lower levels of perceived stress and higher levels of life satisfaction than did those with tetraplegia. Conversely, no differences in QOL were observed between African Americans with paraplegia and those with tetraplegia.

Five items were evaluated as psychosocial variables within this study: time spent working or volunteering, time spent in recreational activities, time spent in self-improvement activities, and having a spouse or romantic partner. Greater number of hours spent working or volunteering was associated with lower perceived stress, increased life satisfaction, and greater QOL specific item scores for Caucasians. However, there was no such relationship observed for African Americans. Increased time spent in recreational activities was associated with high QOL item scores for Caucasians, but not for African Americans. Increased time spent in self-improvement activities was associated with decreased stress for Caucasians, but not for African Americans. For Caucasians, having a spouse or romantic partner was associated with increased life satisfaction. For African Americans, a relationship was observed between having a spouse or partner and decreased perceived stress in addition to increased life satisfaction. An association between increased QOL item scores and having a spouse or partner was observed in both groups. In general, as was hypothesized, all of the psychosocial outcomes were associated with the studies indicators of QOL amongst the Caucasian participants. This posited relationship was not, however, observed among the African American participants, barring the observed relationship regarding having a spouse or partner.

Lastly, as race was a focus of the analyses, the remaining demographic variable that was subject to investigation consisted solely of participants' age. Caucasians exhibited a relationship between increased age and lower QOL item scores. There were no observed relationships between the QOL measures and age for African Americans.

For Caucasians, many of the aforementioned factors were associated with the various instruments aimed at assessing QOL. However, for African Americans, only one items (having a spouse or partner) had any such association. The specific etiology of these observed differences in QOL between Caucasians and African Americans with SCI remains unclear. There are, however, numerous factors that necessitate further evaluation in terms of their potential contributory effects concerning these differences. The primary factor involves the innumerable sociocultural and ethnic differences between non-minorities (Caucasians) and minorities. The need for systematic consideration of ethnic diversity and multicultural issues have been noted in terms of general rehabilitation[31,32] and, vocational rehabilitation,[23] as well as within the intricate relationship existing within behavioral health and biopsychosocial mechanisms.[1] This same consideration must be examined in the assessment of QOL. One hypothesis to assist in explaining the observed differences is that the concept of QOL is differentially defined by the two groups. Thus, the instruments utilized in the present study may not be effectively identifying and assessing the issues related to QOL for African Americans. If unable to identify the factors associated with improving a particular groups' QOL, it is difficult to appropriately allocate resources so they will have the greatest impact. Similarly, such imprecise assessment may further translate into limited resources being diverted into treatments or interventions that may be of little consequence for a particular group.

To this end, the continued study of QOL amongst ethnically diverse populations is a requisite to the development and implementation of successful treatments and interventions within the field of rehabilitation, and the general realm of health care.

Limitations

This study has some important limitations that should be noted. The data utilized for these analyses were archival in nature. Thus, there was no ability to purposively select the instruments aimed at assessing QOL, and there were limitations on the variables available for analyses in terms of their association with QOL. Furthermore, there were large discrepancies in the sample sizes used form comparison between Caucasians and African Americans. Moderate sized relationships which might be classified as statistically significant among Caucasians could be deemed insignificant among African Americans for this reason alone. Also, distributional anomalies, which were most severe in the African American sub-samples made drawing definitive conclusions tenuous. Future studies would benefit from incorporating additional and broader measures of QOL. It would be of further benefit to include additional variables within each of the three factors discussed (physical / injury-related, psychosocial, and demographic). Oversampling of African Americans would be of benefit to allow for greater equity in sample size between the two groups, which would of course assist in the statistical analyses. Finally, use of statistical techniques appropriate for abnormal distributions, particularly censored ones, would be beneficial in future work.

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The International Journal of Psychosocial Rehabilitation
Volume 9, Number 1
July 2004– June 2005

Coping with Public Labeling of Clients with Mental Illness in Hong Kong: A Report of Personal Experiences

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Citation:
Yip K-S. (2005). Coping with Public Labeling of Clients with Mental Illness in Hong Kong:
A Report of Personal Experiences. **International Journal of Psychosocial Rehabilitation. 9,** 166-179

Abstract

This paper reported a phenomenological study of public attitude towards persons with mental illness. In-depth interviews were done to eight persons with mental illness and their family members in Hong Kong. Their personal experiences in daily interaction with members of communities were explored. Their perceptions of stigma and label of mental illness; their experiences in being labeled and stigmatized as well the consequences and their coping with this labeling was explored.

Introduction

Persons with mental illness have long been labeled and stigmatized by the public as dangerous, violent and mythical (Link, et.al 1987; Albrecht, Walker & Levy, 1982; Wilson, Nairn & Coverdale, 1999; Ng, 1997; Repper & Brooker, 1996; Ojanen, 1992; Byrne, 1999). Related studies can be roughly divided into three main components, the stigma and label of mental illness; the labeling and stigmatization process; and the consequences of labeling and stigmatization. Goffman (1963) adopted the term `stigma' from Greeks implying a mark that represent immorality. Goffman further elaborated that stigmas can be manifested and latent (Goffman, 1961; Link, et.al., 1989; Penn & Martin, 1998). While stigmas represent an actual deficit or immorality, label and stereotypes involve discrimination without the actual deficits (Angoustinos & Ahrens, 1994; Judd & Park, 1993; Kruger, 1996). Studies showed that persons with mental illness are the most rejected among disabled groups (Albrecht, Walkeer & Levy, 1982; Link, et.al, 1987). They are labeled as unpredictably violent, dangerous, insane and mythical (Phelar & Link, 1998; Ng, 1997; Janes, 1998; Ng, 1997) Torrey (1994) asserted that the existence of seriously mentally ill respondents who exhibit violent behavior undermines efforts by health advocates to reduce the stigma of mental illness by denying an association with violence.

Regarding the labeling and stigmatization process. Jones, (et.al. 1984) asserted that the process of stigmatization depends on six dimensions such as conceability, course, disruptiveness, aesthetic qualities, origin and peril. In Jones' (et.al, 1984) terms, the stigma of mental illness contains high peril (unpredictable threat to others), various conceability and aesthetic qualities among individuals (some with good appearance, some with poor personal hygiene or odd and bizarre behaviors), poor course (chronicity of mental illness increases overtime) and very disruptive to oneself. In Chinese traditional culture, people may interpret the origin of mental illness is due to one's misdeed in this life or previous life. Lemert (1951) and Goody (1978) asserted that deviant behaviors and discrimination happens in a vicious cycle. The more the individual being discriminated, the more deviant his or her behaviors become. Wilson (et al, 1999) found out that the image of dangerousness of mental illness is constructed by special effects like appearance, music and sound effects, lighting, language, intercutting, jump cutting, point of view shots, horror conventions and intertextuality in television program. The public belief of `dangerousness to self or others' increased drastically from 4.2% in 1950 to 44% in 1996 in the United States (Phelan, Link, 1998). Labeling and rejection of persons with mental illness tends to increase in personal contact and self interest. (Page, 1977; Trute and Loewen, 1978; Byrne, 1999; Desforges, 1991, Angermeyer & Matischinger, 1996). Some studies showed that many clinicians may fail to address the problems of stigma in the process of intervention (Gingerich, 1998; Angermeyer & Matchinger, 1996). Link's (et.al, 1987 & 1999) studies showed that in terms of mis-beliefs of violence and dangerousness, the general public labels persons with mental illness even in the absence of odd and bizarre behaviors.

The impacts and consequences of stigmatization and labeling is highly disruptive both the individual and the society. Related studies show that persons with mental illness choose not to use mental health services because of fear of labeling (Leaf, Bruce, Tischer & Holzer, 1987; Kessler, et.al., 2001). Sirey's (et.al. 2001) study showed that persons with mental illness opt not to continue treatment where labeling effects are manifested in treatment centers. Studies also showed persons with mental illness is also self-labeled and stigmatized themselves as shame, insane, crazy, low self esteem and guilt. All these defeat their competence in recovery and normal social functioning (Link, 1982; Link 1987; Link & Phelan, 2001; Ritsher et.al., 2003). Finally, because of labeling of mental illness, persons with mental illness are spontaneously excluded and discriminated in normal social and daily activities (Link, 1982, Link, 1987; Link, et.al, 1987; Corrigan, 2000; Corrigan & Watson, 2002; Farina & Felner, 1973; Farina, et.al., 1973; Farina, et.al., 1974)).

Similarly, stigmatization and labeling of mental illness are common in Hong Kong (Cheung, 1990; Mak, et.al., 1996; Chu, et.al., 1996; Pearson & Yiu, 1993; Yip, 1991). Mak (et al, 1996) study implied about 45% of people in Hong Kong think that persons with mental illness should best be kept in hospitals. However, there are no related study to explore the experiences of persons with mental illness in labeling and stigmatization in Hong Kong. In this paper, the writer tries to describe a phenomenological study in this area.

Research Methodology

Aims of this Study

The aims of this study were as follows:

1. To examine what contribute to the label and stigma of mental illness in Hong Kong.
2. To explore the process of labeling and stigmatization of the public towards persons with mental illness in the community.
3. To examine consequences and coping of labeling on persons with mental illness

Respondents

Twenty clients were referred by rehabilitation agencies but only eight of them and their family members were willing to participate in this study

Their general profile can be shown in the following table:

Subjects	**Sex**	**Age**	**Family Member interviewed**	**Remarks: Medical Background**
A	F	30	Sister	A suffered from major depression disorder for six years. She experienced and failure in public examination, courtship and employment. She had been hospitalized. By the time of the study, she was recovered with constant follow up from a private psychiatrist.
B	F	35	Mother	B suffered from schizophrenia for 12 years. She was looked after by her aged mother. By the time of the study, B lived in a psychiatric half way house.
C	M	45	Sister	C suffered from schizophrenia for twenty years. He had been hospitalized many times. By the time of this study, C was still pre-occupied with chronic residual symptoms deluding that he was the famous movie star in marital art, Bruce Lee.
D	M	50	Wife	D suffered from affective psychosis for ten years. He was deeply frustration by his previous employment. By the time of the study, D was mentally stable with constant follow up in a psychiatric outpatient clinic.
E	M	33	Mother	E suffered from depression for seven years. He was deeply puzzled by the leaving of his girl friend. By the time of the study, E lived in a psychiatric half way house for rehabilitation.
F	F	28	Sister	F suffered from affective psychosis for six years. She was looked after by her elder sister. By the time of the study, F was mentally stable with constant follow up in a psychiatric outpatient clinic.
G	F	35	Mother	G suffered from schizophrenia for 20 years. She deluded that she was a famous dancer. She had frequent relapse and had been hospitalized five times. By the time of this study, She stayed in a psychiatric half way house.
H	F	40	Mother	H suffered from depression for five years. She was deeply frustrated by the ex-marital relationship of her husband. By the time of this study, her mental condition was quite stable and she lived in a psychiatric half way house for rehabilitation.

The Empirical Phenomenological Approach

Justification of the use of a phenomenological approach

Studies in labeling and stigmatization of mental illness are mostly quantitative in examining public attitudes towards mental illness. There were only a few of them focus on the views of persons of mental illness (Corrigan and Watson, 2002; Corrigan, & Lundin, 2001). The views and experiences of persons with mental illness was neglected in the research and related literature. All these are crucial in generating effective measures for intervention and service. Thus, in this study, the empirical phenomenological approach was involved in data, hoping that experiences and views persons of mental illness can be fully respected and revealed.

The Phenomenological Approach

Van Kaam (1966) described this approach as follows:
`The empirical phenomenological approach involves a return to experience in order to obtain comprehensive descriptions that provide the basis for a reflective structural analysis that portrays the essences of the experience. The approach seeks to disclose and elucidate the phenomena of behavior as they manifest themselves in their perceived immediacy (van Kaam, 1966:15)

Giorgi (1985) outlines two descriptive levels of this approach: the original data from open-ended questions and dialogue and reflective analysis and interpretation respondents' account or story (Giorgi, 1985 & Moustakas, 1994). In this study, during the interview process, the writer tried to start with descriptive narrative provided by the respondent who is viewed as co-researchers. The writer and the respondent were engaged in smooth dialogue. Questions concerned were aturally flowed out from the dialogue. In the whole process, the writer avoided any interpretation or evaluation of the respondent (von Eckartsberg, 1986)
Phenomenological Data Analysis

Melearu-Ponty mentioned three criteria for phenomenological analysis, genuine descriptive account by respondents; researcher's interpretation reduce to minimum and search for essence (Melearu-Ponty, 1962 and Giorgi, 1985). In this study, once collected, the data were read and scrutinized so as to reveal their structure, meaning configuration, coherence and the circumstances of their occurrence and clustering (von Eckartsberg, 1986). The writer focuses on the how respondents' personal experiences in daily interaction with members of community. In what way the construction, process, consequences and coping of label and stigma of mental illness were naturally flowed out from respondents' own narration.

Findings

What Contributes to the Stigma and Label of Mental Illness

The Views of Persons with Mental Illness

In this study, respondents with mental illness expressed the following views towards the stigma and label of mental illness.

Respondent D:
`There is no such thing as mental illness. I am not a mental patient. We are being labeled as mentally ill simply because my family, my friend, my doctor and my boss perceive that I am mentally ill. Mental illness is an excuse used by them to isolate, to blame and to oppress us and deprive our rights to enjoy normal daily life.'

Respondent A:
`I am mentally ill. My doctor and my parents told me that depression is a serious mental illness. I have to depend on medication to counteract my symptoms. I felt dreadful, I am hopeless and worthlessness

as I am a mental patient. The medication make me better, I have to follow the instruction of my doctor and my parent so as to suppress my depressive mood.'

Respondent F
`Mental illness is a terrible stigma. People look down upon you simply because you have a record of mental illness or showing any sign of mental illness. For those who know your record of mental illness, including your friends, your colleagues, they may labell any thing you have done. Even you do a good job, they do not believe in that. If you have some minor strange behaviors, or impulsive emotion, they would quickly label them as symptoms of mental illness. For those who do not know your record of mental illness, if you appears normal, no one beware that you are a person with mental illness.

The Views of Family Caregivers

C's Sister
`C can be easily labeled by others as a person with mental illness. His symptoms are so obvious. He always deludes that he is the famous movie star " Bruce Lee" (a former Chinese marital art master who is an international movie star). He tries to dress and perform like `Bruce Lee'. Our neighbors, relatives and friends all know that he is `insane' and some even tries to make fun of him. Others try to avoid him fearing that he may suddenly broke into violence and aggression.'

E's mother
`Ever since the leaving of her girlfriend, E was so depressed. He refused to go to work. He refused to clean himself. His personal hygiene was poor that his odd smell clearly showed that he was `. Many neighbors gossiped behind us saying that he was schizophrenic and with potential violence. In fact, he was too depressed to care about his personal hygiene. He was only a young man with a broken heart.'

B' s mother
`When B is in good mood, she appears gentle and kind. She was able to work and interact with others normally. However, whenever she feels stressful, she cried bitterly and deluded that she was deserved by her boyfriend. She might delude that the richest man in Hong Kong had fallen in love with her. '

Stigma and Labels are both Objectively and Subjectively Constructed

From the above narration by respondents and their family members, it is interesting to note that stigma and label and mental illness can both be objectively and subjectively constructed. Objective facts are odd and bizarre behaviors (C's odd behaviors and delusion to be Bruce Lee), poor personal hygiene or outlook (E's poor personal hygiene and bad body smell). All these are easily misinterpreted by others as signs for `violent', `myths', `troubles' and `craziness'. (Phelan & Link, 1998; Ng, 1997: Torrey, 1994). However, it can also be subjectively constructed. D asserted that the label was only subjectively interpreted by others if even she did not exercise any symptoms and bizarre behaviors only because of previous record of mental illness. This seems to concur with the studies done by Link (et.al. 1999). In this study, persons with mental illness seemed to be more sensitive to others' subjective construction of label of mental illness. Their family members tended to be more sensitive to objective construction of mental illness as they faced symptoms and odd and bizarre behaviors daily. Furthermore, mental state and symptoms might affect the receptivity of the label of mental illness. For example, as C was indulged in his active delusion of the marital art movie star, he ignored others' stigmatization. A's depressive mood might intensify her internalization of the stigma of mental illness. Her psychiatrist might intensify this stigma so that to increase A's drug compliance. Nevertheless, as F's mental state was stable, she was highly sensitive to others' labeling. Finally, though family members were empathic to their relatives with mental illness. They understood that their relatives' conditions changed overtime. Sometimes they were better and sometimes they were worse. They also understood their relatives' feelings behind symptoms and odd and bizarre behaviors.

The Interactive Process in Public Stigmatization and Labeling

Nearly all respondents and their family members had unpleasant experiences in being labeled and stigmatized by others in the community.
Respondent B and her mother had the following experience in a supermarket.

`My mother and me shopped in a supermarket. I wore a patient uniform and was a bit dirty. When I entered the supermarket, everyone looked at me. Some gossiped behind me. No one approached me. Suddenly, the manager of the supermarket approached me and asked my mother what sort of things I wanted to buy. I said I preferred to look around and buy a box of drink. She pointed out where the drinks placed and left us alone. However, she still kept an eye on us. Other customers avoid coming close to us but they stayed at a distance. I could hear what they said. Some said I was crazy and was a mental patient. Some said it was a pity that a pretty young woman became insane. Some even said my mental illness was a consequence of some bad deeds done by my mother. Other questioned about my potential dangerousness. When I came near the drink and snack corner. Some were afraid that I would pick out some glass bottles and threw at them. They were very alert when I picked up some bottles of drinks from the shelf and put them down rudely. When I came close to the shelf placing kitchen utensils, they were very nervous. They even approached the manager and warned her that I might pick up some kitchen knives. I passed along this corner quickly. They became more relaxed than before.'

C's sister and C had the following unpleasant experience.

`One day my brother walked aimlessly and played marital art in the middle of a street in a busy commercial area in Hong Kong. Because of the fear of being stigmatized, I tried to stay a bit away from him. People stared at him. They tried to keep at a safe distance away from him while he was playing marital art. Finally, he slowed down and went to a Chinese restaurant. He sat down quietly and ordered for some food to eat. His untidy hair and strange body postures symbolized that he was a mental patient. People in the restaurants sat at their seats and kept looking at him. When he stood up and went to the toilet, they moved away so as to keep a `safe' distance away from him. Most of the time, he dared to look at them. However, if my brother looked back, they would appear nervous.'

D described the following experiences in an arcade.

` I sat on the corner of the ground of an arcade. They surrounded me. I sat on the ground saying that I was sacked by my bad employer. I was sent by the King of Heaven to punish any bad employer in this world. People laughed at me. Some even invited me to punish their bad bosses. Some were pity about me. Some took a glance and walked away..'

E said that she was frustrated by the following experiences in a children playground.

` Once I walked in a children playground within a public park. Nearly, all parents there stared at me and watched me closely. They were highly anxious with my behaviors fearing that I might harm their children. At first I kept sitting at the corner of the playground. I felt very sad and cried. They tended to pull their children back. After a short while, I started to shout that I was deceived by someone. I hated every young woman who always deceived men. At that moment, everybody in the playground looked at me. They were very tense. Some parents immediately stood in front of their children. Some even embraced their small kids and started to go away. Some moved along to search for guards in this park. A young father even nervously picked up a stick and ready to defend him and his child.'
F had the following unpleasant experience in a shop.

`People around me watched me closely in the shoe shop, especially the shopkeeper. She simply walked very close to me and tried to ensure that I would not frighten other customers. I appeared normal except my body posture was rigid and tense because of the side effect of the medication. I picked up some shoes and tried to wear them. She could not tolerate any further. She persuaded me that no shoe in her shoe shop was suitable for me and advised me to went out and find another shop.'

The following unhappy experience was described by G's mother.

` I and my daughter, G shopped in a large department store. Because of her delusion as a modern dancer, she taped foot or danced slowly. No sooner, it caught the attention of two sale girls. They tried to predict what my daughter was going to do in the next movement. Finally, to prevent further troubles, they called upon guards in the department store. With the help of a guard, these two sale girls escorted us to leave the department store.'
H had the following unhappy encounter in a Chinese restaurant.

` I was advised to leave the Chinese restaurant simply because of my depressive mood. In fact, I had done nothing to disturb them. I only cried bitterly for my misfortunes and yelled out my inner anger towards life. However, the manager together with other waiters and customers all agreed that I was irrational and insane. When I walked out of the Chinese restaurant, many customers appreciated the prompt action of the manager saying that he was determined to stop my disturbance. What I needed was institution and detention rather than fooling around in the community.'

The Socially Constructed Process in Public Stigmatization and Labeling: Interactive Action and Response

The experiences of respondents and their family members showed that stigmatization and labeling of mental illness was a socially constructed process by members in the public areas. The construction process involved several elements: public areas, symbols or icons representing mental illness, action and response among persons with mental illness and the public. These public areas could be; supermarket (in B's experience); arcade (in D's experience); children playground (in E's experience); shoes' shop (in F's experience); department store (in G's experience) and Chinese restaurant (in H's experience). In all these public areas, people come and go and engaged in well defined activities such as shopping in shops and departmental stores, sitting in public transport, dining in restaurants. According to respondents' experience, stigmatization and labeling started with certain behaviors, symptoms and signs that symbolized mental illness. It might be depressive mood and crying (in D's, E's and H's experiences). It could also be odd and bizarre behaviors (C's marital art; E's ventilation of her anger towards men and F's dancing). It might be some signs (F's rigid and tense body posture due to side effect of medication or B's patient uniform). All these signs created disturbances to the well defined norms within these public areas. People there interpreted them as possible `outburst' of unpredictable and mythical danger, violence and danger'. Following such construction of label of mental illness was the arousal of fear and immediate need of self protection. That might be the reason why people in public places tried to watch closely but keep a safe physical distance to respondents in this study. For instance, B and her mother was watched and gossiped by others in the supermarket. C was watched by others in the street and in the Chinese restaurants; D, E and F was watched by others in arcade, shops and department store. Instead of immediate rejection and exclusion, respondents in this study were watched by others for a certain period of time. Thus, B was able to look for some good in the supermarket. C was able to play marital art in the middle of the street in a commercial area. D was able to cry bitterly in the arcade. E was able to stay quite a while in the children playground; F was able to try some new pairs of shoe in a shoe store. G was able to dance in the department store. They might be afraid that immediate exclusion would provoke sudden outburst of the violent and crazy behaviors.

Within this period of time, people around or responsible persons in public areas spontaneously gossiped, discussed, assessed and prepared for suitable actions. For example, in B's experiences, customers in the supermarket spontaneously gossiped behind her. In G's case, her bizarre dancing in the department store was watched by two sale girls. They assessed, discussed and planned for appropriate actions. In E's experience, parents in the children playground were so anxious about every action of E. They were well prepared to defend for their children if E broke into violence and aggression.

Rejection, exclusion and defense finally evolved if these signs of mental illness far exceeded the tolerance limits and threats clearly manifested. Respondents F, G and H were finally being excluded from the shoe store, Chinese restaurant and department store. However, it was interesting to discover that, this sort of tolerance limit was in fact, subjectively constructed by the public, especially by those who were responsible to maintain order and safety in public areas. For instance, F was excluded from the shoe store by the sale girl only because of her rigid and tense body posture. G was escorted by a guard and two sale girls to leave the department store.

In fact, not all people in public areas labeled persons with mental illness. People with religious beliefs or similar situations may be empathic to persons with mental illness. In this study, A had the following pleasant experience in a bus.

` I got on a bus and sat on a seat on the upper deck. I cried bitterly, saying that I was so frustrated by my failure in courtship, public examination and employment. Later, a middle aged woman in nice dress approached me. She hold my hands tightly and comforted me. She said that she had similar experiences when she was young. She had very poor results in public examination and her boy friend left her suddenly. But she worked through all these because of her religious belief. She was a devoted Christian. She even prayed for me and comforted me. Later she gave a business card to me and told me to ring her anytime I needed help. I looked at the card. Oh, she was a minister of a Christian Church.'

Consequences of Labeling: Social Exclusion and Coping

The findings in this study showed that social exclusion and discrimination were common among persons with mental illness because of the results of stigmatization and labeling. Different coping strategies were used by various respondents. Some were healthy ones and some were unhealthy ones.

A tried to be patient hoping she could be recovered in the future.

` I am still troubled by my failure in courtship, public examination, and employment. I am still deeply frustrated by others' labeling and stigmatization. I need to depend on medication to ease my depressive mood. But with my support from my sister, I know that sooner or later I can be better. In fact, the worst situation has gone. My psychiatrist told me to wait patiently.'

B's mother was so angry and shameful towards the labeling and discrimination.

B's mother said: ` I had taken care of B for 12 years after her onset of schizophrenia. I do not mind the never ending burden of caring B's daily life, reminding her to take medication and comforting her when she felt upset. However, the reaction of the public, especially our neighbors make us felt angry and shameful. A few of them are helpful but most of them gossiped behind us. They always think that the occurrence of my daughter's mental illness is due to my bad deeds done in my previous life (in Buddhism, one's life fortune is pre-determined by what s/he had done in his or her previous life).

Whenever we walked by, they stared at us strangely. I felt shameful in facing their eye contacts. We have done nothing harmful to the neighborhood. Why should they discriminate us. I am seventy three years old now. I worried one day when I died, who can take care of B? Facing the labeling by our neighbors, B always quarrels with them. It makes the discrimination even worse.' (B's mother cried bitterly in the interview)

Facing the labeling and stigmatization, C's sister avoided going out with C.

`My brother was so confused in his residual psychiatric symptoms. He always deluded he was the famous marital art movie star, Bruce Lee. Members in our community all knew that he was the `crazy dragon'. Some even address him simply as `Silly Bruce'. Guards in nearby shopping arcade tried to stop him going inside. People around gossiped and excluded him. I was caught in a dilemma. On the one hand, I dared not to go out with him fearing of others' labeling. On the other hand, I was afraid he was being caught by the police because of potential dangerousness towards other by practicing marital art in the open area. He also feared of others' labeling. He said that there were too many ones being jealous of her excellent marital art skills and reputation. Thus, we rarely went out, instead, we locked ourselves in our home. He tried to practice in his room by punching sand bags and watching movie of Bruce Lee. Apart from reminding him to have regular medication, we could do nothing.'

D felt humiliated and inferior towards the public labeling.

D said: `I feel humiliated by others. I am constantly labeled by others as an `insane and crazy person. It is nothing wrong to feel frustrated. Every one wants some supernatural forces to ride off those bad guys. However, others' labeling makes me felt deeply inferior and humiliated. I dare not to look into others' eyes. I get a feeling that their eye contact judging me as a patient that I have to lock up in hospital. By the way, I am only an insane mental patient. No one wants to employ me nor no one dares to make friend with me. I feel lonely, helpless and inferior. My social worker helped me to have a job in a sheltered workshop, but it was really boring there. I preferred to work as a guard in an arcade. I hoped one day, I can find such a job.'

E described that public labeling intensified his depressive symptoms.

E said: ` I dare not look into others' eyes. I am a patient with depression. People know that I have mental illness. They look down upon me. I am sad, useless and hopeless. Every body looks down upon. To be abandoned by my girl means that I am worthless. Others' exclusion further proves that I am worthless and hopeless. I think I am the most worthless male in Hong Kong. Everyday, apart from sleeping, eating and idling in the park near the psychiatric half-way house, I could do nothing. I deeply hoped that one day my girlfriend can come back to me '

F firmly asserted that labeling and stigmatization was a burden for her recovery. Nevertheless, she tried her best to live a normal life.

F said: ` I struggled very hard in these years to get ride of the label of an insane person. Others' discrimination made me fear that it was nearly impossible to be recovered or live a normal life again. I dared not to go out, I dared not to find employment or even dared not to go to church thinking that all of them may tease at my symptoms. Fortunately, my church members and my sister were very supportive. They accompanied me to go out. They tried to persuade with other church members that I had a lot of strengths and ability. They encouraged me to show concern to others. I hope all members in the community try not to discriminate, or to exclude clients with mental illness. Their normal respect is crucial and vital for our recovery. In fact, the most important thing for recovery is to try my best to live a normal life including a normal job, a normal daily life pattern, normal social activities and normal family. .'

G's mother described her worry with G.

`I was so worry about G. She was my own daughter. She became a schizophrenic patient when she was only 15 years old. My husband died five years ago. I am the only one to take of her. I am 55 years old now. I was so worry about G's future. I hope one day she can marry a good guy and take care of her. However, her mental symptoms still prevails. Everywhere she went, she was labeled by others as a `crazy dancer. Her social worker in the halfway house encouraged her to work in a sheltered workshop, but she always slept there. She was only suitable to be a dancer. Now I can take care of her. But one day I die who can take of her.'

H tried to live independently after her divorce.

`Being divorced by my husband was dreadful. But to be a depressive patient was even dreadful. Within these five years, my life was ruined by depression. Everyone looked down upon saying that I became crazy after the divorce. I could not take care of my son. I could not go to work. But now with the help of my mother, my social worker and my psychiatrist, I am much better. I begin to recognize that I have to stand on my own and be independent. I have to construct my own future by reminding myself and training myself to live a healthy life. My social worker helped me to found a good job as a cleaner in a arcade. My mental state is stable. I hope sooner or later I can discharged from this halfway house, return home and live together with my beloved mother and my beloved son.'

Healthy or Unhealthy Coping

Public stigmatization and labeling brought along social exclusion of persons with mental illness. In this study, respondents were excluded from public areas like Chinese restaurants, department stores, children playground and arcade. All respondents and their family members felt angry, being looked down by others, and deeply humiliated. Different respondents and their family members constructed various ways in coping social exclusion. Some of them were unhealthy ways and some were healthy ones. Unhealthy coping implied that respondents and their family members internalized others' stigmatization and labeling in form of self stigmatization. For example, B's mother felt shameful and dared not to look at others' eyes as her neighbors gossiped that her daughter's mental illness was a punishment of her misdeeds in her previous life (in Buddhism, everyone's fate is a result of one's behavior, in previous life and this life). Similarly, D felt lonely, helpless and inferior because of being looked down by others. E also dared not to look into other's eyes thinking others might judge that she was mentally ill. Together with self stigmatization might be self exclusion. For instance, C's sister dared not to go out with C fearing that he might be caught by the police because of odd and bizarre behaviors. B always quarreled with those who labeled her. To avoid that, B's mother tried to keep B at home. As a result, one's competence for recovery was greatly hindered. D always felt that he was only a mental patient and no one wanted to employ him and no one wanted to make friend with him. E also felt that he was useless and hopeless. He was the most worthless male in Hong Kong. Apart from sleeping, eating and idling, he could do nothing. G's mother and D's sister also felt helpless and hopeless towards their relatives' mental illness. Healthy coping meant building up a positive attitude so that one could be positive and constructive in recovery and living a normal life. All these positive attitudes and coping strategies were needed to be supported by empathic social workers, church members, family members and neighbors. For instance, with the full support from her sister, A tried to be patient with a hope that one day she could recover from her depression. By means of the help of his social worker, D also hoped that one day, he could find a good job. With the spontaneous and full support from her church members, F tried to live a normal life including a normal job, normal daily pattern, normal daily activities and normal family.

Conclusion: Constructing A Supportive Community

As a conclusion, this paper describes the personal experiences of clients with mental illness about in facing the labeling by members of communities in Hong Kong. It seems that public stigmatization and labeling of persons with mental illness in the community of Hong Kong is a spontaneous social construction process between the members in the community and persons with mental illness. As a result, social exclusion and self stigmatization may occur that hinder recovery and community integration of persons of mental illness. All these have important implications to psychiatric rehabilitation intervention and services. Related professionals, policy makers should try their best to build up a caring and supporting community for persons with mental illness. First, facing spontaneous labeling by members in the community, persons with mental illness should be empowered to counteract labeling and public stigmatization (Krauger, 2000; Stormwell, 2002). Anti-oppressive psychiatric rehabilitation and community program may include the following:

1. Helping clients with mental illness to express and communicate their unpleasant feelings of being discriminated properly to members of community. Assertive training of feeling expression sentences like: `I feel uneasy about your staring. I hope you regards me as a normal person' may be a good start for such anti-oppressive assertion'.

2. Encouraging family members of clients to interact with their neighbors and members in the community to share their burdens and difficulties in family caregiving so that they can solicit their respect and concern in accepting clients with mental illness to interact normally in the community.

3. Exploring and identifying neighbors, friends and members in the community who are empathic with clients with mental illness and allying them to support a normal interaction of clients of mental illness in the community.

Secondly, it is important to nurture constructive and gradual interaction among persons with mental illness and members in the community. It may first start with interaction with acceptable members in the community and fully recovered persons with good social functioning. Once such interaction is facilitated and encouraged, those members in the community who are neutral to mental illness may be more willing to interact with persons with mental illness. With their support, the community may gradually move one step forward to accept persons with some mild odd and bizarre behaviors and residual mental symptoms. Finally, a supportive community for persons with mental illness should be also protected by related legislation like anti-discrimination ordinance and appropriated mental health education so that members in the community can nurture their respect to concern to persons with mental illness.

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