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This private *NON-PROFIT* professional publication and associated web-based, information archive service is dedicated to the enhancement of practice, program development, program evaluation and innovations in mental health and substance abuse treatment programs worldwide. Its goal is to provide a public forum for practitioners, consumers and researchers to address the multiple service needs of patients and families and help determine what works, for whom under a variety of circumstances.

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# Needs and Appropriateness of Help According to Types of Professionals and Their Users

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## Abstract

The discrepancies in needs-identification and the appropriateness of help according to patients' profiles, types of healthcare professionals, and users are examined based on 159 pairs of professionals and users. The Camberwell Assessment of Need (CAN) was used to assess: the number, severity and diversity of needs according to professionals and users, their degree of agreement and the appropriateness of help in meeting needs. The results show that patients tend to select as their primary healthcare provider a type of professional in accordance with their profile. Types of professionals tend to prioritize or neglect various needs in accordance with their background. The user/professional pairs with the highest agreement were those that obtained the most appropriate help. No type of professional can then identify all of its patients' needs. More cross-vocational training programs as well as interdisciplinary needs-evaluation and diversified care, which include systematically the patient's perspective, are thus necessary.

**Keywords:** needs-assessment; agreement between professionals and users; appropriateness of help; mental health types of professionals; patient profiles

# Introduction

In the past several years, considerable consensus has emerged in the field of mental health on the necessity of considering the patient's needs as a starting point for service planning. Evaluating patients' needs has become a key component of the rehabilitation process (Andresen, Caputi, & Oades, 2000). Numerous evaluation tools have been devised to support this development; of these, the Camberwell Assessment of Need (CAN) is the most frequently used (Phelan, Slade, Thornicroft, Dunn, Holloway, Wykes et al., 1995). Most studies using the CAN instrument have demonstrated moderate agreement between users and professionals in needs identification (Slade, Phelan, & Thornicroft, 1998; Slade, Leese, Ruggeri, Kuipers, Tansella, & Thornicroft, 2004). Other instruments have produced similar results (Comtois, Morin, Lesage, Lalonde, Likavëanova, & L'Écuyer, 1998; Gibbons, Bédard, & Mack, 2005). Authors explain the divergence in needs-perception by pointing to the different factors that affect users and professionals. In their view, socio-cultural environment, education, and past experiences play a primary role in users' identification of their needs, whereas professionals are more influenced by training and professional values (Nielsen, Middleboe, Werdelin, Petersen, Mackeprang, Mortensen et al. 1999; Slade, 1996). Chaplain and Perkins (1999) state that the perceptions of people in the same profession are more closely aligned than with those of professionals from other disciplines. For instance, two nurses will tend to think alike more than, say, a nurse and a psychiatrist or a nurse and a psychologist. The same observation has been made of other health professionals (Meredith, Wells, & Camp, 1994; Shao, Williams, Lee, Badgette, Aaronson, & Cornell, 1997), even when they come from different countries (e.g. Australia and Singapore) (Parker, Chen, Jua, Loh, & Jorm, 2000). However, no study has attempted to explain the divergence in the perceptions of types of professionals in relation to their patients' clinical and socio-demographic profile and service-utilization. Correlations between needs-identification and the adequacy of services have also been neglected. This paper, drawn from a larger study on integrated service networks in Quebec, Canada (Fleury, Mercier, Lesage, Ouadahi, Grenier, Aubé et al., 2004), aims to: (1) examine patients' clinical and socio-demographic profile and service-utilization according to the profession or occupation of their most significant professional or mental healthcare provider; (2) assess the level of agreement in the number, severity and diversity of the needs identified by professionals in accordance with their occupation and their respective patients; and (3) evaluate the appropriateness of the help provided by services according to types of professionals and users.

# Method

## Data collection

Needs-analysis was performed with the French-language version of the Camberwell Assessment of Need (CAN) instrument (Bonsack & Lesage, 1998), whose reliability has been tested in several countries (Slade, Phelan, Thornicroft, & Parkman, 1996; Arvidsson, 2003). An important characteristic of the CAN is its capacity to encompass patients' needs and the types of care provided by relatives and established services. The CAN includes five categories of needs and 22 domains. The categories of needs are: (1) Basic (accommodation, food, daytime activities); (2) Health (physical health, psychotic symptoms, psychological distress, safety to self, safety to others, alcohol, drugs); (3) Functioning (self-care, looking after the home, childcare, basic education, money); (4) Social (company, intimate relationships, sexual expression); and (5) Services (information on disorder and treatment, transportation, telephone and benefits). There are five sections in the CAN. In the first, for each of the 22 domains, the patient indicates their perceived need severity on a three-point scale (no problem=0, moderate problem due to help given=1, serious problem whether or not help is received=2). When a moderate or serious problem is reported, the patient must complete the other sections of the questionnaire pertaining to the level of help received from relatives or services (none=0, low=1, moderate=2, high=3); the level of perceived need for help from services (none=0, low=1, moderate=2, high=3); and finally, adequacy of that help (right type of help provided – 1=yes or 0=no) and satisfaction (related to the amount of help provided – 1=yes or 0=no). In every section, patients can also answer “I don’t know”, which is considered as missing information. The CAN is based on a semi-directed interview which takes 30 to 45 minutes, and can be administered at the patients’ residence or elsewhere to their convenience.

Additional data were drawn from patients’ records, related to their socio-demographic (gender, age, income, education and current type of residence) and clinical profile (principal and secondary diagnosis, and life span: number of suicide attempts, criminal record, drug and alcohol abuse, and history of violence), and their use of health services (number and length of hospital stays between January 2002 to May 2004, number and type of resources used during the last year). In a brief complementary interview, patients and professionals were also asked to answer a question on their perception of the patients’ mental health state. Users also had to provide information on their service trajectory in the past year, such as the type and number of professionals involved in their care and the duration of their follow-up. The data collection has involved research assistants with a professional clinical background and trained for the purpose of the study.

## Study design and cohort description

The study had a cross-sectional design based on patients living in six districts of the province of Quebec, Canada, chosen by convenience as most representative of semi-urban (areas 1, 2 and 3), rural (area 4) and urban (areas 5 and 6) settings. Population size ranged from 20,000 in area 4 to 128,000 in area 6 (Fleury, Grenier, & Lesage, 2006). Targeted patients, aged 18 to 65 years, had to have been hospitalized in the last year and diagnosed with severe mental illness according to ICD-9 code 295 (Schizophrenia) or 297 (Delusional Disorder). Subjects were randomly selected from a list of 937 patients provided by hospital archives in the different districts. Sampling size was set at 30 patients per district, except for one rural district, set at 10, and an urban district at 60. From the list of eligible patients, we selected the first who agreed to participate in the study, for a global objective of 190. That number could not be reached in only one district. The final sampling was 186 patients, or 97.8% of the objective. It was representative of Quebec’ hospitalized population at the time of the data collection in terms of gender ($\chi2=3.97$, df=1, $p\leq0.01$), and age, with the exception of one urban territory (49.4; SD 10.3 versus 41.2; SD 12.6 for Quebec; $\chi2=29.52$, df=4, $p>0.05$ – MED-ECHO, 2003-2004). Each participant signed a consent form approved by the relevant ethics boards.

The 186 patients selected were then asked to identify the professional whom they perceived as most significant and considered as their main mental healthcare provider; professionals identified in this manner were judged to be in the best position to answer the CAN. One hundred sixty-five professionals were identified. Professionals chosen by users included: 72 nurses (43.6%); 28 social workers (16.9%); 20 psychiatrists (12.1%); 22 educators (special or psycho-educators) (13.3%); 7 human relations officers (4.2%); 6 community workers (3.6%); 4 social agents (2.4%); 4 psychologists (2.4%); and 2 occupational therapists (1.2%). Nurses, social workers and community workers were present in the six districts covered by the study. Nurses were found mainly in urban district 6, where they constituted 64.4% of the significant professionals and in semi-urban district 1 (53.3%). Social workers were very few in number in districts 3, 5 and 6, and particularly present in the surrounding regions (1, 2 and 4). In district 2, they represented 40% of professionals chosen by users. Psychiatrists were more concentrated in district 5, where they made up 50% of the significant professionals. Most of the educators were found in district 3, while the community workers were found mostly in district 6. Finally, professionals' profile in district 4 was heterogeneous, with no category of professional standing out. Community workers, human relations officers, and social agents have a university education in related social sciences branches (psychology, psycho-education, social work, communication, and criminology, etc.) and provide community follow-up. The difference in their appellations seems to be related principally to the organization with which they are affiliated (local community health centre, hospital or community resources). In this study, we refer to those professionals as "community workers." Considering their small number, psychologists and occupational therapists have been excluded. Therefore, this study centres on 159 user/professional pairs.

A majority of the 159 patients were men (102 or 64.2%), whose mean age was 49.8 years (SD 11.8), single (109 or 68.6%), had a high-school education (85 or 53.5%), and were living autonomously in an apartment (86 or 54.1%). A diagnosis of schizophrenia was nearly the rule (155 or 97.5%). Nearly half of the cohort (79 or 49.7%) had a chronic syndrome such as mental retardation or personality disorder (as per DSM-IV). A history of family psychiatric problems was also reported for 72 patients (45.3%). Moreover, 49 patients (30.8%) had a history of problems with alcohol, 48 (29.1%) with drugs, 48 (30.2%) a history of violence, and 40 (25.2%) problems with the law. Fifty (31.4%) had tried to take their own life, averaging 1.80 lifetime suicide attempts (SD = 1.23). Users perceived their mental health state more positively (Figure 1) than professionals did (Figure 2). Only 16 users (10.1%) considered it to be bad, whereas 32 (20.1%) very good or excellent, compared to 39 professionals (24.5%) who estimated it to be bad and 13 (8.3%) very good. The average number of patient hospitalizations between January 2002 and May 2004 was 1.92 (SD = 1.47). The length of stay was less than 7 days for 53 users (33.3%) and between 1 and 2 weeks for 44 users (27.7%). On average, patients used 2.0 mental health resources in the past year (SD = 1.01), mainly outpatient clinics (111 or 69.8%), community resources (34 or 17.9%), local community health centres (28 or 17.6%), and specialized clinics (28 or 17.6%). Fifty-two (32.7%) mentioned being followed by a psychiatrist and a general practitioner. Twenty-nine (18.2%) had been seen by the same psychiatrist and 28 (17.6%) by the same general practitioner for more than ten years. Sixty (37.7%) reported consulting another professional as well, mainly a social worker (24 or 15.1%).

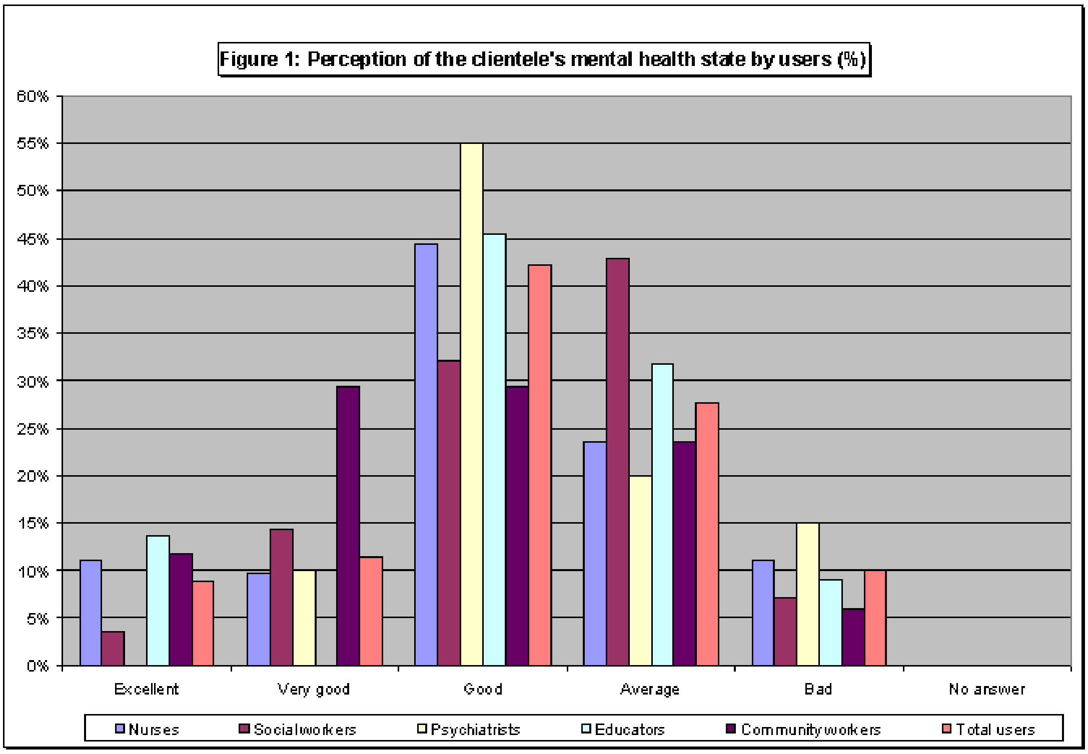

Figure 1: Perception of the clientele's mental health state by users (%)

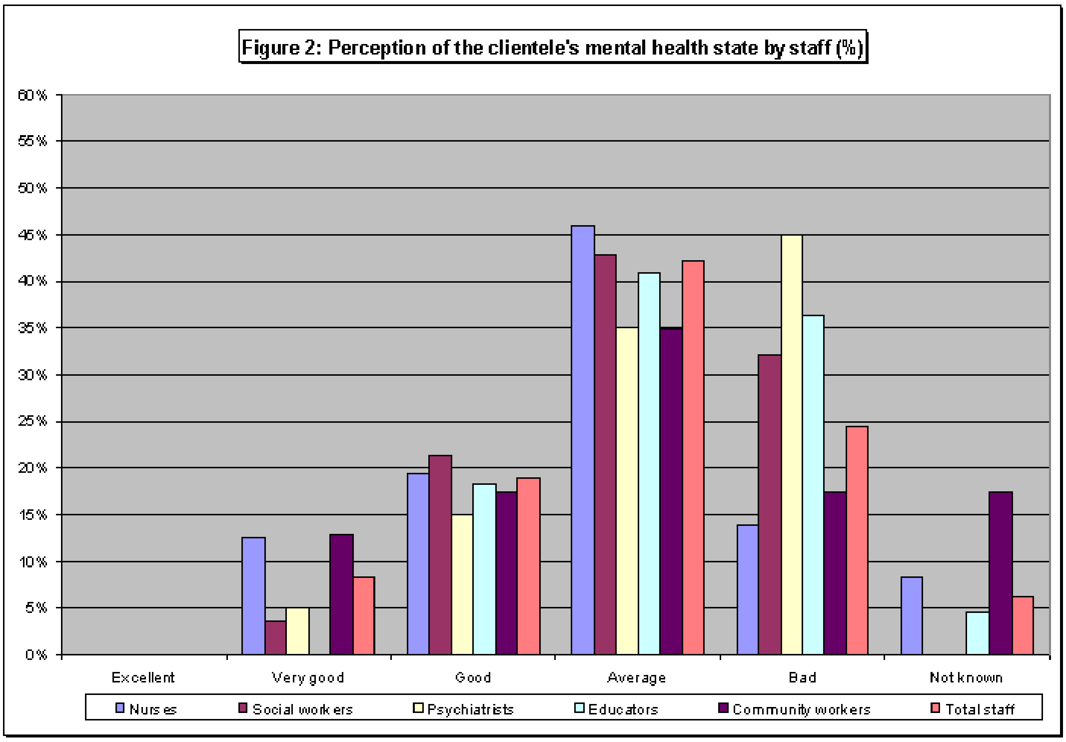

Figure 2: Perception of the clientele's mental health state by staff (%)

Statistical analyses of the data were conducted, using SPSS software (version 11.5). To measure the agreement between patients and professionals on overall needs-identification, the Kappa coefficient was used. Kappa measures the amount of agreement obtained between two raters beyond that which would be expected by chance alone (Spitznagel, & Helfzer, 1985; Crewson, 2005). Agreement is considered almost perfect when k ≥ 0.80; substantial if k is between 0.61 and 0.80; moderate, between 0.41 and 0.61; fair, between 0.21 and 0.40; and slight, between 0 and 0.20 (Middelboe, Mackeprang, Hansson, Werdelin, Karlsson, Bjarnason et al., 2001).

# Results

## Users' profile according to type of professionals (of the primary healthcare provider)

Patients who identified nurses as their most significant professionals had a socio-demographic profile similar to the patients' general profile. Most of them were diagnosed with paranoid schizophrenia (34 out of 72 or 47.2%), and many had antecedents of violence (28 or 38.9%). The number of suicide attempts was rather high (28 or 38.9%). Of all the types of professionals, nurses' perception of their patients' mental health state was the most positive, with 78% rating it average to very good. Their users ranked second compared to patients of the other types of professionals, with 88.8% perceiving their mental health state from average to excellent. These patients were the main users of community follow-up. Twenty-nine out of 72 (40.2%) mentioned being followed by a psychiatrist and a general practitioner, 17 of them (23.6%) by the same general practitioner, and 16 (22.2%) by the same psychiatrist for more than ten years. Twenty-eight out of 72 (38.9%) reported consulting another professional as well, mainly a social worker (14 or 19.5%).

The social workers' patients came mainly from rural or semi-urban settings (24 out of 28 or 85.7%). They were the only group with an almost equal number of women and men (12 patients out of 28 women or 42.9%). They also had the lowest rate of bachelors (15 out of 28 or 53.6%). They had mainly schizo-affective problems (13 out of 28 or 46.4%); a minority (4 out of 28 or 14.3%) also had another diagnosis. Psychiatric family antecedents (16 out of 28 or 57.1%) and suicide attempts (10 or 35.7%) were especially high. The social workers were also confronted with more cases of alcohol abuse than other professionals (13 out of 28 or 46.4%). Antecedents of violence were scarce (5 or 17.9%). The social workers' perception of their patients' mental health state was within the norm compared to overall professionals, with 68% considering it to be average to very good. Their patients' perception was the second-highest of the user cohort, 92.8% evaluating it from average to excellent. These patients constituted the main users of resources (2.6 resources per user). Eighteen patients (64.3%) reported being followed by another professional, nine (32.1%) by a psychiatrist and a general practitioner – seven (25%) for more than ten years.

The psychiatrists' patients were by far the most autonomous. Except for one, they lived in apartments, mostly in urban settings (13 or 65%), were rather young (averaging 42.6 years of age, SD 13.0), educated (12 out of 20 or 60% had completed junior college or university), and more than any other, single (16 out of 20 or 80%). They had fewer legal antecedents (3 or 15%), suicide attempts (also 3 or 15%) and chronic syndromes (7 or 35%). But, many had family psychiatric antecedents (15 or 75%), and a history of drug use (10 or 50%) and violence (7 or 35%). Psychiatrists perceived their patients' mental state the most negatively, with 80% considering it average or bad. Conversely, 85% of their users judged it from average to very good; however, nobody in that group rated it excellent. The psychiatrists' patients made scarce use of resources (1.8 per user), merely visiting outpatient clinics occasionally. Three users (15%) mentioned being followed by another professional as well as by a psychiatrist for the past ten years.

The educators' patients differed from those of other professionals in many aspects. They were older (on average, 50.6, SD 7.7), a significant number were separated, divorced or widowed (7 out of 22 or 31.8%, against 33 out of 165 or 20% for the cohort). Many lived in intermediary resources (8 or

36.4%), and most in semi-urban settings (17 or 77.3%). The main diagnosis for these patients was schizo-affective disorder (13 or 59.1%), and a high number also had a chronic syndrome (17 or 77.3%). The rate of suicide attempts was the highest (8 or 36.4%). But, few patients had legal antecedents (4 or 18.2%), problems of violence (4 or 18.2%), and drug (3 or 13.6%) or alcohol abuse (2 or 9.1%). The educators' perception of their patients' mental health state was the second-lowest among all professionals, 77.2% judging it to be from average to bad. Conversely, 90.9% of their users evaluated it from average to excellent. The educators' patients were the main users of specialized clinics. Nine (40.9%) reported being followed by another professional, mainly a social worker (6 or 27.3%). All were followed by a psychiatrist, and 7 (31.8%) by a psychiatrist and a general practitioner – two (9%) for more than ten years.

Finally, the patients who chose community workers were the youngest (averaging 39.3 years, SD 13.5), the most urban (13 out of 17 or 76.5%) and the least-educated (6 or 35.3% had completed elementary school only). These patients' main diagnosis was paranoid schizophrenia (7 or 41.7%). They had few antecedents of violence (4 or 23.5%), legal problems (3 or 17.6%), or alcoholism (3 or 17.6%). Community workers ranked third in the perception of their patients' mental health state, 64.7% evaluating it from average to very good. Community workers' patients were the most numerous to judge it very good or excellent (47.0%), with only patient (5.9%) considering it bad. Community workers' patients were among the most infrequent users of resources (1.8 per user), preferring services unrelated to mental health. Six patients (35.3%) were followed by another professional as well, generally a social worker (4 or 23.5%), and five (29.4%) by a psychiatrist and a general practitioner. One patient had been consulting the same general practitioner for more than ten years, and another, the same psychiatrist for as long.

### Number, severity and diversity of needs according to professionals and users

Table 1 shows the number of problems – overall (total of moderate and serious) and serious – identified by professionals and users. Professionals reported that more than 40% of users had overall needs in the following areas: psychotic symptoms (126 or 79.2%); company (95 or 59.7%); daytime activities (84 or 52.8%); money (71 or 44.7%); psychological distress (69 or 43.4%); and looking after the home (66 or 41.5%). In needs-identification, self-care was the area where professionals and users most disagreed (44 versus 13 for users). More than 40% of users perceived problems in psychotic symptoms (124 or 78.0%), company (86 or 54.1%), food (77 or 48.4%), daytime activities (75 or 47.2%), money (72 or 45.3%), and psychological distress (71 or 44.7%). Information on disorder and treatment stood out as the area where users perceived the most problems as compared to professionals (62 versus 38 for professionals). As for serious problems, professionals and users agreed that they occurred more frequently in company, daytime activities, psychotic symptoms, intimate relationships, money, transportation, sexual expression, and psychological distress. In the 14 remaining areas, the proportion of users with serious problems was less than 10%. Professionals identified more serious problems in self-care (12 vs. 0) and basic education (10 vs. 4), whereas users identified them in information (15 vs. 3) and benefits (5 vs. 1).

**Table 1: Number and percentage of users' needs according to professionals and users (N=159)**

| **CAN categories and domains of needs** | **Total needs** | | | | **Serious needs** | | | |
|---|---|---|---|---|---|---|---|---|
| | **Professionals** | | **Users** | | **Professionals** | | **Users** | |
| | **N** | **%** | **N** | **%** | **N** | **%** | **N** | **%** |
| **Basic** | | | | | | | | |
| Daytime activities | 84 | 52.8 | 75 | 47.2 | 51 | 32.1 | 37 | 23.3 |
| Food | 61 | 38.4 | 77 | 48.4 | 3 | 1.9 | 5 | 3.1 |
| Accommodation | 45 | 28.3 | 48 | 30.2 | 2 | 1.2 | 1 | 0.6 |
| **Subtotal** | **190** | | **200** | | **56** | | **43** | |
| **Health** | | | | | | | | |
| Psychotic symptoms | 126 | 79.2 | 124 | 78.0 | 33 | 29.7 | 22 | 13.8 |
| Psychological distress | 69 | 43.4 | 71 | 44.7 | 22 | 13.8 | 18 | 11.3 |
| Physical health | 59 | 37.1 | 59 | 37.1 | 8 | 3.8 | 7 | 3.8 |
| Safety to self | 19 | 11.9 | 18 | 11.3 | 5 | 3.1 | 7 | 4.4 |
| Drugs | 20 | 12.6 | 12 | 7.5 | 2 | 1.2 | 3 | 1.9 |
| Safety to others | 18 | 11.3 | 13 | 8.2 | 4 | 2.5 | 5 | 3.1 |
| Alcohol | 17 | 10.7 | 11 | 6.9 | 3 | 1.9 | 2 | 1.2 |
| **Subtotal** | **328** | | **308** | | **77** | | **64** | |
| **Social** | | | | | | | | |
| Company | 95 | 59.7 | 86 | 54.1 | 50 | 31.4 | 50 | 31.4 |
| Intimate relationships | 40 | 25.1 | 43 | 27.0 | 26 | 16.3 | 29 | 18.2 |
| Sexual expression | 31 | 19.5 | 30 | 18.9 | 17 | 10.7 | 20 | 12.6 |
| **Subtotal** | **166** | | **159** | | **93** | | **95** | |
| **Functioning** | | | | | | | | |
| Money | 71 | 44.7 | 72 | 45.3 | 26 | 15.3 | 22 | 13.8 |
| Looking after the home | 66 | 41.5 | 62 | 39.0 | 4 | 2.5 | 2 | 1.2 |
| Basic education | 18 | 11.3 | 14 | 8.8 | 10 | 6.3 | 4 | 2.5 |
| Self-care | 44 | 27.7 | 13 | 8.2 | 12 | 7.5 | 0 | 0.0 |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Childcare | 6 | 3.8 | 7 | 4.4 | 2 | 1.2 | 3 | 1.9 |
| **Subtotal** | **205** | | **168** | | **54** | | **31** | |
| **Services** | | | | | | | | |
| Information on disorder & treatment | 38 | 23.9 | 62 | 39.0 | 3 | 1.9 | 15 | 9.4 |
| Transport | 30 | 18.9 | 40 | 25.2 | 24 | 15.1 | 20 | 12.6 |
| Benefits | 12 | 7.9 | 11 | 6.9 | 1 | 0.6 | 5 | 3.1 |
| Telephone | 6 | 3.8 | 2 | 1.2 | 2 | 1.2 | 2 | 1.2 |
| **Subtotal** | **86** | | **115** | | **30** | | **41** | |
| **Total** | **975** | | **950** | | **310** | | **279** | |

Table 2 indicates the average number of needs (moderate, serious and overall) pointed out respectively by types of professionals and users, as well as the percentage of serious problems among overall problems. Needs identified by users averaged 5.97 (SD 3.40), of which 1.75 (SD 1.84) were serious (29.4%). As for professionals, the average number of overall problems they noted was 6.13 (SD 3.44) per patient, i.e. 4.18 moderate problems (SD 1.63) and 1.94 serious problems (SD 1.82). Serious needs thus represented nearly a third of all overall problems. Psychiatrists pointed out many fewer problems (moderate and serious) than any other type of professionals, with serious problems twice as low as the average. Conversely, community workers and social workers mentioned more moderate and serious problems than the average. Community workers, at a rate of 2.82 (SD 2.39), perceived more serious problems than any other type of professionals. Nurse showed converse profiles, mostly reporting moderate problems and few serious problems. Finally, educators listed needs nearest the average. Educators and community workers were the only ones to perceive more problems on average than their respective patients.

**Table 2: Average number and percentage of needs according to types of professionals and their patients**

| Types of professionals/users | Moderate needs | Serious needs | Overall needs | Ratio needs Serious / Overall |
|---|---|---|---|---|
| Nurses | 4.50 | 1.87 | 6.37 | 29.4% |
| Users | 4.64 | 2.14 | 6.78 | 30.5% |
| Social workers | 4.54 | 2.25 | 6.79 | 33.1% |
| Users | 5.46 | 1.93 | 7.39 | 26.1% |
| Psychiatrists | 2.70 | 1.00 | 3.70 | 27.0% |
| Users | 3.95 | 1.20 | 5.15 | 23.3% |
| Educators | 4,14 | 2.00 | 6.14 | 32.6% |
| Users | 2.95 | 1.36 | 4.31 | 31.6% |
| Community workers | 4.23 | 2.82 | 7.06 | 38.1% |
| Users | 3.76 | 1.29 | 5.05 | 25.6% |
| **Professionals total** | 4.18 | 1.95 | 6.13 | 31.8% |
| **Total needs per user** | 4.22 | 1.75 | 5.97 | 29.4% |

Of the 22 CAN domains regarding overall needs: nurses noted fewer problems in company (40.0% in total, as compared with 45.3% of professionals); social workers noted fewer problems in transportation (just 10.0% of the problems; 17.6% in the view of professionals) and psychotic symptoms (14.7%). Only two domains caught the attention of psychiatrists: psychotic symptoms (identified by all of them) and company (13 out of 20 or 65.0%). Educators reported a higher number of problems in intimate relationships (25.0% in total; as compared with 13.8% for professionals), safety to self (21.1%), transportation (20.0%), benefits (16.7%), and safety to others (16.7%). Needs related to sexual expression (19.4% in total; 10.7% for professionals), safety to others (16.7%), basic education (16.7%), psychological distress (15.7%), drug use (15.0%), and intimate relationships (15.0%) were the main domains mentioned by the community workers. Two domains, childcare and telephone, were clearly mentioned less frequently by all types of professionals and reported mostly by the nurses.

As for serious needs, nurses were the only ones to identify at least one serious problem in each of the 22 CAN domains. They pointed out few serious problems in the social category of needs, but a great number in services and functioning. More than their patients, they mentioned serious needs in daytime activities (22 vs. 15) and transportation (13 vs. 9). But, they listed many fewer problems than their patients in intimate relationships (12 vs. 5), information on disorder and treatment (8 vs. 2), money (16 vs.11), sexual expression (12 vs. 8), and benefits (4 vs. 1). Psychiatrists reported problems in nine domains only. The few serious needs were found predominately in company, psychotic symptoms, and psychological distress. Conversely, social workers, educators, and community workers noted the highest percentage of serious problems. The most serious problems encountered by social workers, educators, and community workers were in the basic needs category. In comparison with their users, social workers pointed out many more serious problems in money (6 vs. 2), daytime activities (13 vs.10), and psychological distress (5 vs.2); and their patients, in company (13 vs. 9). Apart from the basic needs category, educators identified numerous problems in services and very few in functioning. They perceived more serious problems than their patients in daytime activities (13 vs. 5), company (11 vs. 5), intimate relationships (7 vs. 2), sexual expression (4 vs. 1), and psychotic symptoms (6 vs. 3).

As for the community workers, they noted more serious problems than their patients in company (9 vs. 3), daytime activities (7 vs. 3), money (7 vs. 2), psychological distress (3 vs. 0), and sexual expression (4 vs. 0), whereas their users perceived more serious problems in information (2 vs. 0).

## Agreement between types of professionals and their users on overall needs perceived

Table 3 shows the level of agreement between types of professionals and users based on the Kappa (k) coefficient. Globally, the degree of agreement between professionals and users was 0.42, a moderate rate. Nurses, social workers, psychiatrists and educators attained moderate agreement, with educators standing out, however, with a coefficient of 0.54. All types of professionals exhibited discordant to fair agreement in the needs domains of daytime activities, basic education, self-care, and telephone.

**Table 3: Agreement between types of professionals and their users on overall needs perceived**

| CAN categories and domains of needs | Nurses (n=72) | Social workers (n=28) | Educators (n=22) | Psychiatrists (n=20) | Community workers (n=17) | Professionals total (n= 165) |
|---|---|---|---|---|---|---|
| Basic | **0.42** | **036** | **0.48** | **0.14** | **0.28** | **0.38** |
| Accommodation | 0.52 | 0.49 | 0.74 | 0.32 | 0.36 | 0.53 |
| Food | 0.47 | 0.38 | 0.50 | -0.05 | 0.13 | 0.34 |
| Daytime activities | 0.22 | 0.23 | 0.22 | 0.35 | 0.23 | 0.24 |
| **Health** | **0,54** | **0.45** | **0.70** | **0.61** | **0.28** | **0.52** |
| Physical health | 0.42 | 0.29 | 0.79 | 0.63 | 0.46 | 0.49 |
| Psychotic symptoms | 0.29 | 0.01 | 0.46 | 0.00 | -0.16 | 0.19 |
| Psychological distress | 0.50 | -0.04 | 0.47 | 0.34 | -0.16 | 0.31 |
| Safety to self | 0.18 | 0.63 | 0.70 | -0.14 | -0.09 | 0.30 |
| Safety to others | 0.16 | -0.05 | 0.61 | 0.00 | 0.30 | 0.25 |
| Alcohol | 0.37 | 0.61 | * | -0.05 | 0.64 | 0.45 |
| Drugs | 0.13 | 0.63 | 0.65 | 0.00 | 0.45 | 0.31 |
| **Social** | **0.23** | **0.30** | **0.41** | **0,63** | **0.25** | **0.31** |
| Company | 0.16 | 0.44 | 0.47 | 0.47 | 0.19 | 0.30 |
| Intimate relationships | 0.09 | 0.05 | 0.04 | 0.62 | 0.27 | 0.14 |
| Sexual expression | 0.23 | 0.18 | 0.46 | 0.00 | 0.00 | 0.21 |
| **Functioning** | **0.36** | **0.39** | **0.49** | **0.03** | **0.29** | **0.38** |
| Looking after home | 0.33 | 0.42 | 0.42 | 0.03 | 0.09 | 0.32 |
| Self-care | 0.23 | -0.07 | -0.08 | 0.00 | 0.21 | 0.14 |
| Childcare | 0.47 | 0.00 | 0.64 | 0.00 | * | 0.44 |
| Basic education | 0.11 | 0.00 | * | * | 0.35 | 0.16 |
| Money | 0.22 | 0.44 | 0.55 | -0.09 | 0.03 | 0.30 |
| **Services** | **0.25** | **0.41** | **0.39** | **0,56** | **0.11** | **0.31** |

| | | | | | | |
|---|---|---|---|---|---|---|
| Information | 0.06 | 0.13 | 0.32 | 0.77 | -0.03 | 0.18 |
| Transport | 0.36 | 0.40 | 0.40 | 0.00 | 0.04 | 0.34 |
| Telephone | 0.31 | 0.00 | * | * | 0.00 | 0.24 |
| Benefits | 0.07 | 0.63 | 0.00 | 0.00 | 0.00 | 0.20 |
| **Total** | **0.41** | **0.42** | **0.54** | **0.47** | **0.27** | **0.42** |

* Kappa coefficient could not be calculated due to insufficiently spread data.

Nurses and their patients demonstrated moderate agreement in health and basic needs, but only fair agreement in the three other needs categories. They fared best in the domains of psychological distress, telephone and self-care – and worst in daytime activities. Social workers and their patients displayed fair agreement in all needs categories, except functioning and health. Specifically, self-care, psychotic symptoms, and psychological distress were needs domains where agreement was slight or discordant. But, it was substantial with respect to drugs, alcohol, safety to self and benefits. As for looking after the home, transportation and benefits, agreement was best achieved by the social workers as compared with the other types of professionals. Agreement between psychiatrists and users was substantial in social and health needs categories, fair in services, and slight in basic and functioning needs. In social needs, the domain of intimate relationships stood out when compared with other types of professionals. Psychiatrists also exhibited the highest level of agreement in the domains of company, daytime activities, and information on disorder and treatment. However, they exhibited slight or discordant agreement in five out of the seven health-needs domains and with regard to food (basic needs category). Educators were the only professionals who marginally presented a moderate rate in four needs categories. The level of agreement was high in the domains of accommodation, food, physical health, psychotic symptoms, safety to others, safety to self, drugs, company, sexual expression, looking after the home, childcare, money and transport, but fair in daytime activities, slight in intimate relationships, and discordant in self-care. The agreement between community workers and users was the lowest one, with a coefficient of 0.27, fair in all categories except in service needs where it was slight. But, it was substantial regarding alcohol use, and highest in identifying basic education problems.

### Appropriateness of help in meeting needs

Professionals reported a rate of appropriate help of 84.8% (827 out of 975) vs. 74.7% (710 out of 950) for users. For professionals, the percentage of needs having received adequate help varies from 71.6% (53 out of 74) for psychiatrists to 91.7% (110 out of 120) for community workers. As for users, the percentage oscillates from 52.3% (45 out of 86) for community workers' patients to 87.4% (83 out of 95) for educators'. The closest rates between users and professionals occur among users/educators (87.4% vs. 91.1% or 123 out of 135) and users/psychiatrists (70 out of 103 or 68.0% vs. 71.6%). The respective total of appropriate help for users/nurses (356 out of 482 or 73.9% vs. 384 out of 459 or 83.7%) and users/social workers (157 out of 207 or 75.9% vs. 169 out of 190 or 84.2%) is near the overall mean. Lastly, there is an important gap on help adequacy between community workers (91.7%) and their patients (52.3%).

## Discussion

The aim of this article was to examine and explain the discrepancies in needs-identification and appropriateness of help according to patients' profiles and types of healthcare professionals and their users. For that purpose, we interviewed 159 user/professionals pairs, using the French-language version of the Camberwell Assessment of Need (CAN) instrument.

Selection of a type of professional as the primary healthcare provider may be explained by users' socio-demographic and clinical profile and resources utilization. Thus, the most autonomous patients, having fewer needs and using scarcer resources, were inclined to opt for a psychiatrist whereas patients living in intermediary resources, being older, presenting chronic syndromes and consulting more specialized clinics tended to choose an educator. Users grappling with numerous problems and utilizing more diversified resources selected nurses and social workers to a greater extent. Nurses were further correlated with patients diagnosed with paranoid schizophrenia and presenting antecedents of violence. Social workers were more favoured by users with schizo-affective disorders and alcohol abuse. Finally, patients preferring a community worker as their most significant professional were young, poorly educated, and lived for the most part in urban settings. These patients used fewer resources and usually considered their mental health state to be better than the rest of the cohort.

The perception of users' needs expressed by different types of professionals varied widely. Psychiatrists had a tendency to identify fewer moderate and serious problems than other professionals. Half of the needs occurred in the health category: in particular, psychotic symptoms. Company was the other domain to which psychiatrists paid more specific attention. Psychiatrists also viewed their patients' state of mental health much more negatively than did other types of professionals. They seemed to associate mental health state more with clinical problems directly related to mental disease such as psychotic symptoms and psychological distress and to interpersonal issues (i.e. company). Conversely, social workers as well as community workers (for the most part made up of professionals with a social science background) listed more moderate and serious needs than other types of professionals. They also identified a greater number of overall problems in the social and functioning categories than in health and services needs. But, these two groups found fewer overall problems in psychotic symptoms, mentioning instead more needs in substance abuse for the first group, and safety to self and others for the second group. They broadly defined their patients' mental health state, relating it more to basic and functioning needs categories, associated with the indirect effects of schizophrenia. Educators and to a lesser extent nurses outlined overall needs more evenly in the five categories. Nurses largely reported moderate problems in all categories, except social needs, but very few serious problems globally. Educators noticed numerous serious problems in all needs categories, save functioning. These results confirm Slade's (Slade, 1994) hypothesis that healthcare providers tend to emphasize needs in certain domains in accordance with their professional background.

With such differences in needs-identification and in light of the Slade study mentioned above, agreement between professionals and users was expected to be difficult to reach. Moderate agreement between users and professionals (0.42) was obtained in our study. This corresponded almost exactly to what Slade et al. (Slade et al. 1998) had reported (0.44). An almost identical rate of moderate agreement was found among psychiatrists, social workers, and nurses. Only educators stood slightly out with an agreement of 0.54, while community workers exhibited a fair one (0.27). Agreement varied considerably from 0.31 in the social needs category to 0.52 in health needs, from 0.14 in the domains of intimate relationships and self-care to 0.51 in accommodation. The higher agreement between educators and users may be explained by the time educators spend daily with their patients in rehabilitation and reintegration. This allows them to be better aware of their patients' current and evolving needs. The only other types of professionals as much in contact with their users are those making regular house calls, such as nurses or social workers in intensive community follow-up. According to Macpherson, Varah, Summerfield, Foy, & Slade, (2003), the agreement between users and healthcare providers is higher when the professional is a clinician engaged in patient aftercare, therefore more aware of users' needs. The low agreement between community workers and their patients may be explained by the users' profile. These patients tend to misjudge or ignore their disease, as shown by the highly positive perception of their mental health state and the underestimation of their psychotic symptoms and psychological distress. Their mistrust of psychiatrists and other mental health specialists may testify to their paranoid schizophrenia. Being younger and less educated, they may also be at an earlier stage of recognition and acceptance of their mental disorder.

Regardless of profession, healthcare providers tended strongly not to recognize some of their patients' needs, such as information on disorder and treatment and benefits. They also had difficulties assessing intimate relationships and sexual expression, as demonstrated by the slight agreement rate between their responses and their patients'. Middelboe, Mackeprang, Hansson, Werdelin, Karlsson, Bjarnason et al., (2001) noted that these four domains are overlooked by professionals because they are not directly related to schizophrenia, which explains the inappropriateness or insufficiency of care to answer those needs. Moreover, schizophrenia is associated with cognitive deficiencies that reduce capacity to store information (Brenner, Hodel, Roder, & Corrigan, 1992; Bengtsson-Tops, & Hansson, 1999), hence the necessity for a professional to be alert when answering patients' questions regarding their mental health.
Psychotic symptoms presented slight agreement as well, but it was primarily due to substantial skews in the ratings' distribution (Issakidis, & Teeson, 1999; Slade et al., 1996). Kappa statistics are unstable when a zero or a small number appears in some cells (Feinstein, & Cicchetti, 1990). In fact, the agreement for psychotic symptoms was 71.7% for all professional/user pairs, ranging from 90% (18 out of 20) for psychiatrists to 68.7% for educators (15 out of 22).

Self-care and drugs as well as company and daytime activities and safety to self and others are also domains where important discrepancies were observed between users and professionals. Olfactory deficits often found among individuals with schizophrenia (Moberg, Doty, Turetsky, Arnold, Mahr, Gur et al. 1997; Hudry, Saoud, d'Amato, Daléry, & Royet, 2002) may account for the small number of patients mentioning self-care problems. Moreover, refusal to wash is one of the negative symptoms generally associated with schizophrenia. Drug users have a tendency to deny their substance abuse problems whether or not they suffer from schizophrenia. The low rate of agreement for company and daytime activities may be due to some users' refusal to join structured or groups activities, especially involving patients only; however, it may also be due to the types of structured activities being inappropriate for patients' needs. Finally, some patients underestimate the danger that they represent to themselves and to others.

In spite of the global moderate agreement between professionals and users, the patients' needs were met at 74.7% according to users and at 83.8% according to professionals. Does this mean that agreement between users and professionals is not as important as is generally believed? The greater the similarity in user/professionals responses, the higher, generally, the percentage of appropriate help given. The sole exception is found among user/psychiatrist pairs, where, despite moderate agreement, the appropriateness of help is under average. Users and psychiatrists nevertheless rate the help adequacy similarly (68% vs. 71.6%). The main dissatisfactions of the psychiatrists' patients pertain to the length of the consultations and intervals between appointments. As for community workers, their patients' profile seems to account for the poor results achieved. Their patients' unmet needs are generally associated with poverty (food, money, basic education, etc.). Moreover, users who identified a community worker as their most significant professional are less inclined to ask for help. They ask for moderate or high level of help for only 30 of their 86 problems (34.9% vs. 46.9% or 446 out of 950 for all users). They also receive less moderate or important (high) help from local services (25.6% or 22 out of 86 vs. 42.0% or 399 out of 950) and from their relatives (13.9% or 12 of 86 vs. 19.7% or 188 out of 950) than the general mean. It would be unfair to associate the gap between community workers and their patients with a lack of competence in this category of professionals. In fact, community workers provide some help to a marginal population which, without them, would be deprived of mental health services.

To sum up, our results show the importance of patients' profiles and types of professionals in needs-assessment. Patients tend to select as their primary healthcare provider a type of professional more closely related to their socio-demographic, clinical and resources utilization profile with regard to the number, severity and diversity of their needs. Types of professionals are more inclined to prioritize or neglect certain needs depending on their own background. The moderate agreement in overall needs and the considerable appropriateness of help between professionals and users obtained in our study seems testify this trend.

# Conclusion

There are certain shortcomings in this study, namely the lack of complete data on the most significant professionals' years of practice and users' length of care with them. These two elements play an important role in understanding patients' needs. Moreover, the size of our sampling, specifically for the community workers as well as the lack of experience of some of the CAN interviewers may have slightly biased certain parts of the data. Also, some variables that may have played a role in the appropriateness of help have not been considered here, including: help given respectively by relatives or services; level of help needed; extent of continuity of care; and network services integration. Moreover, it would be interesting to analyse the assessments of different professional disciplines on the same patients, or to observe the degree of agreement between healthcare providers and users at two measuring times.

Nevertheless, to our knowledge, this study is the first to provide an exhaustive comparison between the perceptions of different types of professionals of their patients' needs and to relate them to their patients' profiles. The results of this study reinforce the importance of considering the viewpoints of both professionals and users in needs-assessment for a more comprehensive perspective. In spite of all the efforts made these past few years to promote the bio-psychosocial model in the mental health field, this study shows that professionals still prioritize some needs to the detriment of others. No professional may claim to know perfectly his or her patient's condition. It is therefore important that mental health services offer more cross-vocational training programs as well as interdisciplinary needs-evaluation and diversified care for patients – systematically including patients' perspective.

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# Nursing and the Teaching of Mental Health Care in Brazil

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## Abstract

This study aims at presenting the configuration of psychiatric nursing teaching in Brazil. A questionnaire concerning psychiatric nursing teaching was sent to 15 nursing schools. A qualitative analysis of the answers was done and the data were grouped according to the characterization of the teaching board and of teaching itself, including the offered disciplines, teaching schedules, place for practical classes, contents approached and extension projects. The obtained results evidenced the recent concern of most schools in offering the students contact with new devices of care to mentally ill individuals, supported on the principles of psychosocial attention, which highlight the need to humanize attendance through entailment, receptivity, and the inclusion of the family in the process of attendance and re-socialization.

**Keywords:** teaching, psychiatric nursing, mental health.

## Introduction

In 1949, the Brazilian legislation determined the obligatoriness of the teaching of psychiatric nursing in nursing graduation courses in the country. Since then, the theme of the teaching in the area has been object of investigation concerning the approached contents and the academic preparation for the execution of nursing care in mental health.

Studying the teaching of psychiatric nursing and mental health has been, for a long time, a present concern in Brazilian nursing, as it can be observed through several works such as those of Ungaretti (1958), Fernandes (1959), Minzoni (1966), Foregatto & Saeki (1973), Arantes (1973), Fernandes (1979, 1982), Fraga et al (1986), and those of Stefanelli (1986), Lobato (1989), Silva (1991), Proença (1993), Braga (1993; 1998), Barros (1996) Kantorski & Silva (2001) and Alencastre et al. (2000).

This thematic has been focused under different aspects over the years, and in the current context the relevance of this debate has been highlighted in the face of the legality of new curricular proposals in Brazilian nursing, as well as specifities regarding the transformation of care practices in mental health. In this article we aim at characterizing the graduation teaching in psychiatric nursing and mental health.

# Method

In this study we performed a qualitative, descriptive and analytic research. The proposed instrument was a questionnaire applied to teachers of psychiatric nursing and mental health from 15 nursing schools of the state of Rio Grande do Sul, southern Brazil.

As a first methodological procedure, we sent a letter to the Nursing Schools informing them about the purpose of our study, the objectives and methodological procedures of the research in order to obtain the agreement of the studied institutions.

We also sent them the questionnaire, instrument of this research, and a free and clarified agreement document to be signed by the informants respecting ethical procedures due to the Brazilian legislation for research involving human beings. The questionnaire consisting of open and closed questions concerning the teaching of psychiatric nursing was sent to 15 nursing schools. Nine of those schools returned the questionnaire filled in.

Regarding the operationalization of data, the following steps were accomplished: ordering, classification, and final analysis. The ordering of data, obtained through the questionnaire, occurred after successive re-readings of the whole material and after data grouping and organization from the meditation on the purpose of the research, resulting generic thematics which will be specified in the results. Data classification occurred from attempts to determine the set of information presented in the questionnaire considering the central convergences and divergences verified.

Data were grouped according to the characterization of the teaching board and of teaching itself, including offered disciplines, teaching schedules, places where the practical classes were taught, contents approached and extension projects. These data were analyzed from the following thematics: contextualization of the trajectory of mentally ill individuals in history and new devices of care in mental health.

We will briefly present (Table 1) a characterization of the teachers in the field of psychiatric nursing and mental health, from the studied institutions, who answered the research instrument.

**Table 1 Teacher's Characterization**

| Teacher's institution of origin | Year of conclusion of graduation course | Time of conclusion of graduation | Time of performance in the area | Qualification |
|---|---|---|---|---|
| 1 | 1972 | 30 years | 29 years and 3 months | Residence in Psychiatric Nursing, Specialization, Mastership, Doctorate |
| 2 | 1972 | 30 years | 30 years | Specialization / Doctorate |
| 3 | 1974 | 28 years | 28 years | Specialization and Mastership |
| 4 | 1976 | 26 years | 25 years | Specialization and Mastership |
| 5 | 1985 | 17 years | 16 years | Mastership |
| 6 | 1986 | 16 years | 7 years | Specialization and Mastership |
| 7 | 1987 | 15 years | 15 years | Residence in Psychiatric Nursing and Mastership |
| 8 | 1990 / 1983 | 12 / 19 years | 12 / 19 years | Specialization and Mastership |
| 9 | 1997 | 5 years | 10 years | Specialization (Interdisciplinary Residence) and Mastership |

In the analysis of data obtained through the questionnaire, two thematics concentrated the anxieties and meditations about the teaching process in nursing schools. Such thematics are: the contextualization of the trajectory of mentally ill individuals in history and the presentation to nursing students of new devices of care in mental health.

# Results

## Contextualization of the trajectory of the mentally ill individual in history

According to Kalkman (1974), until 1880, nursing practice in psychiatric hospitals served the custody of the patient and it was based on Florence's principles, which were: the cleanness of wards, personal hygiene, fresh air and exercises, good sleeping conditions and adequate feeding.

In Brazil, up to the First Republic nursing assistance had only a healing character and it was performed by religious people. Hospital employees were Charity Sisters (a group of nuns), who held administrative power, and laymen, usually former patients or servants.

From the opening of Pedro II Hospital, in 1852, in Rio de Janeiro, a dispute of power between the Charity Sisters and the doctors took place. In Brazil, the context of dispute between the Charity Sisters and the psychiatrists represented a dispute for the hegemony in this new space – the hospital – which included the medical profession claim of bringing together exclusively the knowledge and the power of intervention and sequestration of madness, and also the administrative power to admit, scrutinize, classify, and to discharge people from madhouses (Machado et al., 1978).

In 1890, Pedro II Hospital became nationalized and its name was changed to 'Hospício Nacional de Alienados'. Doctors ascended to power ad nuns left the hospitals. Due to the shortage of employees the Government had to appeal to French nurses. In this context, on September 27th, 1890, the Professional Schools of Nurses of the 'Hospício Nacional de Alienados' (Alfredo Pinto School) was created, officially beginning the teaching of nursing in Brazil (Kantorski & Miron, 2002).

Foucault (1993), Goffman (1990), Castel (1978, 1987), approaching the history of madness, the birth of psychiatry and the medical procedures concerning madness, instituted since the classic, middle and modern ages, reinforce that madhouses, which in the classic age had as their main function to serve as guest-houses, started to constitute themselves in cloistering and internment institutions which have picked up modern medicine hospital connotation and have to cope with modern economical, political and social demands.

Birman & Costa (1994) assert that after Second World War the context regarding the therapeutic impotence of psychiatry, the high levels of chronic stages of mental illness and social incapacitation made the theoretical field of assistential psychiatry reach another dimension, configuring two significant periods of criticism and reformist propositions, to be known: movements of criticism to asylum structure involving reformulations circumscribed inside the madhouses, such as institutional psychotherapy (in France) and therapeutic communities (in England and in the United States), reaching its extreme with family therapies; and in a second moment sectional or preventive psychiatry (in the United States) which in a certain way overcomes the previous proposals, expanding the reformations to beyond the asylum space and introducing psychiatry in the public space with its new object, that is, mental health. Amarante (1995, p. 29) complements this discussion by adding the emergency of anti-psychiatry (England) and the Italian experiences which emerge from Basaglia as ruptures with the reform proposals presented so far, for questioning "...the medical-psychiatric device itself and the institutions and therapeutic devices related to it."

The psychiatry trends of reformist character, have built a more humanized knowledge and performance directed to the patient as a whole, emphasizing biologic, psychological, and socio-cultural aspects involved in this process. And, for that, it was necessary to explore the particularities concerning the psychic suffering and its trajectory over the years.

Understanding the history of madness in the world and all the problematic which underlies its trajectory, is part of the curriculum of universities such as 1, 3, 5, 6, 7, and 9, which emphasize the need to de-stigmatize the mad individual, stimulating nursing students to have contact with mentally ill individuals.

Prejudice toward mentally ill individuals is still accentuated in our society. In this scene, universities, and in particular the teaching of psychiatric nursing – object of our study – have taken up an important role towards the de-stigmatization of the mentally ill individual, redefining the space of the disease, which despite being important in the patient's life does not totalize him. The referred deconstruction goes through the capacity of teaching to re-place the individual who suffers, while a human being with family, friends, desires, limitations and deprivations, and whose needs health services and its professionals – among them, the nurses – must be able to welcome, to assist, and to look after.

## New devices of care in mental health

The need to present nursing students with new devices of care to mentally ill individuals is part of the syllabus in such schools as 1, 3, 5, 8, and 9. The development of practical classes in the basic attention network, outpatient clinics, and other community mental health services and the problematization of several forms of intervention in mental health predominant in our society articulate themselves with the principles of new mental health policies in the country. These policies stress the need to accomplish the principles of hierarchization of health attendance and the consequent promotion of activities that might replace those primarily institutionalized ones, putting to practice the concepts of assistance to the human being as a whole, through the importance of entailment with the patient, receptivity, the therapeutic relationship, and through the inclusion of the family as part of this therapeutics, and the preparation of the patient for social re-insertion.

We verify (Table 2) the therapeutic and /or practical presence of contents related to care devices, such as Psychosocial Attention Centers, as open services which provide care to individuals with severe and persistent mental illness, in a daily regime with a multi-professional staff, based on individualized therapeutic plans which aim at individual's psychosocial rehabilitation.

**Table 2 Contents and Places for Practical Classes**

| Institution | Places for practical classes | Priority contents |
|---|---|---|
| 1 | Psychiatric Clinics and<br>General Hospital Units | The healthy individual (structure, development and characteristics of the vital cycle). Existence crisis (mental health – disease process and nursing intervention), models and modalities of attendance in mental health, Mental disorder itself and groups and their dynamics |
| 2 | Psychiatric Clinics and<br>Psychosocial Attendance Centers | Psychopathology of psychic functions, Main groups of mental illness, Psychiatric reform, Interpersonal therapeutic relation and Psychopharmacology |

| | | |
|---|---|---|
| 3 | Units of basic attention and<br>Mental Health Care Facility | Mental health epidemiology, Citizenship and mental health, Psychiatric reform and Law of psychiatric reform in Rio Grande do Sul, Declaration of Caracas, II National Conference of Mental Health Report, Psychosocial rehabilitation and nursing assistance in mental health |
| 4 | Basic Health Units and /or<br>Outpatient Clinics (90%) and<br>Psychiatric Clinics (10%) | Nursing advice, Structure and development of personality, Student / client therapeutic relation, Disturbance of mood and reasoning, Collective mental health |
| 5 | Psychiatric Unit and Psychosocial Center | Self-knowledge, Communication, Therapeutic relationship, Mental health policies, Psychiatric perturbation |
| 6 | Psychosocial Attention Center | Psychiatric and mental health review |
| 7 | Town General Hospitals, Mental Health Outpatient Clinics and Psychosocial Attention Center, Groups of socio-therapy in the district (group of chronic psychiatric patients), Community | The area of mental health as a field of nurses' performance, Mental health policies, Nursing intervention in situations of psychic suffering, Investigation of psychic functions and the study of psychopathologies and their respective nursing care |
| 8 | Psychosocial Attention Center, Psychiatric Hospital, Technical visit to School-hospital, and Psychiatric Clinic, and visits to places where proposals concerning psychiatric reform are developed | Psychiatric reform, Communication, Psychosocial rehabilitation, Psychic function (psychic exam), Psychopathologies and Psychopharmacology |
| 9 | Psychosocial Attention Center, Project Home Visit (where nursing students visit patients at home), Psychiatric Hospital | Policies of mental health ( history of madness and world-wide ambit transformations, mental health policies in Brazil and in Rio Grande do Sul), The process of de-institutionalization and nursing: paradigms of a new model of assistance, psychosocial rehabilitation, main psychic disturbances (definition, nursing diagnosis, intervention, evaluation), Family, groups and psychic structure |

Institution 1, though developing its practical classes exclusively in psychiatric internment units, tries to instrument students through theoretical contents, aiming at the contact with mentally ill individuals in different assistance and community services. It approaches the individual - professional interpersonal relation as a therapeutic possibility, emphasizing self-care and re-socialization.

Institution 4 develops its work by offering individual nursing consultations, individual and group therapeutic actions and home visits.

Institution 2, however, develops its practical classes in the psychiatric hospital, preconizing the relation student - psychiatric patient through interpersonal therapeutic relation. The emphasis on psychopathologies of the psychic functions and the main groups of mental illness direct the teaching of the discipline, which highlights the classical hospital-centered point-of-view in the teaching of the institution.

Institution 7 proposes the insertion of students in several levels of health attention (outpatient clinics, community, hospitals) to enable them to develop nursing interventions in situations of psychic suffering, so much linked to mental illness itself as to other painful situations which the individuals may be undergoing (victims of terminal disease, patients in pre-surgical situation, among others). For such, besides curricular activities of the discipline, the institution keeps an extra-curricular agenda for the performance of theoretical discussions about the situations experienced in practical classes, through the Group of Nursing Studies in Mental Health, which is coordinated by teachers of the area and in which students of the course partake. It also holds a Group of Socio-therapy in which students who are attending the discipline of Nursing in Mental Health take part.

In case we analyze the institutions which have inserted themselves in services typically constituted in the context of recent transformations in Brazilian psychiatric assistance, such as Psychosocial Attention Centers, we are to highlight the following ones: 2, 5, 6, 7, 8, and 9. Out of the 9 institutions which answered the research instrument, 6 have clearly demonstrated a curricular concern regarding the education of generalist nurses. Such concern is expressed through the insertion of the student in the practical field, anchored to mental health services which have been structured supported on principles of psychiatric reform.

In 1989, Bill number 3.657/89 authored by deputy Paulo Delgado was presented to the Brazilian National Congress, being approved only in April 2001, predicting the re-structuring of Brazilian psychiatric assistance with the progressive replacement of madhouses by new treatment and receptivity devices.

In the last two decades, the psychiatric reform movement in Brazil has been strongly influenced by the Italian democratic psychiatry movement. The progressive incorporation of psychiatry reform principles is materialize in the Brazilian context through regulations 189/1991 and 224/1992 from the Health Ministry and through the creation of new services. Regulations 189 and 224 have established the remuneration of new procedures, such as: individual and group consultations to professionals such as nurses, psychologists and social assistants; attendance in therapeutic workshops, psychosocial attendance centers, day-hospital, emergency and internment in general hospitals; they also regulated and defined minimum patterns for running mental health services aiming at the construction of a diversified assistance network. In February 19th, 2002, governmental regulation 336 classified Psychosocial Attention Centers in crescent order by comprised population and by complexity, defining minimum professional staff, establishing its target clientele – severe and persistent disturbance cases – and determining its functioning in a specific area independent of any hospital structure.

We can see, through data presented on table 3, and other information obtained from the questionnaire, that these changes demanded curricular reformulations which, until 2000, in some schools coincided with the increasing of disciplines teaching schedules, especially concerning practice hours, such as the case of institutions 8 and 9. In institution 8, students have the disciplines of Mental Health I (60 theoretical hours per semester) and Mental Health II (120 theoretical-practical hours per semester); and in institution 9, students have classes on the disciplines of Mental Health (60 theoretical hours + 30 practical hours per semester) and Psychiatric Nursing (30 theoretical hours + 60 practical hours per semester) totalizing 180 hours per semester.

Other institutions, such as 3, 4 and 6, carried on with their original curricular schedules, but re-adapted training schedules, allowing more hours for practical classes in community services. In institution 2, the unification of the disciplines of Psychiatric Nursing and Mental Health with the Supervised Training in a discipline called Psychiatric Nursing and Mental Health increased teaching schedules, but practical classes still converged to Psychiatric Hospitals. However, the new proposal of the discipline intends to include the graduation student within the community by offering practical classes in two Psychosocial Attention Centers, allowing the students to get in contact with new alternatives of attention to mentally ill individuals.

In institution 7, the disciplines of Psychology Applied to Health (30hs) and Methodologies and Dynamics of Group Work (60hs) were incorporated to the curriculum, increasing the schedule of the area in 90 hours. Institution 1 was the only in which there was a decrease in teaching schedule for Psychiatric Nursing II (theoretical-practical) from 180 to 150 hours per semester. This change created problems to the community services due to the increase on the number of students in the practical field concentrated in only two days-a-week, causing a lack of continuity to the patients' attendance. The development of a new methodological proposal, aiming at the unification between theory and practice in the very spot where the practical classes take place, caused a change which both teachers and, specially, students emphasized as positive, for favoring and facilitating the learning process.

**Table 3 Disciplines and Schedules**

| Institution | Offered disciplines | Partial teaching schedule | Total teaching schedule |
|---|---|---|---|
| 1 | Nursing in Mental Health I | 90hs (theory) | 270hs |
| | Nursing in Mental Health II | 150hs (theory-practice) | |
| | Nursing in Mental Health III | 30hs (workshops) | |
| 2 | Psychology Applied to Health I | 30hs (theory) | 255hs |
| | Psychology Applied to Health II | 30hs (theory) | |
| | Psychology Applied to Health III | 30hs (theory) | |
| | | 45hs (theory) and 120hs | |

| | | | |
|---|---|---|---|
| | Psychiatric Nursing and Mental Health | (practice) | |
| 3 | Mental Health I<br>Mental Health II | 60hs (theory)<br>120hs (60hs - theory and 60hs - practice) | 180hs |
| 4 | Mental Health | 120hs (60hs - theory and 60hs - practice) | 120hs |
| 5 | Name of discipline not mentioned | 105hs (theory) and<br>85hs (practice) | 190hs |
| 6 | Collective Health II | 90hs (theory - practice) | 90hs |
| 7 | Nursing in Mental Health<br>Psychology Applied to Health<br>Methodologies and Dynamics of Group Work | 60hs (theory) and 120hs (practice)<br>30hs (theory)<br>60hs (theory) | 270hs |
| 8 | Mental Health<br>Psychiatric Nursing | 60hs (theory) and 30hs (practice)<br>30hs (theory) and 60hs (practice) | 180hs |
| 9 | Mental Health I<br>Mental Health II | 60hs (theory)<br>120hs (theory - practice) | 180hs |

Kantorski & Silva (2001) while studying the four public universities of Rio Grande do Sul noticed that, yet in the middle of 90's, the disciplines of the area have been marked by the focus on the normal and on the pathological as the vital cycle passes by, demonstrating influences from both the preventive psychiatry discourse and the psychoanalysis, being predominantly inclined towards the psychodynamic focusing. Training in the area remained taking place almost exclusively in large scale psychiatric hospitals, emphasizing psychopathologies.

We can observe that some content choices are basically reflected upon the academic life and the development of future professionals, who will work in the area, such as the scarce inclusion of contents concerning the systematization of health, family participation in patient's treatment, the psychosocial rehabilitation and transformation of practices and services in metal health. However, a change concerning previous studies has been taking form, especially when the study widens and includes both, public and private universities. As we can see on Table 3, previously presented, new concepts and contents concerning the changes in the context of psychiatric practices have started to mix with the classical psychiatry contents.

The inclusion of contents concerning the new theoretical referentials of psychiatric reform and the development of practical classes in the mental health services network (including psychosocial attention centers and nucleuses, day-hospitals, shielded boarding houses, psychiatric units in general hospitals, therapeutic workshops) to the nursing graduation curricula retake the academic space as a living laboratory for production, constitution, formation, and socialization of knowledge which is inserted in a psychosocial attention paradigm process of transformation.

Besides curricular changes, it was possible to notice a concern from schools in offering a complementary formation to nursing students and in assisting the community, through university extension projects (Table 4). Six institutions, out of the 9 which answered the questionnaire, develop extension projects, focusing on mental health care practices to individuals and groups, extra-curricular academic formation, improvement level formation for workers in the area of mental health.

**Table 4 Extension Projects in the Field of Mental Health**

| Institution | Extension Project |
|---|---|
| 1 | Extension Course in Mental Health with 90hs teaching schedule, developed in 3 modules: discussion concerning Psychiatric reform and its repercussion for the nursing activity, approach and deepening of questions concerning mental illness and nursing care, and discussion concerning interpersonal relations, group work, and the repercussions of contact with pain and death for the nursing workers |
| 2 | Boarding school in Psychiatric Nursing for students who are attending or have already attended the discipline of Psychiatric Nursing, aiming at deepening knowledge in the field; Group of relapse prevention for chemical dependents; Capacitating courses in Mental Health for the Brazilian Health System ( *Sistema Único de Saúde*) |
| 3 | Community Extension Project in Mental Health, enabling continued assistance, without interruption during non-school periods, offered to volunteers who had attended the discipline (Mental Health) |

| | |
|---|---|
| 4 | Outpatient Clinic level nursing consultation in Mental Health, Counseling to over-weight and hypertension groups, Research on socio-cultural factors contributing to alcoholism |
| 5 | Does not have knowledge |
| 6 | There are no project models of this kind |
| 7 | Nursing study groups in Mental Health and District Socio-therapeutic Group |
| 8 | Asystematic projects developed by students with Psychosocial relationship proposals |
| 9 | Home Visit Project, in which students assist psychic suffering patients go through their rehabilitation process and entailment to the local mental health network |

# Conclusions

The obtained results allowed us to characterize Psychiatric Nursing teaching by evidencing the theoretical-practical content emphasis on the therapeutic interpersonal relationship and on the need of contextualizing care in Mental Health in face of the transformations occurred in nursing services, in later decades, within the Brazilian reality.

We noticed that the total teaching schedule varies from 150 to 270 hours per semester, distributed between theoretical and/or practical disciplines. The places where trainings are carried out vary from large scale hospitals and internment units in general hospitals to basic attention units, psychosocial attention centers, and so on.

We highlight the recent concern of most Nursing Schools in offering the students the contact with new care devices to mentally ill individuals, based on the psychosocial attention principles, which stress the need to humanize the attendance through entailment, receptivity, and the inclusion of the family in the process of assistance and re-socialization.

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# Process Levels and Service Complexity as Predictors of Time Demand in Rehabilitation Counseling

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## Abstract

Predictors of Time Demand were investigated as a means of estimating case and caseload difficulty in Rehabilitation Counseling. Differences in the time investment of 100 rehabilitation counselors were investigated among a statewide sample of 1330 cases. Criterion time variables were comprised of various groupings of the federal status codes prescribed by the United States Rehabilitation Services Administration (e.g., planning, counseling, restoration, training, and placement). Time was thereby partitioned to represent the roles and functions of rehabilitation counselors. Using the data reduction facilities of the SPSS AnswerTree program (SPSS, 2001), the rehabilitation planning, training and placement variables were categorically significant, parametrically confirmed and cross-validated. Four case types of optimal statistical and practical significance resulted. The rehabilitation process was reduced to new and existing cases, which were each split into high and low service complexity groups. The results of the study have implications for quality improvement and organizational development in mental health and rehabilitation program management.

**Keywords:** Rehabilitation, caseload difficulty, time demand, burnout, workload.

# Introduction

Objective measures of time demand have significant potential for program improvement and research in Federal-State vocational rehabilitation agencies (Main, 2002). Time demand as a construct, however, has not been sufficiently explored or operationalized in vocational rehabilitation. Fortunately, the federal status codes used by most state rehabilitation agencies provide a means of exploring the differential aspects and potential groupings of time usage in state rehabilitation agencies. In this study, counselor time invested in each of the federal status codes of a Midwestern state rehabilitation agency was investigated.

Workload measurement was designed to address problems caused by inequities in time demand. In the workload measurement literature it is widely accepted that systemic workload inequity has a negative impact upon organizational effectiveness and efficiency, and upon workforce morale (Kern, 1987, 1988, 1993; Peat, Marwick, & Mitchell, 1978a, 1978b; USDHEW, 1972, 1978; Walls & Moriarty, 1977). The underlying assumption is that in controlling these imbalances, objective workload measurement techniques are superior to subjective workload estimation.

Workload management problems develop when factors that impact time demand differently are not adequately understood or accounted for (Ebb, 1994; Tarvydas and Peterson, 1999). Problems associated with unbalanced workloads include: low morale due to overwork, confusion as to the nature and extent of the work expected, arbitrary and subjective case assignments, increased need for detailed supervisory intervention, and agency difficulty in justifying the need for additional staff and funding (Haring, 1974). Exploring the nature of time demand in the rehabilitation process is needed.

This study addressed several issues of importance. Theoretically, the categories of the dependent time variable that best represent the primary roles and functions of the rehabilitation counselor were investigated. Criterion time categories correspond to the functional roles of the work being assessed. According to Kreitner (1995), effective organizational development calls for the ongoing monitoring and adjustment of the role and function of workers. Workload design and redesign are both strongly related to the role and function of the worker as it exists in the present and as it is envisioned in the future. The operationalization of time demand has implications, then, for understanding, structuring and restructuring the work of rehabilitation counseling. Additionally, identifying optimal ways to group the time variable should improve the feasibility of conducting workload measurement research, and help to identify factors that need to be investigated in the future.

Limitations compromising the accurate partitioning of time demand in this study include several internal and external threats to validity. Internally, selection and instrumentation require consideration (Campbell & Stanley, 1963; Cook & Campbell, 1979; Gall, Borg & Gall, 1996). Although the sample was not randomly selected, the systematic selection of every 12th case on each caseload approximated random selection, and sample size (N=1330) was adequate. Regarding instrumentation, the accuracy of the time log used for data collection was enhanced through multiple significance testing and it was cross-validated (SPSS, 2001). The time log was self-report, however, and susceptible to data recording error such as Hawthorne, compensatory rivalry, novelty or disruption effects. Careful adherence to standardized procedures was emphasized, with an evaluation of extreme scores and alternative measures of central tendency (Peat et al., 1978b). Externally, validity is established largely by the technical description given in the procedures section of this report, which should adequately provide for replication (McMillan and Schumacher, 1989).

The purpose of the study was to identify the strongest available predictor of time demand and use it to partition the dependent time variable into comparative and optimally cross-validated models. The criterion time variable was comprised of counselor time investment in minutes reported within 14 functional service categories. The 14 service categories represented the essential roles and functions of the rehabilitation process as formerly developed and mandated through the Rehabilitation Services Administration’s Federal Status Codes. The Federal Status Codes were used to operationalize the first two of six predictor variables (i.e., rehabilitation process levels, case movement, service complexity, caseload size, percent of active cases, and disability type) selected according to their potential for predicting time demand. The null hypothesis was used to test each model.

## Literature Review

Several bodies of research relate to counselor time utilization. These include workload management, work role and function, caseload difficulty, and burnout. Of these, the workload management literature is the only one that directly postulates the pivotal nature of time demand, however.

### *Workload Management*

In workload management theory, demoralization occurs when workers face increased time demand on factors that are unrecognized or unaccounted for (Haring, 1974). Conversely, morale and productivity increase as time demand is perceived as fair and controlled (Kern, 1987, 1988, 1993; Peat et al., 1978a, 1978b). The general practice of accounting for time demand is rooted in systems theory. The basic contention is that workers can be easily penalized for systemic problems they cannot control (Lubeck & Davis, 1991), especially when individual production goals compete with team-oriented quality improvement targets (Glaser, 1993). The role and function of work is not a direct aspect of workload management theory, but criterion time categories do correspond to the key functions of the work being assessed (Kern, 1993; Peat et al., 1978b).

### *Role and Function*

There is little indication in the role and function literature that time demand is considered an aspect of this construct. In organizational development, however, time is seen as integral to the structure and design of work. According to Kreitner (1995), effective organizational development calls for the ongoing monitoring and adjustment of the role and function of workers. Workload design and redesign are both strongly related to the role and function of the worker as it exists in the present and as it is envisioned in the future.

Time demand is inferred in the rehabilitation role and function literature as well. The Federal Status Codes, developed and initially mandated by the Rehabilitation Services Administration, strongly reflect both time demand and the roles and functions of the profession. These groupings, in order, are: referral, intake, eligibility determination, plan development, counseling services, restoration services, training services, job placement, employment, successful closure, unsuccessful closure after plan development, unsuccessful closure before plan development, and post-employment.

Although counselor role and function has been as much a matter of legislated philosophy as of research, some functions are more preeminent and have endured both inquiry and legislative change. Planning, for example, may be the most integral.

Although the name of the Individualized Written Rehabilitation Program was recently

changed to the Individualized Plan for Employment in the Workforce Investment Act of 1998 (National Governor's Association, 1998), the planning function remains largely unchanged as the centerpiece of the vocational rehabilitation process.
Recent developments in the rehabilitation role and function literature have been centered in the emergence of counselor specializations (Goodwin, 1992). Counselor specialties often effect changes in the structure of work in the organization. Due to the complexity of the field, counselors are increasingly working with specialty caseloads rooted in either the counselor functions themselves (e.g., job placement services) or in serving specific disability groups (Roessler & Rubin, 1995).

Support in the rehabilitation literature for time demand as an aspect of the role and function of rehabilitation counseling is admittedly indirect and scant (Goodwin, 1992; National Governor's Association, 1998; Roessler & Rubin, 1995). This report on the Main (2002) doctoral dissertation is the first study to directly link the two. When references to time or time demand are found in rehabilitation research, it is most often in the context of caseload difficulty.

## *Caseload Difficulty*

Caseload difficulty research made an early contribution to the emergence of the present priority within public VR agencies of serving persons with most severe disabilities (Miller et al., 1965). Several tools were developed in the late 1960's to give counselors more credit for working with people with more severe disabilities. Closure weights were developed as proportions of unsuccessful to either successful or total case closures and used as difficulty norms for various client groups (Noble, 1973). Weights were used to add additional numeric value to successful rehabilitations (status 26 closures) from more difficult client types. Correlations between weighted closures and simple case counts were between .94 and .97, indicating a minimal benefit from the use of weightings, however. Calls for more comprehensive caseload difficulty taxonomies, including measures of time demand, went largely unheeded (Wallis & Bozarth, 1971; Walls & Moriarty, 1977).

Due to the difficulty and expense involved in implementing weighted closures, Walls and Moriarty (1977) developed an alternative in which a flexible variety of performance measures could be profiled as percentages or stanines in comparison to national, state or area norms. The average time that clients were staying in a particular status (e.g., 02-10) was suggested as an example of possible time measures that could be included in counselor outcome profiles.
Zadny and James (1977) asked 319 counselors in seven states to estimate their time spent in travel, placement-related travel, and nine case process measures. These were counseling, paperwork, coordinating services, placement, job development, public relations, planning, and professional growth. Time estimates were correlated with two sets of factor analyzed measures representing six outcome dimensions. Total rehabilitations, rehabilitations of persons with severe disabilities, and the percentage of cases closed as not rehabilitated comprised the number of successful closures factor. The nature of successful closures factor was comprised of the percent of all closures that were competitive, the percent of closures in sheltered workshops, and average earnings at closure.

There were no significant correlations in the nature of closures factor, but several relationships in the number of closures factor were significant at the .01 level. The percent of cases closed not rehabilitated was inversely related to time spent in placement (r = -.22), job development (r = -.27), hours spent out of the office (r = -.31), miles traveled per week (r = -.31), travel time spent in job development (r = -.38), and travel time spent in placement (r = -.39). Rehabilitations for clients with severe disabilities were related to time spent in job development (r = .20) and planning (r = .22). Total rehabilitations were inversely related to time spent in coordinating services (r = -.20) and planning (r = -.23). The investment of time in placement related activities was recommended. (Zadny & James, 1977)

McAnally and Linz (1988) surveyed the collaborative case management practices of a number of community entities having some role in services for persons with developmental disabilities. Of the 60 rehabilitation counselors that responded to the survey, the average caseload size was 159, with a range of between one and 40 cases for individuals with developmental disabilities. Counselors estimated that between one and 30 percent of their time was given to clients in this population, but reported a lack of knowledge about the services of the other agencies. Five barriers to effectiveness were reported by rehabilitation counselors including: the degree to which interagency interaction was required, caseloads that were seen as too large, the amount of paperwork required, the number of collaborative meetings required, and lack of sufficient funding.

Chan, Rosen, Wong and Kaplan (1993) used discriminant analysis to differentiate a group of 18 students from 18 experienced counselors on the basis of caseload process measures (p<. 001). A computer-based multiple case management simulation was developed to measure six task groupings. Three caseload measures were significant (total number of status changes, index of preferred actions, index of inappropriate status changes) and three measures were not significant (money spent on clients, number of actions taken, appropriate closures). Using the classification function, 89% of the participants were accurately classified. This study approximates the use of time standards because participants were given one hour to process eight case types.
Related to caseload difficulty, concern over stress in rehabilitation counseling has also been more recently voiced. Professional disengagement, compassion fatigue, and burnout, have been acknowledged (Greenwood, 1995; Roessler & Rubin, 1995), and counselors have been cited as experiencing disempowerment in the effort to empower persons with disabilities (Emener, 1993). Most importantly, organizational stressors such as role overload (e.g., caseloads that are too large or too active) have been clearly outlined in rehabilitation stress management models (Wood, 1999), and the impact of the organizational system on counselor-client ratios has been given ethical consideration. Tarvydas & Peterson (1999) directly cite the demoralization that occurs for some counselors when counselor-client ratios are not kept consistent with the complexity of the caseload management system and the difficulty of the client population served. Clearly, workload management has potential for addressing these issues.

## *Interpretive Summary and Variables*

The criterion time variable and the process level predictor of this study are both supported in the rehabilitation literature. The work of Zadny and James (1977) revealed that time spent in placement and job development out of the office as well as time invested in coordinating services in the office contributed to effectiveness. This held true for persons with severe disabilities as well. The administration of rehabilitation workloads, such as decisions related to specialty caseloads (Goodwin, 1992; Roessler & Rubin, 1995), would be facilitated by the ongoing identification of discrepancies between the expected and actual structure of time demand.

The most notable factor that is not directly operationalized in the present study is severity of disability. The dichotomous designation of severity of disability required by the Rehabilitation Services Administration did not evidence enough variability on the criterion to be of use in this study. This omission requires deliberation because relationships between severity of disability and other factors have been previously demonstrated (General Accounting Office, 1991; Zadny & James, 1977). Upon first consideration it appears that this study does not contain a measure of severity of disability with an adequate spread of scores or categories to demonstrate that time demand is related to the number or magnitude of functional limitations created by the disability. State agencies were first mandated to focus their efforts on serving persons with severe disabilities in the Rehabilitation Act of 1973. The presumption within the field then and now appears to be that that time demand is unrelated to severity of disability and that caseload difficulty is a function of severity of disability and disability type (Randolph, 1975).

The possibility that time demand is independently or negatively related to severity of disability must be considered, however. Specialty services may have become so well organized around disability groups with most severe disabilities that the actual time needed to serve a person in this category is less than might be expected. Similarly, persons with severe disabilities who are fairly well established in their careers may need only one or two VR services. In essence, time demand itself is the primary mediator of severity of disability to the counselor. On this basis the criterion variable is taken also as an indication of severity of disability.

Six independent variables were used as predictors of time demand (i.e., rehabilitation process levels, case movement, service complexity, caseload size, percent active, and disability type). Case movement is informed by the work of Chan et al. (1993) who obtained an indication that when time is held constant, different counselor experience levels and rates of task processing (e.g., number of status changes, number of preferred actions, and number of inappropriate status changes) emerge. The independent variables service complexity, caseload size and percent active appear to be substantiated by the professional judgment of the rehabilitation counselors surveyed by McAnally and Linz (1988). These counselors cited overly large caseloads, excessive paperwork and meetings, and insufficient funding as barriers to effectiveness.

The long history of support for accounting for disability type in rehabilitation research is particularly clear from the studies on caseload difficulty in rehabilitation (Cooper & Pearce, 1980; Miller & Barillas, 1967; Miller et al., 1965; Noble, 1973; Sermon, 1972; Silver, 1969). There is definitely an awareness reflected in the literature that different case types vary dramatically in their difficulty level. There is some indication (Wallis & Bozarth, 1971; Walls & Moriarty, 1977) that successful and unsuccessful clients do not necessarily differ on several matched factors (i.e., age, gender, education, referral source and disability type). This leaves open the possibility that factors related to time demand might account for some of this difference.

The finding that no case differences existed between weighted and unweighted cases (Silver, 1969; Wallis & Bozarth, 1971; Walls & Moriarty, 1977) suggests that case difficulty or workload may be similar when time demand is not accounted for. The specific recommendation for the use of time-in-status as a performance measure by

Walls and Moriarty (1977) raises two issues. The recommendation directly calls for a real time measure, and it substantiates the need to control for the effects of time demand in performance appraisal to avoid biased penalties and rewards. This appears to apply to estimated time spent serving persons of a specific disability type (McAnally & Linz, 1988), and to production goals set on the basis of successful closure rates (Cooper & Pearce, 1980). Efforts to give added weight to more difficult closures based on disability type were short lived, possibly due to the fact that time demand was not taken into consideration (Randolph, 1975).

Overall, workload measurement is intended to enhance organizational control over factors that create time demands upon caseworkers. The rehabilitation literature suggests that time is a primary resource in state rehabilitation agencies, and that workload management problems may occur when the balanced utilization of counselor time is impeded. Symptoms of burnout (Greenwood, 1995; Roessler & Rubin, 1995) and disempowerment (Emener, 1993) in the rehabilitation workforce might be improved through workload management.

# Methodology

The design used in this study was a status survey, quasi-experimental comparison group procedure on the dependent variable time demand. Categories of the dependent and independent variables were reduced using categorical data analysis, and the resulting case types were parametrically cross-validated against a random sample of about 50 withheld cases. Subjects were cases active in March and April of 1999 in a Midwestern state rehabilitation agency.

## *Procedure*

The sample consisted of 1330 systematically selected general VR cases. The cases were open at the time of initial data collection in March of 1999. Each 12th case on every caseload was selected and each of 105 counselors was then given a list of the cases chosen for the study. In addition, each counselor selected the first four new referrals received in the data collection period. Of the 1330 cases in the original sample, 993 (74.7%) were classified as having a severe disability. Primary disability groups included 392 with psychological disabilities, 345 orthopedic, 251 with diseases and related conditions, 142 with visual impairments, 98 with hearing impairments, and 39 with a brain injury. Top referral sources were 333 from education, 253 from healthcare, 226 from welfare and social services, and 296 were self-referrals. Twenty-six percent had more than one disability and 16% had more than three services listed on their rehabilitation plans.

Time logs were used to record time investments in each of the process categories for one month. Counselors self-reported their time investments for each case in minutes. Demographic information used to determine client types was also recorded on the time log form. Data was taken directly from the computer information system of the state agency or from the case file. Of 15 variables for which data were collected by the state agency, five were selected and modified as independent variables for the study. No validity or reliability studies of the time log instrument were conducted, but the reliability of the log was largely confirmed through the parametric cross-validation in the analysis.

The analysis began with the evaluation and implementation of the recommendations suggested by Peat et al. (1978b) and others to enhance accuracy and reduce the impact of skewed time distributions. Peat recommended the use of the mode for work unit

standards and the removal of extreme scores and case types that do not apply to the whole sample. Adjustments were also made for missing values.
Secondly, the strongest predictor of time demand was identified through the categorical data reduction of the six predictor variables on the criterion time variable. Categorical data reduction is the term used in the AnswerTree program (SPSS, 2001) to describe the process of running multiple significance tests among competing predictor variables, identifying the most significant predictors and splits in each target variable. The process results in a diagram called a tree in which each category is called a node, and each split is called a branch. When the data is reduced until no further splits are statistically significant, terminal nodes are attained.

Third, the strongest predictor was used to partition the time variable from comparative theoretical and empirical standpoints. The most viable models, finally, were cross-validated against a random sample of approximately 50 withheld cases.

### *Measures*

The dependent variable for the study was time reported in minutes. Rehabilitation process levels was the first independent variable, comprised of the 14 federal status codes (i.e., referral, intake, eligibility determination, plan development, counseling services, restoration services, training services, job placement, employment, successful closure, unsuccessful closure after plan development, unsuccessful closure before plan development, and post-employment). These process levels could be theoretically partitioned into groupings that represent various roles and functions of rehabilitation counseling (e.g., planning, counseling, restoration, training, placement, etc.).

The second predictor variable was the dichotomous number of federal status code changes, per case, in the month of data collection, taken as a measure of case movement (one or more than one). This variable gave an indication of the relative speed at which different case types move through the rehabilitation process. The third predictor was the number of specific service categories from the month prior representing service complexity (one or more than one). Fourth, caseload size was dichotomized as small or large (below the median; at or above the median). Fifth, the proportion of cases that demanded time for each counselor was taken as a measure of the percent of active cases (below 50% and 50% and up). Finally, disability type included visual, hearing, orthopedic, mental illness, developmental disabilities, learning disabilities, and all other conditions.

### *Data Analysis*

Categorical data reduction was used to identify the strongest predictor of time demand and to test various partitions of the dependent time variable. Viable partitions were cross-validated parametrically. The Chi-Squared Automatic Interaction Detector (CHAID) methodology within the SPSS Answer Tree program (2001) has parametric and nonparametric facilities, and was used for all data analysis procedures. In the categorical models, the chi-squared maximum likelihood-ratio test of significance was used for each level and branch of the tree. For the parametric models and cross-validation samples, Analysis of Variance tests of significance were used. Probability levels were computed in each branch of the analysis using an appropriate Bonferroni adjustment.

# Results

Surprisingly, it was not necessary or possible to implement the recommendations of Peat et al. (1978b) that the mode be used for work unit standards, and that extreme scores and case types that do not apply to the whole sample be removed. The mean seemed to be the best summary statistic in most cases because the distribution of time in the sample was inverted, flat, and positively skewed. Mean, median and mode minutes per case were 70, 35 and zero, respectively. No time demand was reported for 304 cases in the original data set, and 312 cases after adjustments, making it infeasible to use the mode as Peat et al. (1978b) suggested.

Furthermore, no outlying cases or caseloads were removed from the analysis. In assessing the impact of outlying scores, the 10 individual cases with the most total minutes reported ranged from 895 to 525. These cases appeared to be valid and proportionately distributed among the disability types. The largest and smallest workloads reported were from blind services caseloads, which limited their extraneous impact. The largest number of minutes reported for a caseload was 2985, or an average of just under four hours spent on each of the 14 cases sampled over the month of data collection. The smallest number of minutes reported for a caseload was zero. This caseload had been recently vacated and assigned to another counselor for triage. None of the extreme cases or caseloads seemed unreasonable and none were adjusted or removed.

Several adjustments were made for missing values, however. Missing values on the total time variable ($N = 41$) were computed as the sum of all process minutes reported. Missing values on the service complexity predictor demanded only slightly less time than the time demanded by cases having one service category and were combined (i.e., coded less than two, or two or more). Three of 100 caseloads missing the caseload size value were coded at the mean caseload size for their respective caseload types (i.e., blind services, 56; general caseload, 90). Missing disability type values were assigned separate codes within their respective caseload types (i.e., visual, hearing, mental health, general). The adjusted data set included an alternative coding system that made use of available information about each missing value. Potentially, the full data set ($N = 1330$) could be used for some analyses, and missing values could be selectively removed.

The full data set was used to identify the strongest predictor of time demand categorically, as recommended by Peat et al. (1978b). The model was nonparametric and automatic, meaning that the insignificant levels of the variables could all be merged or reduced.
The rehabilitation process levels entered the model first (Chi-square = 215.3811; $p = .0000$) and the levels were reduced to three groups. Planning was merged with new cases. Service categories 14, 16, and 18 (i.e., counseling, restoration, training) were merged with existing cases, and the placement category remained a single group. The strongest predictors, in order, were process levels, percent active, service complexity, and case movement (Chi-square > 4.8190; $p < 0.0282$).

Cross-validation, however, fell short of the parametric capacity of the AnswerTree program. Parametric confirmation had to be customized. In other words, the parametric version of the AnswerTree program identified more accurate group splits that were not used in this reduced, categorical model. Two terminal case movement nodes on the high complexity, new cases branch were not confirmed ($F = .6011$; $p = .2750$), and multiple interactions were found in the cross-validation sample (N = 68) that did not exist in the confirmation sample (N = 1262). Also, four of the nine, terminal cross-validation sample nodes had less than five cases. Parametric confirmation of the process levels predictor was strong. The null hypothesis was rejected, but a parametric model with stronger splits and branches was clearly indicated for future workload measurement purposes.

Several theoretical models were tested, meaning that different partitions of the process levels predictor were forced into the analysis and could not be reduced. One of the strongest of these was a symmetrical five group model (i.e., planning, counseling, restoration, training and placement). The theoretical rehabilitation process groups better approximate the role and function literature. Cases with missing federal status codes were removed from this model to avoid their extraneous mergers with the theoretical groupings (N = 1175). The five theoretical process categories were each significant when tested using the parametric confirmation facility of the CHAID procedure ($p < .0211$, $F > 5.4135$). The null hypothesis was again rejected. Service complexity was the strongest nonparametric predictor of rehabilitation planning, counseling and restoration service groups (Chi-square > 8.4063, $p < .0038$), and the percent active variable was the strongest predictor of training and placement groups (Chi-square > 17.7934, $p < .0001$). Six terminal nodes did not cross-validate, however, not improving on the reduced model.

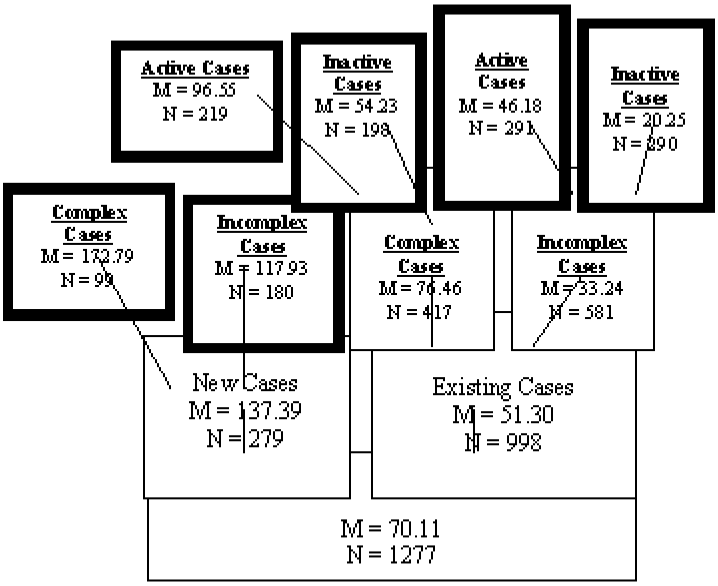
Therefore, an automatic, parametric data reduction was used and cross-validated to more fully tap the practical utility of the AnswerTree program. For this automated model, the modified means were used as the process variable and the process groups were scaled ordinally. Although the nominal scaling of the process categories produced more nodes with more exacting mergers, the ordinal scaling of the groups was simpler, more logically understandable, and more consistent with the theoretical process categories.

Two process levels resulted ($F = 202.4067$; $p = .0000$). Cases in status codes 00, 01 and 02 were merged into a new-cases node (i.e., referral, new and applicant statuses, respectively). Cases above status 02 comprised an existing-cases node (i.e., eligible, plan completed, counseling, restoration, training, existing, and placement statuses, respectively).

Service complexity was the strongest predictor for both new and existing cases ($F >14.6111$; $p < .0003$). The base standards in Figure 1 are based on the process and complexity nodes of the second level, before the third variable entered the model. In the existing-cases node, percent active was the third and final variable to enter the model ($F >19.0323$; $p = 0.0000$).

Each of the six terminal nodes cross-validated in the predicted direction. No interactions were created in the cross-validation sample (N = 53), and only one node contained less than five cases (N = 3). The optimal splitting function of the AnswerTree program was strongly implemented, and no reasons were discovered for customizing the model. Therefore, the case type means from this automatic model appeared to be optimal for the further development of workload standards. Figure 1 displays these means.

Figure 1. Schematic of Final Answer Tree Model



# Conclusions

The utility of workload management in rehabilitation was supported in several ways. First, caseload size and disability type were not strong enough predictors to enter the workload model. This suggests that time demand is a mediator of caseload difficulty and severity of disability. Secondly, disability type was not represented in the final model that accounted for 21.17% of the variance in time demand. This suggests some independence between the two variables and lends support to time measurement as superior to the variables typically used to estimate workload (Haring, 1974). Third, multiple significance testing (SPSS, 2001) enhanced the theoretical workload models through parametric confirmation, and provided empirically superior alternative models. Workload measurement procedures were enhanced. Last, the operationalization of roles and functions was supported by the strength of the rehabilitation process, case movement, and service complexity variables. This supports time demand as a mediator of the roles and functions of rehabilitation counselors (Goodwin, 1992; Kreitner, 1995; Roessler & Rubin, 1995).

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# How Psychosocial Sport & Play Programs Help Youth Manage Adversity: A Review of What We Know & What We Should Research

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## Abstract

A review of theories and practices pertaining to the possible underlying dynamics of international community-based resilience enhancing psychosocial sport and play programs, established to help children and youth experiencing adversity in their lives. Sport and play activities (with play being inclusive of any organized movement, exercise, game or artistic activities) can have a stabilizing impact on most children through supporting and encouraging their resilience processes, with resilience being described as the process of, and capacity for, successful adaptation despite challenging or threatening circumstances. Psychosocial sports and play programs are a relatively new approach to helping children manage adversity, so more field investigations need to be implemented to establish best practices methodology, and to discover the impact that sport and play activities may have on the enhancement of children's resilience. Additionally, more funding must be allocated for research on the effectiveness of these psychosocial sport and play programs.

**Keywords:** Psychosocial rehabilitation, sport & play, resilience, youth, stress, trauma

## Introduction

In recent years, the United Nations, individual governments, international non-governmental humanitarian aid organizations, and sports corporations have been turning to psychosocial sport and play programs as an innovative method to address numerous health and social problems (with the use of the term "play" being inclusive of any organized movement, exercise, game or artistic activities). Projects are being initiated that use sports and play activities with children as psychosocial interventions in a variety of situations, including (but not limited to):

- In and after wars or conflicts to provide opportunities for "peace building" between conflicted parties
- In response to pandemics to provide healthcare education, support and services
- In response to social problems, such as providing opportunities to help reintegrate homeless children and child soldiers into society, or to address issues of poverty
- After disasters to help re-establish social and psychological stability

### II. The Role of Sport and Play in Development and Rehabilitation

Psychosocial sport and play programs aim to restore children's social well-being and psychological health within their community through group-focused practices, tailored to fit the contexts of local culture, traditions, needs and resources (Boyden & Mann, 2005; Duncan & Arntson, 2004 ; Eisenbruch, 2004; Grotberg, 2001; Henley, 2007). These programs hope to fulfil key healthcare functions in two ways: 1. By offering the majority of affected children direct psychosocial support via sport and play programs that also teach important values and skills, etc., and 2. By helping to identify those children who are unable to effectively participate in these programs due to the severity of their stress or trauma, offering more individual psychological attention through referrals to mental health specialists (Statham, 2004; Yule, 2000).

Play has long been understood to provide children with the experiences they need in order to learn social skills and values. Through play, children become sensitive to other children's needs and values, learn to handle exclusion and dominance, manage their emotions, learn self-control, plus to share power, space, and ideas with others. At all levels of development, play provides opportunities for children to feel comfortable and in control of their feelings by allowing the expression of emotions in acceptable ways. Further, sport and play activities provide children with the opportunity to negotiate and resolve conflict (Erikson, 1977; McArdle, 2001; Piaget, 1959; Winnicott, 1968). Thus the concept behind psychosocial sport and play activities is that these will assist children and adolescents address a myriad of social and psychological challenges simultaneously in gentle and non-intrusive ways through accessing the natural predilection to play (Bell & Suggs, 1998; Henley, 2007).

## Managing Adversity

Humanitarian and social crises are any occurrences that can cause loss of human life or the deterioration of health and health services on a scale that requires an extraordinary helping response from outside the affected community. These events can result in the experience of severe stress or trauma in any population, irrespective of their cultural background (Dougherty, 1999). Trauma is defined as the direct or indirect exposure of a person to a life-threatening event, and the concurrent experience of intense feelings of terror or horror (APA, 1996). Fortunately, the ability of human beings to cope effectively with traumatic experiences should not be under-rated, and traumatic experiences rarely develop into psychiatric illnesses (Bonanno, 2004; Bonnano, 2005; Creamer, Burgess, & McFarlane, 2001; Kleber & Brom, 1992). In studies of Western populations, 60% to 90% of affected people have been found to be able to integrate the traumatic experience by themselves (Connor & Davidson, 2003; Kleber & Brom, 1992). In this context, "integrating the experience" refers to an individual's ability to resolve its traumatic experience and return to pre-disaster levels of functioning (de Jong et al., 2002). The ability of a person to manage severely stressful or traumatic experiences has been identified as the process of resilience (Alvord & Grados, 2005; Boyden & Mann, 2005; Luthar & Cicchetti, 2000; Masten, 1997; Ungar, 2005)

## Enhancing Resilience Processes In Children Through Sport and Play

Resilience is understood to be the process that enables some survivors of high-risk environments to experience social competence, empathy, caring, problem-solving skills, critical and creative thinking, task mastery and a sense of purpose and connectedness in the face of adversity and distress (Connor & Davidson, 2003). It is believed that successful resolution and integration of severely stressful or traumatic experiences by children can even contribute to increased resilience in response to future stressors (Alvord & Grados, 2005; Apfel & Bennett, 1996; Boyden & Mann, 2005; Connor & Davidson, 2003).

Research on resilience has identified key protective factors in a child's life that can buffer and prevent the impact of such risk factors as severe stress or trauma (Markstrom, Marshall, & Tryon, 2000; Tiet et al., 1998). The most significant protective factor is the child's connection with and attachment to beneficial friends, family and unrelated adults. For children particularly, experiencing caring, accepting and encouraging relationships with family and non-family adults (such as teachers, coaches and mentors) has a significant and positive impact on their development. Even for older children and teenagers who have already been exposed to and adversely affected by long-term hardship, the late establishment of healthy adult-child relationships can help intercept the child's negative life trajectories and prevent future exposure to high-risk situations (Alperstein & Raman, 2003; Luthar & Cicchetti, 2000; Rutter, 1998; Wolff & Fesseha, 1999).

As children and adolescents benefit from quality role models (Boyden & Mann, 2005; Ungar, 2005), group sports and play activities offer important opportunities for them to be engaged by older members of a community. These adults are the ones who can provide structured activities that encourage the development of children's sense of self-worth, support their ability to communicate more effectively, and help them have healthier relationships with peers - and having healthy peer relationships is yet another significant protective factor. It must be emphasized that a key aspect of the healthy adult-child relationship is the role that adults play in teaching values such as teamwork, fair play and ethics, and the social skills that support these values (Boyden & Mann, 2005; Dumont & Provost, 1999; Duncan & Arntson, 2004). Thus, the impact of the sport worker in the psychosocial sport and play program is of crucial importance, though it must be noted that coaches in psychosocial sport and play programs must have skills beyond solely teaching sport and game activities. These coaches should also be able to facilitate the understanding of emotions and inter-personal communications between children, and help children develop effective coping skills. These teaching skills require special training, which will help the coaches effectively intervene in many challenging situations, as well as enable them to deal with any of their own unresolved issues that they may face living in the same adverse conditions as the children they hope to help. When adults give their support to children, and encourage the children to help others, they are in turn helping to enhance the value and resilience of the community, for engagement in and connection to a community which is seen as another significant protective factor (Moscardino, Axia, Scrimin, & Capello, 2007; Wolkow & Ferguson, 2001).

While many psychosocial sport and play programs provide children with the chance to get involved with others through joining competitive teams, the context of interventions are primarily focused on the process of helping children restore their psychological and social functioning in a cooperative environment. These programs offer children the opportunity to learn new problem-solving skills in managing their own emotions and behaviours, as well as to have healthy peer relationships. Of note, these problem-solving skills have also been found to be a strong predictor of improved resilience in children, as improved problem-solving skills can enhance the possibility that life's challenges will be resolved successfully (Boyden & Mann, 2005; Fok & Wong, 2005; Grotberg, 2001; Place, Reynolds, Cousins, & O'Neill, 2002; Save the Children, 2004).

## Implications and Recommendations

It has long been recognized that play is instrumental in a child's healthy development, and the ability to play is one of the signs used to determine if a child is healthy or meets age-related developmental requirements. Additionally, when a child is under extreme stress or has been traumatized, this is often seen through symbolic repetitive behaviors suggesting aspects of the traumatizing event through play. Thus the use of psychosocial sports and play programs provide important opportunities for trained sports workers to help enhance children's resilience, facilitating emotional and social stabilization, and the acquisition of new skills and abilities.

While it is hoped that psychosocial sports and play programs can make a positive contribution towards the enhancement of a child's resilience, this can only occur under certain conditions - a sport is often mistakenly viewed as having some sort of intrinsic nature in and of itself (either good or bad), but is actually a neutral or empty practice that is filled with meanings, values, and ideas of the culture in which it takes place, and influenced by the individuals who participate (Guest, 2005).

There is compelling practical, anecdotal and theoretical evidence to suggest that psychosocial sport and play programs can be helpful with children who have experienced severe stress or trauma, but there is yet little empirical evidence proving it. This is a challenge that the initiators of (and donors to) psychosocial sports and play programs now face. While their focus has been primarily on raising and spending money on the development and implementation of programs, there has been a significant lack of money being spent on collecting empirical research data on short-term outcomes and long-term impacts. Empirical data is crucial to ascertain which interventions are the most effective in helping enhance resilience in children and adolescents, and thus enable them to more effectively adapt in a post-crisis environment. Empirical data can also be helpful in improving organizational accountability, potentially increasing future fundraising abilities as a result. Additionally, empirical field research of psychosocial sports and play programs can help establish a comparable database to facilitate the identification of best practices and the accurate evaluation of different resilience-focused programs. These psychosocial studies will then be comparable with classical psychological and medical studies, and will thus become empirically competitive. This can help both to map out the borders of effective psychosocial practices, defining where and when psychosocial programs reach their limits, and also identify when traditional forms of psychological and medical help would be more effective and efficient.

Psychosocial research has unique challenges it must address in order to gather useful data (Duncan & Arntson, 2004). The following areas should be considered for future research on psychosocial sport and play programs in international settings:

- Identifying stressors, and assess the impact of these stressors on children's behavior, emotional stability and mental health.
- Assessing child and adolescent resilience levels, particularly before and after their participation in sports and play activities in order to identify any behavioral and psychological changes that may occur.
- Using resilience measures in international settings with children, to measure the reliability of these tools to effectively assess strengths and difficulties (though these tools will need to be translated into local languages, and then re-validated).

- Observing the impact of psychosocial sports and play activities on children's behavioral and psychological status over time, paying particular attention to whether certain sports are more effective.
- Identifying changes in behavior and progress in school during the time a youth is participating in sports, to note the influence of participation in other areas of their lives.
- Assessing coach and child interactions, and compare which coaching styles may be more effective in helping children.
- And in order to do any of the above assessments, a project must identify practical, measurable outcomes, both short-term and long-term, and evaluation of the effectiveness of a program will require the inclusion of either a cluster-randomized trial, or if that is not possible, then with the inclusion of a control group.

# Conclusion

Psychosocial sport and play programs look to be an important development in potentially helping children manage and thrive in the aftermath of traumatic or severely stressful experiences, and it appears that the "active ingredient" of these programs is in the enhancement of children's resilience processes. A crucial component of any program will be the quality of relationships between the children and the adults who work with them, as programs run by adults offer children the opportunity to establish healthy attachments with them, to teach children how to effectively manage the various challenges they face in an effective manner, and offer encouragement throughout the process. Furthermore, since sport encourages group participation in community settings, these psychosocial sport and play programs provide a predictable and structured environment where even communities with histories of conflict can come together to play in a peaceful and safe environment, thus encouraging community reintegration. Therefore, sport may be utilized to support communication and self-sustaining development for an entire affected community. Likewise, psychosocial sports and play programs can provide the international academic research community with the opportunity to gain a better understanding of how to enhance resilience through psychosocial programs and practices.

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# Rehabilitation and Recovery From Stressful Events - a Model

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## Abstract

The paper describes the theoretical context of the tentative diagnosis IRF (Impaired Recovery Function). It is postulated that general level of stress upon the organism is positively correlated with need of recovery and at the same time negatively correlated with the ability to perceive signals of need of recovery. At a crucial point, the point of IRF, the inability to perceive the signals of need of recovery, and the drive to keep those signals unnoticed, explains the tendency to sustain or even raise, the level of stress. Since the need of recovery is not manageable the level of stress is destructive. Within the IRF-project health is defined as an intact recovery function (balance among needs). Preventive health care is defined as interventions maintaining the recovery function (RF) whereas medical care is defined as interventions restoring the RF.

**Keywords**: recovery function, need of recovery, health

# Introduction

This paper is developed upon a conference presentation in Copenhagen (Eriksson, 2004a) and a note on it in a WPA newsletter (Eriksson, 2004b). The topic is the tentative diagnosis IRF (Impaired Recovery Function) that is based on "four parameters of health" (Eriksson, 2003).

The four parameters of health are results of an attempt to conceptualise health-related conditions out of an understanding of recovery from stressful events. IRF is a theoretically defined condition where the general level of function of the organism no longer is enough to handle the accumulated level of need of recovery (see fig 1). It is postulated that general level of stress upon the organism is positively correlated with need of recovery and at the same time negatively correlated with the ability to perceive signals of need of recovery. At a crucial point, therefore, the inability to perceive the signals of need of recovery, and the drive to keep those signals unnoticed, explains the tendency to sustain or even raise, the level of stress (see fig 2 right). Since the need of recovery is not manageable the level of stress is destructive.

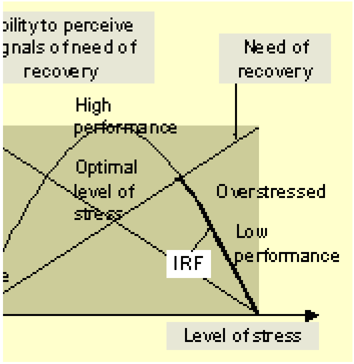
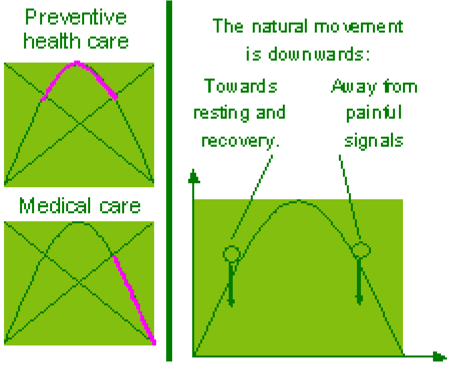


Figure 2



The IRF-project permits an integrative view on health-related matters. One concerns a definition of health: "health is an intact recovery function (balance among needs)". Since the recovery function (RF) is the system that enables the individual to recover, it is related to culture as well as tradition; the RF is contextual. In health care, it is also possible to define preventive health care as interventions maintaining the RF. Medical care in turn could be defined as interventions restoring the RF (see fig 2 left).

The IRF-diagnosis perhaps can be used to tie theory to operational definitions. One aim could be to construct an operational definition of the very IRF-diagnosis. Theoretically, within the model, IRF is a risk factor for prolonged negative health developments resulting in conditions as panic disorder, obesity, chronic fatigue syndrome, diabetes, pain syndromes and burnout (with its classical finding of impaired cognitive function).

On the issue of nosology further developments of the theory have been made regarding personality-related matters. Steps have been taken towards theoretical integration of personality disorders, melancholia and the effect of SSRI (Eriksson, 2005).

The IRF-project put emphasis on the assessment and the categorization of the individuals' ability to restore their systems of the recovery function. Rehabilitation, then, should be guided by the aim of the restoration. This has some clinical implications. Coping, for instance, is an easy thing when the stress-level is low enough. In the model that equals a high level of function or a decent buffer zone. When the level of stress is too high, coping is more complex. The earlier strategy to raise the level of stress to raise the level of function no longer works. Instead the clinician has to persuade the patient that less is more. In the model a lower level of stress, as seen on the right hand of figure 1, leads to a higher level of function. In fact the medicine is very bitter. In early phases of too high levels of stress the sense of well-being is raised at the cost of level of function. In rehabilitation, the thing is turned up side down: the level of function is raised at the cost of a lowered sense of well-being.

Of course this is all familiar for practitioners. The suggested model offers a conceptual structure for these experiences and hopefully can be used to support the implementation of rehabilitation programs that build upon the same ideas.

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# The psychotic among us:

## The Emerging View of Psychosis and its Possible Implications for Stigma

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## Abstract:

All forms of stigmatization, it is argued, are underpinned by an erroneous assumption that the stigmatized group is fundamental different or 'other'. There also tends to be an under appreciation of the diversity of the members within the group. This is equally true of stigmatization in areas such as race, criminality and morality etc. as it is in psychiatry where stigmatization of the mentally ill is a perennial problem. Some of psychiatry's (and society's) most cherished and 'taken for granted' orientations around the relationship between *madness* and *sanity*, and between *rationality* and *irrationality* serve to perpetuate unhelpful assumptions that people suffering from psychosis are fundamentally different and *un-understandable.* Although this has been the prevailing conceptualization of psychosis over the years, a different view now seems to be emerging which challenges our previous assumptions and which, potentially, will have implications for stigma.

**Keywords:** stigma, psychotic symptoms, continuum, normality, pathology

# Introduction

> *The early nineteenth century British Psychiatrist John Haslam argued early in his career that reason and madness were as distinct as black and white, straight and crooked; in old age, however, he confessed that he knew no one who was in his right mind, save only the Almighty* (Roy Porter *The Faber Book Of Madness [1]* )

Much has been written on the subject of stigmatization in psychiatry in recent years and Numerous strategies have been advanced to combat it. One of the key factors underpinning and perpetuating stigma is the construction of certain groups as 'fundamentally different' or 'other'. Erving Goffman, author of an influential early work on stigma [2], recognized the common experiences among different 'stigmatized persons'. " *They have enough of their situations in life in common to warrant classifying all these persons together for purposes of analysis*" and this exaggerated attribution of 'otherness' to certain groups is no less important as a factor in other areas where stigmatization is seen including *race* , *ethics ,* *criminality etc* where discriminatory attitudes are predicated on misconceived binary models of black/white or good/evil etc . An added dimension in the phenomenology of discrimination is the erroneous assumption of 'sameness' or homogeneity amongst the members of 'the other' group members so that the group is represented , to use Gilroy's phrase, in a *monochromatic* form [3] that denies or minimizes its internal diversity or heterogeneity. One might claim that Psychiatry's most visible symbols of 'otherness' have been identified and removed. To some extent, this is the case. Mental asylums, for example, situated on the margins of cities or towns, by their very location, once served as great symbols of 'separateness'. Prominent Parkinsonian side effects associated with the older generation of antipsychotic medication also served to accentuate and highlight the person's 'difference' and the newer generation 'atypical' antipsychotic medication represents, in this regard, a positive development.

Despite this, there is still something fundamentally stigmatizing about the way in which psychosis has been constructed in modern societies and reproduced in the most influential psychiatric orthodoxy including classification systems that serves to accentuate rather than attenuate a psychotic person's sense of estrangement from society. Common place assumptions about *sane/insane* and *rational/irrational* have, arguably, served to perpetuate stigma. The origins of society's interest in such conceptualizations of the relationship between rational and irrational are, if one follows Foucault, to be traced to the European enlightenment , when society, increasingly intent on defining itself as 'scientific' and 'rational' sought to distance itself from all that it perceived as irrational.[4] But Foucault's 'archaeology' tends not to be to everyone's taste and other writers are content to trace this dualistic trend to psychiatry's misappropriation of a biomedical model of sickness based on notions of organ *function/dysfunction* . The two developmental perspectives are probably not mutually exclusive and whatever the ultimate origin, we can say at least , that this model in which madness and sanity are separated by a fundamental dividing line , perpetuating a sense of *us and them* , is reproduced in so called *Neo- Kraepelinian* psychiatry. Also referred to as the 'disease model' or 'either – or model' of psychosis, the Neo-kraeplinian model has dominated psychiatry and has governed the way in which we have conceptualized psychosis. Jaspers' doctrine: 'an abyss of understanding separates the schizophrenic from the normal person.' [5] did not help , leading to the widespread belief, held almost as an article of faith by psychiatrists for decades in the fundamental *non understandability* of psychosis . The position embraced by Jaspers proved influential and legitimized a rather nihilistic attitude on the part of Psychiatrists when it came to trying to understand and ascribe meaning to the person's subjective experience. This was to prevail over the decades despite challenges from various corners. Rd Laing, for one, took particular exception to

Jaspers' view professing his aim 'to make madness and the process of going mad comprehensible' in the preface to *The Divided Self.* [6]

Psychotic symptoms are beginning to be seen differently. Far from being considered *un understandable, they* are increasingly being understood as reflecting a person's real life experiences. Rhodes and Jakes for example, showed that the content of delusions often reflects the person's biographical experiences and personal concerns [7]. Bentall, too, [8] cites evidence to support the claim that that delusions may often contain a 'nugget of truth' in reflecting an individual's life experiences such as *powerlessness* and *victimization* . A Great deal of interest in understanding the content of delusions, then, has been re- awakened and these recent steps amount to small but significant attempts towards bridging Jasper's notorious *abyss.* There has recently been renewed interest too, in the study of 'hallucinations in the sane'. In addition to the special conditions in which hallucinations have been well described e.g. post bereavement, solitude and the twilight periods between sleep and wakefulness etc, there have been attempts to enunciate the prevalence of hallucinations in various other 'normal' populations. Bentall and Slade [9] for example, found that as many as 15.4% of a population of 150 male students were prepared to endorse the statement 'In the past I have had the experience of hearing a person's voice and then found that no one was there'. Millham and Easton [10] reported a prevalence of auditory hallucinations amongst mental health nurses as 84% based on a questionnaire study. Evidence for the continuity of psychotic experience across the illusory boundary between 'normal and 'pathological' also comes from analysis of delusions. Writers , advancing the continuity or dimensional argument in delusions stress the widespread nature of 'abnormal' and bizarre beliefs ( be they UFO's , Fairies or Goblins ) in the 'normal' population . A powerful contemporary analysis is offered by American psychologist, Louis Sass who further constricts the 'ontological gulf' between sane and insane, though from the other direction (so to speak). In *paradoxes of delusion* , [11] drawing on a broad repertoire of clinical cases and literary references , Sass argues that people experiencing delusions are not as oblivious to conventional reality as might be commonly supposed . To the contrary, Sass argues that a sort of 'double orientation' is embraced. All this lends support to a continuum or dimensional model of psychosis and undermines the Neo- kraeplinian 'either/ or' disease paradigm which has prevailed for decades and which has contributed to estrangement and alienation experienced by sufferers of psychosis. A less binary and therefore a potentially less alienating and less stigmatizing view of psychosis seem to be emerging. In this view , the artificial Neo Kraeplinian dichotomy is essentially being eroded and being replaced by a 'continuum model of psychosis' and this is supported by findings from genetics [12] as well as epidemiology. Psychosis , no doubt interferes with a person's sense of self but the way in which society responds or accommodates or interprets (or allows the person to interpret) their experience is not without significance. To the contrary, emerging evidence from Cognitive behaviour therapy demonstrates that the outcome can be favourable depending on attribution or imputed meaning. It is noteworthy that The new conceptualization seems to converge with an orientation towards *sanity* and *insanity* which, although anathema to 'scientific' psychiatry, has been more willingly entertained in the humanities : Albert Camus explored this relationship In *Caligula* [13] , in which he contrasted the consequences of individual insanity with collective insanity, a theme which recurs in the writing of Erich Fromm [14] , Aldous Huxley [15] and RD laing [16]

We may also be informed by examining the Anthropological literature. The outcome of psychosis in developing countries , where the forfeiting of role or status in society is not as inevitable a corollary of psychosis as it is in developed countries , has consistently been shown to be superior than in developed countries. [17] This is not to romanticize psychosis nor to be dismissive or ignorant of the suffering associated with it for the person and their carers but psychosis occurs against a backdrop which might be considered to be the 'deep structures' within society , as the Belgian anthropologist , Devereux called them. [18]. these 'deep structures', though traditionally of interest to Anthropologists, have regrettably, tended to fall outside the concern of psychiatry. The possibility that the 'deep structures' in modern society, act to alienate or estrange a psychotic person more than is absolutely necessary , is not a particularly palatable one but one which anthropology / ethnography sensitizes us to considering.

Based on these tentative reflections on some aspects of the social phenomenology of stigmatization , there appears to be reason to suppose that the emerging view of psychosis represents a small step in the right direction when it comes to the amelioration of stigma experienced by people suffering with psychosis . Therapists working individually with people suffering from psychosis have employed a strategy of emphasizing the continuity of 'symptoms' across the illusory boundary between 'pathological' and 'normal'. [19] In some respects then , the widespread 'uptake' of the continuity model the evidence for which is superficially presented above, takes these therapeutic strategies and applies them on a ' society wide scale'. As a continuation of this argument, it is not surprising that the very concept of 'schizophrenia' as a unitary entity has come under renewed attack. Linguistic categories themselves, by their very nature, when applied to people or to groups of people, perpetuate the very myths that we seek to dispel; those of *distinctiveness*, *difference* and internal *homogeneity*. The term *schizophrenia* is no exception in this regard and its dubious utility both in terms of predicting symptoms ( construct validity ) and in terms of predicting outcome (predictive validity) have been explicated by Bentall and Slade [9] lending support to the claim of its *meaninglessness* as a useful or justified concept . The term 'schizophrenia', as the argument goes, encompasses too diverse or heterogeneous a group of people to be a meaningful concept and the question of whether or not it has any positive function that counters its stigmatizing function needs to be confronted squarely

## Concluding Remarks

I wish to end on a personal note. Working with psychotic young people in deprived suburb of North London , I learned one valuable lesson ; their successful reintegration into communities following psychotic illnesses is eminently achievable and made all the more likely by not insisting that they inhabit diagnostic categories which reinforce their distinctiveness from the community at large. Innovative community mental health service delivery models including Assertive outreach teams (loosely modeled on the Stein and Test model [20] originally developed in Madison county, Wisconsin USA ) embrace principles such as community re integration , non stigmatizion and non reinforcement of difference etc . and in the pursuit of these principles, there is a tendency to eschew excessive emphasis on practices that reinforce difference ( one of the ways in which this is done is by not insisting that a person embrace the label of 'schizophrenia') We are reminded of the critiques , developed in the existential tradition [21] which oppose the external imposition of such categories, arguing that they conflict with an individual's right to self determination . Laing's description of schizophrenia as a 'straitjacket that restricts psychiatrists and patients', comes to mind. [22] The case for the abandonment of Szasz's 'sacred symbol of psychiatry' [23] seems stronger than ever and although two centuries years have passed since Pinel unchained the mentally ill, the chains likely to prove toughest of all to remove , though no less damaging or stigmatizing , it seems, are the linguistic ones.

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# Homeless Mentally Ill Persons: A bibliography review

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## Abstract

In this article, some of the most important worldwide studies concerning the homeless mentally ill persons are reviewed. Firstly, the psychosocial and demographic characteristics of homeless people in different countries are compared. A historical overview of the issue is also provided so that the reader can fully grasp the complexity of this current problem. Secondly, the relationship between homelessness and mental illness is examined. As we put forward in the fourth and fifth parts of our study, the findings of many studies support the conclusion that the homeless mentally ill are at a higher risk for dying prematurely in comparison with the general population due to the mental illness they are suffering from and owing to their homelessness situation as well. Not only, do they die early, but also they have a poorer quality of life than that of the general population. Later on, the main conclusions reached in the articles that have been reviewed are analyzed. Our literature review sheds light on some of the causes of the complex phenomenon of homelessness. These causes should be taken into account when fighting against homelessness and developing preventive programs. Finally, some of the initiatives that have been carried out to end up with this huge problem are studied in-depth in order to suggest recommendations for best practices.

**Key words:** Homelessness, Mentally-ill people, Mortality rates, Bibliographic review, Preventive programs.

# Homeless People: A worldwide vision

Completely accurate and comprehensive statistics are difficult to acquire for any social study, but this is especially true when it comes to the ambiguous, hidden, and erratic reality of homelessness. Although each country has a different approach to counting homeless people and, therefore, comparisons should be made with caution, some of the most recent statistics (1) indicate that the approximate average number of homeless people at any given time in the European Union is 3,000,000; 750, 000 in the U.S. (1% of the entire U.S. population); 200,000 in Canada and 99,000 in Australia.

Canada is viewed by many as having far too high a number of homeless people, with some of the highest per capita rates of any developed nation. For instance, Canada has about 200,000 homeless, while the United States, with nine times Canada's population, has only 750,000.

Besides, the number of homeless people worldwide has grown steadily in recent years. In some Third World nations such as Brazil, India, Nigeria, and South Africa, homelessness is rampant, with millions of children living and working on the streets. In spite of their growing prosperity, homelessness has also become a problem in the cities of China, Thailand, Indonesia, and the Philippines.

The number of Americans living below the poverty threshold, officially defined on the basis of a standard of consumption updated every year to take inflation into account, rose from 29 million in 1980 to 39 million in 1993 (2). The rate of poverty has risen from 11.4% in 1978 to 15.1% in 1993 for the entire American population, from 30.6% to 33.1% for Blacks, from 21.6% to 30.6% for Hispanics.

Regarding ethnicity (3), it is estimated that, in the U.S., 49% are African-American (compared to 11% of general population); 35% are Caucasian (compared to 75% of general population), 13% are Hispanic (compared to 10% of general population), 2% are Native American (compared to 1% of general population) and 1% are Asian-American (compared to 3% of general population).

40% are families with children, 41% are single males, 14% are single females and 5% are minors unaccompanied by adults. It is noteworthy that 1.37 million (or 39%) of the total homeless population are children under the age of 18 (3).

With regard to their educational level, 38% have less than a High School diploma , 34% have a High School diploma or equivalent (G.E.D.); 28% have more than a High School education (3).

Only 13% have regular jobs and 50% receive less than $300 per month as income. Regarding their location: 71% reside in central cities; 21% are in suburbs and 9% are in rural areas (3).

With regard to health concerns (4), it is estimated that 22% are considered to have serious mental illnesses; 30% have substance abuse problems; 3% report having HIV/AIDS; 26% report acute health problems other than HIV/AIDS such as tuberculosis, pneumonia or sexually transmitted infections; 46% report chronic health conditions such as high blood pressure, diabetes or cancer and 55% report having no health insurance (compared to 16% of general population).

Traditionally, single men have constituted the overwhelming majority of the homeless. In the 1980s there was a sharp rise in the number of homeless families in certain parts of the United States; notably New York City. Most homeless families consist of an unmarried mother and children. A significant number of homeless people are teenagers and young adults, mostly runaways or street children. A 1960 survey by Temple University of Philadelphia's poor neighborhoods (5) found that 75% of the homeless were over 45 years old, and 87% were white. In 1986, 86% were under age 45, and 87% were minorities.

The increasing numbers of homeless in the cities raises the question of the extent and causes of this situation. As it has been shown above, homelessness has become a worldwide problem. The increase of "borderline" or "at risk" situations are accompanied by a fall in the low cost housing and other rooms that might be accessible to the poorest. A policy of prevention must remain a priority objective to avoid them finding themselves on the street.

By comparing the sociodemographic characteristic of homeless people living in different countries, some studies have tried to shed light on the causes of this growing problem. One example of this approach is the study carried out by Marpsat (6). The author of the study came to the conclusion that the age, sex and marital status of homeless people living in France were similar to those of the homeless who lived in the U.S. The homeless on both sides of the Atlantic had a very poor state of health, but alcohol and drug-related problems appeared to be fewer in France. Finally, poverty and structural factors such as a reduction in the availability of low cost housing or the shortage of jobs played a vital role in both countries. From one country to another, some of the characteristics of the homeless were close, like the similarity in the way they lose their housing, but also in the consequences of this situation, for example in terms of health. Other features such as the presence of certain ethnics or national minorities depended on the characteristics of the country. For instance, in the United States, some people who have had a rough passage like the Vietnam War veterans, and ethnic minorities (Blacks, Hispanics, etc.) are worse hit than others. For example, over three years, the likelihood of a Black using a public shelter in New York or Philadelphia is fifteen to twenty times greater than for a White man. In the U.S., it is estimated that 500,000 veterans experience homelessness at some time during the year. Veteran Affairs only provides housing to chronically sick veterans. Summing up, the analysis of the structural causes of the situation in both countries and the individual characteristics of the persons affected bore many similarities.

In the United States as well as in France there are fewer older persons among the homeless than among the population with a place to live. The main reason for this is the effect of high mortality among the homeless. In the United States, the mean age on dying scarcely gets beyond fifty for the homeless (2). In this respect, a detailed analysis is carried out in the fourth and fifth parts of our study.

Regarding the sex and marital status, the study (6) revealed that, in both countries the proportion of women is well below that of men. More than one-half of the homeless are single, and around a third are divorced or widowers.

## HISTORICAL BACKGROUND

Most experts in the field generally agree that modern homelessness began in the U.S. in the 1980s. During Ronald Reagan's duel-term presidency (1981-1989) a variety of drastic budget reductions are credited with undermining many urban populations, most notably those of poor and minority demographics (7). In his first year of office Reagan halved the budget for public housing and Section 8 (the government's housing voucher subsidization program). Such changes resulted in an inadequate supply of affordable housing to meet the growing demand of low-income populations.

Not only did this situation occurr in the U.S., but also happened in other countries. In the U.K., the Conservative government introduced a programme of "Care in the Community" that provided neither adequate care for the mentally ill nor community support. Between 1988 and 1995 the average daily number of long-stay beds available in hospitals for the mentally ill was cut by half to 18,644. During the same period the proportion of the average hospital budget spent on mental health fell from 14.4 percent to 12 percent.

The 1980s also witnessed a continuing trend of deinstitutionalizing mental-health hospitals in the U.S. It is believed that a large percentage of these released patients ended up in the homeless system. The movement in state mental health systems shifted towards community-based treatment as opposed to long-term confinement in institutions. Unfortunately, as a result of the lack of local community programs, many patients ended up in the streets.

In response to the ensuing homelessness crisis of the 1980s, concerned citizens across the country demanded that the federal government provide assistance. After many years of advocacy and numerous revisions, Reagan signed into law the McKinney-Vento Homeless Assistance Act in 1987—this remains the only piece of federal legislation that allocates funding to the direct service of homeless people.

The McKinney-Vento Act paved the way for service providers in the coming years. During the 1990s homeless sherlters, soup kitchens, and other supportive services sprouted up in cities and towns across the nation. However, despite these efforts and the dramatic economic growth marked by this decade, homeless numbers remained stubbornly high. It became increasingly apparent that simply providing services to alleviate the symptoms of homelessness (i.e. shelter beds, hot meals, psychiatric counseling, etc.), although needed, were not successful at solving the root causes of homelessness.

Besides, critics claim that Bill Clinton's 1996 welfare reforms increased the number of families entering homelessness. At any rate, policies set into motion in the 1980s were never adequately reversed during the Bush Senior or Clinton administrations and disparities between rich and poor continued to widen. Conditions, therefore, remain ripe for becoming homeless.

Now, for the first time, government officials are calling for an end to homelessness. To accomplish this goal the Interagency Council on Homelessness (ICH), the federal branch that was created under the McKinney-Vento Act, has adopted a strategy largely devised by the National Alliance to End Homelessnes (one of many homeless advocacy organizations), which centers on the production and implementation of local 10-year plans to end chronic homelessness. The idea is to get all of the necessary parties—local/state governmental agencies, businesses, non-profit organizations, service providers, faith-based entities, and homeless individuals—working in collaboration to devise and implement a 10-year plan for their respective community.

Rather than channeling funds into direct services that seemingly sustain homeless lifestyles, these result-oriented plans are designed to focus efforts and funds on the creation of permanent supportive housing (PSH) for the most troubled and difficult, "chronic" homeless population. Considering that it is actually cheaper to house someone than it is to fund the otherwise needed myriad services, this approach is touted as being a cost-effective solution.

Many service providers applaud the government's focus on ending homelessness, as opposed to managing it, and realize the necessity of incorporating all sectors of society in order to accomplish such a goal. However, critics express concern that the majority of the homeless population, who are not considered "chronic," will be neglected; if federal funds are stipulated only for this 10% demographic—although no doubt deserving—what will become of the other 90%? These concerns are exacerbated by a failure to receive sufficient additional allocations while already struggling with budgets spread extremely thin.

Historically, the main features of homelessness have changed with the passing of time. Over the last two decades the face of homelessness has changed substantially. For instance, in the early 1980s the homeless population in Canada was mostly made up of older men the majority of which had mental health problems or were alcoholics. Today younger men and children make up a large segment of the homeless population. Less than 20% of the homeless have drug or alcohol abuse problems. Almost half of all homeless people have jobs. This change has been attributed to changing economic circumstances that have seen minimum wage jobs no longer be able to pay for accommodation in some of Canada's cities. The federal government has not built subsidized housing since the early 1990s and families and the poor who used to take advantage of these services are now forced to live on the streets.

Presently, no plan has been in effect for a full 10-years so achievement is difficult to gauge; the best indications reveal mixed success. Although many cities have seen chronic numbers dip, it is unclear whether or not homelessness as a whole is decreasing. The hope is that necessary modifications can be made to existing plans, and that newly devised plans can implement the strategies that work and avoid the ones that don't.

## THE RELATIONSHIP BETWEEN HOMELESSNESS AND MENTAL ILLNESS

With regard to the link between homelessness and mental illnesses, some studies have been carried out all over the world. In the U.K., the "Pressure Points" report (8) estimates that in a third of all cases, those who lose their accommodation are suffering from mental illness. This perpetuates a vicious cycle in which the stress of homelessness often exacerbates the illness and makes it difficult for those suffering to gain access to housing and healthcare in the future. Once homeless, many mentally ill people can remain without permanent housing for several years. Many local doctors are reluctant to accept the homeless onto their lists.

People suffering from serious mental disorders (such as psychotic disorder, severe depression…) find it difficult to maintain a household. It has been estimated that half of all homeless persons have some form of mental illness. In some cases, it is not always clear which came first; the homelessness or the mental illness. According to the National Alliance for the Mentally Ill (NAMI), there are 50,000 mentally ill homeless people in California alone because of deinstitutionalization between 1957 and 1988 and a lack of adequate local service systems (9). The deinstitutionalization has led, according to many authors, to an increase in homelessness. Many mentally ill persons ended up in the strets after being released from mental hospitals.

On the other hand, it is estimated that 38% of homeless suffer from a substance abuse problem. Debate also exists about whether drug use is a cause or consequence of homelessness. However, regardless when it arises, an untreated addiction makes moving beyond homelessness extremely difficult.

In the U.K., the “Pressure Points” report (8) estimates that:

1* Six out of ten homeless people experience some form of mental distress. The homeless are 11 times more likely to suffer from illnesses such as depression, than the general population.
2* One person in five sleeping rough has a severe mental health problem, such as schizophrenia. More than one in six rough sleepers has stayed in a psychiatric hospital as an inpatient.
3* People who sleep rough are 35 times more likely to kill themselves than the general population. The average age of death by suicide for rough sleepers is 37 years old.

Mental health problems often start before homelessness and can directly cause a loss of accommodation, but they can also be the reason people remain homeless for many years. In the U.S. 80% of those who experience homelessness do so for less than 3 weeks; 10% are homeless for up to two months 10% are so called “chronic” and remain without housing for extended periods of time on a frequent basis. The “chronic” homeless struggle with mental illness, substance abuse, or both. It appears that suffering from a mental illness or a substance abuse problem might make homeless a chronic problem.

The author of the study conducted in France (6) reached the following conclusions:

- Among the homeless there are more people having physical or mental health problems and alcohol and drug-related problems than in the rest of the population. Yet, the research available does not indicate with certainty whether these difficulties have been the cause of the person's homelessness or are a consequence of this situation. The use of alcohol and narcotics, and even some forms of mental illness, are seen by some authors as forms of adaptation to street life.

- In the USA, the problems of alcoholism and drug abuse concern men more than women, the latter suffering more from mental disorders, including depression.

- The rate of stay in a psychiatric hospital is just 19% for single men, 27% for single women, but only 8% for women with children.

- The results obtained for Paris seem to show a prevalence of mental health problems among the homeless close to that of the United States, with however better access to care, if not better medical follow up.

- In France, the problems of alcoholism and drug abuse, although higher than for the rest of the population, are in fact seemingly lower than those in the USA.

- Several groups stood out because of specific difficulties: for example, the under 25's suffer more from dependency on hard drugs and personality disorders; the women have more often been institutionalized for psychiatric problems and have fewer alcohol and personality disorder problems than the men; middle aged men who use the emergency shelters have more alcohol-related problems.

## MORTALITY RATES AMONG THE MENTALLY ILL

The burden of mental illness on health and productivity in the United States and throughout the world has long been underestimated. Data developed by the massive Global Burden of Disease study (10) conducted by the World Health Organization, the World Bank, and Harvard University, reveal that mental illness, including suicide, accounts for over 15 percent of the burden of disease in established market economies, such as the United States. This is more than the disease burden caused by all cancers.

This study developed a single measure to allow comparison of the burden of disease across many different disease conditions by including both death and disability. This measure was called Disability Adjusted Life Years (DALYs). DALYs measure lost years of healthy life regardless of whether the years were lost to premature death or disability. The disability component of this measure is weighted for severity of the disability. For example, disability caused by major depression was found to be equivalent to blindness or paraplegia whereas active psychosis seen in schizophrenia produces disability equal to quadriplegia.

Using the DALYs measure, major depression ranked second only to ischemic heart disease in magnitude of disease burden in established market economies. Schizophrenia, bipolar disorder, obsessive-compulsive disorder, panic disorder, and post-traumatic stress disorder also contributed significantly to the total burden of illness attributable to mental disorders.

The projections show that with the aging of the world population and the conquest of infectious diseases, psychiatric and neurological conditions could increase their share of the total global disease burden by almost half, from 10.5 percent of the total burden to almost 15 percent in 2020.

The facts are that major depression is the leading cause of disability (measured by the number of years lived with a disabling condition) worldwide among persons age 5 and older. For women throughout the world depression is the leading cause of DALYs. In established market economies, schizophrenia and bipolar disorder are also among the top 10 causes of DALYs for women.

The following chart shows the disease burden in Established Market Economies. This burden is measured in DALYs (lost years of healthy life regardless of whether the years were lost to premature death or disability).

| | | |
|---|---|---|
| **The Leading Sources of Disease Burden in Established Market Economies.** | | |
| | Total (millions)* | Percent of Total |
| All Causes | 98.7 | |
| 1. Ischemic heart disease | 8.9 | 9.0 |
| 2. **Unipolar major depression** | 6.7 | 6.8 |
| 3. Cardiovascular disease | 5.0 | 5.0 |
| 4. **Alcohol use** | 4.7 | 4.7 |
| 5. Road traffic accidents | 4.3 | 4.4 |
| 6. Lung & UR cancers | 3.0 | 3.0 |
| 7. Dementia & degenerative CNS | 2.9 | 2.9 |
| 8. Osteoarthritis | 2.7 | 2.7 |
| 9. Diabetes | 2.4 | 2.4 |
| 10. COPD | 2.3 | 2.3 |
| **Disease Burden by Selected Illness Categories in Established Market Economies.** | | |
| | | Percent of Total |
| All cardiovascular conditions | | 18.6 |
| **All mental illness including suicide** | | **15.4** |
| All malignant disease (cancer) | | 15.0 |
| All respiratory conditions | | 4.8 |
| **All alcohol use** | | **4.7** |
| All infectious and parasitic disease | | 2.8 |
| **All drug use** | | **1.5** |
| **Mental Illness as a Source of Disease Burden in Established Market Economies.** | | |
| | Total (millions)* | Percent of Total |

| | | |
|---|---|---|
| All Causes | 98.7 | |
| Unipolar major depression | 6.7 | 6.8 |
| Schizophrenia | 2.3 | 2.3 |
| Bipolar disorder | 1.7 | 1.7 |
| Obsessive-compulsive disorder | 1.5 | 1.5 |
| Panic disorder | 0.7 | 0.7 |
| Post-traumatic stress disorder | 0.3 | 0.3 |
| Self-inflicted injuries (suicide) | 2.2 | 2.2 |
| **All mental disorders** | 15.3 | 15.4 |
| *Measured in DALYs (lost years of healthy life regardless of whether the years were lost to premature death or disability). | | |

The chart reveals that all mental illnesses including suicide account for the 15.4% of the total disease burden. The National Institute of Mental Health has estimated that, in 2002, 31, 655 people died by suicide in the U.S. More than 90 percent of people who kill themselves have a diagnosable mental disorder such as depressive disorders or a substance abuse disorder. In addition, mental disorders are the leading cause of disability in the U.S. and Canada for ages 15-44. Furthermore, it is estimated that over 3 million persons with mental illness are dying prematurely each year on account of risk factors which can be prevented.

According to the Global Burden of Disease study (10), schizophrenia ranks among the top causes of disability in developed and developing countries worldwide. People with schizophrenia have a 50 times higher risk of attempting suicide than the general population. Suicide is the number one cause of premature death among people with schizophrenia, with an estimated 10 percent to 13 percent killing themselves and approximately 40% attempting suicide at least once. Other figures that should not be overlooked are that as much as 60% of males attempt suicide and teenagers with schizophrenia have approximately a 50% risk of attempted suicide. These suicides rates can be compared to the general population, which is somewhere around 0.01%. The Treatment Advocacy Center states that the extreme depression and psychoses that can result due to lack of treatment are the usual causes. Drug or alcohol abuse raises the risk of violence in people with schizophrenia, particularly if the illness is untreated. Most people with schizophrenia are far more likely to harm themselves than be violent toward others.

Besides a higher rate of suicide, people with mental illness have high rates of physical illness and are at and increased risk of developing, and die prematurely from coronary heart disease, obesity and some cancers (11). Additionally, medication used in treating mental illness has marked side effects including weight gain, hyperglycemia, diabetes and gastrointestinal problems. On the other hand, malnutrition is frequently a consequence of self-neglect, which can be a common feature of mental illness. Mentally ill people can have a lifestyle involving inadequate and disordered eating, high caffeine intakes, little physical activity and smoking, which contributes to poor physical and mental health.

People with mental illness are at particular risk for developing the so-called "Metabolic syndrome" (11). This may be the result of lifestyle impacts cited above; may be due to the impact state on motivation and energy levels; may be an effect of the medications… Although the relative contribution of the various factors to increase the risk of developing metabolic syndrome and cardiovascular disease in this population is poorly understood, the evidence suggests that the psychotropic medications may play an important role.

On the other hand, most authors agree that the earlier that schizophrenia is diagnosed and treated, the better the outcome of the person and the better the recovery. Early intervention and early use of new medications lead to better medical outcomes for the individual. The earlier someone with schizophrenia is diagnosed and stabilized on treatment, the better the long-term prognosis for their illness. Recent research increasingly shows that the disease process of schizophrenia gradually and significantly damages the brain of the person, and that earlier treatments (medications and other therapies) seem to result in less damage over time. Therefore, it is vital to make both psychotropic medications and psychosocial rehabilitation more accessible to those in need of them.

The National Institute of Mental Health (12) estimates that approximately half of all individuals with severe mental illnesses have received no treatment for their illnesses in the previous 12 months. These findings are consistent with other studies of medication compliance for individuals with schizophrenia and manic-depressive illness (bipolar disorder). The majority (55 percent) of those not receiving treatment have no awareness of their illness and thus do not seek treatment. The 45% who acknowledged that they needed treatment but still were not receiving it, cited as the main reasons for this that their health insurance would not cover treatment and that treatments were too expensive. After 10 years, 10% percent of the people diagnosed with schizophrenia die (mostly because of suicide). After 30 years, 15% of them are dead. Therefore, unless treatments are more available for most people with mental illness, they will continue to lose years of healthy life and die prematurely.

Approximately, in the U.S, 200,000 individuals with schizophrenia or manic-depressive illness are homeless, constituting one-third of the approximately 600,000 homeless population (according to data from Department of Health and Human Services) (12). These 200,000 individuals comprise more than the entire population of many U.S. cities, such as Hartford, Connecticut; Charleston, South Carolina; Reno, Nevada; Boise, Idaho; Scottsdale, Arizona; Orlando, Florida; Winston Salem, North Carolina; Ann Arbor, Michigan; Abilene, Texas or Topeka, Kansas. At any given time, there are more people with untreated severe psychiatric illnesses living on America’s streets than are receiving care in hospitals. Besides, as many as one in five (20%) of the 2.1 million Americans in jail and prison are seriously mentally ill, far outnumbering the number of mentally ill who are in mental hospitals. The vast majority of people with schizophrenia who are in jail have been charged with misdemeanors such as trespassing. It is noteworthy that most of these people are not receiving a proper treatment.

Although the greatest cost of schizophrenia is the non-economic costs to those who have it and their families, we shouldn’t forget that, regarding the cost of schizophrenia to society, it is estimated that the overall U.S. 2002 cost of schizophrenia was $62.7 billion, with $22.7 billion excess direct health care cost ($7.0 billion outpatient, $5.0 billion drugs, $2.8 billion inpatient, $8.0 billion long-term care). The National Institute of Mental Health has stated that nearly 30 percent ($19 billion) of schizophrenia's cost involves direct treatment and the rest is absorbed by other factors (lost time from work for patients and care givers, social services and criminal justice resources). Schizophrenia, long considered the most chronic, debilitating and costly mental illness, now consumes a total of about $63 billion a year for direct treatment, societal and family costs. Federal costs for the care of seriously mentally ill individuals now total $41 billion yearly and are rocketing upward at a rate of $2.6 billion a year.

In economic terms, in the UK, some 80 million working days are lost each year at a cost of £3.7 billion. The NHS spends around £1 billion on treatment and personal social services another £400 million. As many studies have shown, if preventive treatments were carried out these costs would diminish.

On the other hand, anti-psychotic medications are the generally recommended treatment for schizophrenia. If medication for schizophrenia is discontinued, the relapse rate is about 80 percent within 2 years. With continued drug treatment, only about 40 percent of recovered patients will suffer relapses.

The American Psychiatric Association (13) published the practice guidelines for the treatment of patients with schizophrenia. Furthermore, experts in the field of schizophrenia reached a consensus regarding the treatment of people suffering from schizophrenia (14). They came to six conclusions supported by scientific evidence and liable to lead to changes in practice:

a) Continuous treatment with a neuroleptic is preferable to discontinuous treatment.
b) Only one neuroleptic need be administered.
c) The systematic prescription of antiparkinsonian anticholinergic medication is not recommended.
d) Antidepressants should not be prescribed during the acute phase.
e) Antidepressants are not necessary in chronic schizophrenics with negative symptoms of the deficit state.
f) Combining psychotherapy with neuroleptic administration yields better results than either of these treatments administered alone.

Besides, international guidelines were in agreement on certain recommendations for anti-psychotic prescriptions (14):

- Monotherapy should be preferred.
- The maintenance dose is the minimum effect dose with minimum side effects.

Theoretically these principles are clear. Yet, in practice studies have shown that psychiatrist only partially comply with these guidelines. High percentages of patients receiving anti-psychotic combinations have been observed (from 34.4 to 54%) (15) and high doses are administered. In Europe, anti-psychotic prescription in schizophrenia is characterized by frequent associations and high doses (16).

Another study was conducted out in order to examine the putative role of neuroleptics in the known excess mortality of subjects with schizophrenia (17). Such a study assessed the link between mortality and the class of neuroleptic. The authors studied the causes of death (suicide, cardiovascular…) and the exposure to neuroleptics in a cohort of 3474 patients with schizophrenia followed from 1993 to 1997. 178 patients died within that period. The risk of all-cause death and suicide were increased in users of thioxanthenes (alone or associated with other drugs), and increased risk of “other causes” of death was associated with use of atypical neuroleptics. These findings suggest the existence of association between certain classes of neuroleptic and death, all cause or specific.

Taking all these facts into account, it can be concluded that there are a lot of work to be done to provide mentally ill people with the proper treatments they require. It is essential to make psychotropic medications more accesible to those in need of them and also provide them with psychosocial rehabilitation. Finally, it is also vital to study and report long term adverse effects of pharmaceutical products.

## MORTALITY RATES AMONG HOMELESS PEOPLE

### Background

In a study published in December of the 2005 (18), O´Connell carried out a painstaking review of the existing scientific literature regarding the mortality rates in homeless people. The article cited above reviewed cohort studies conducted in the past 15 years in major cities such as Philadelphia, Boston, New York, Stockholm, Toronto and Copenhagen. Besides, in this paper mortality among several sub-groups of the homeless population is reviewed.

Since the 1970s, more attention has been paid to the association between mortality and homelessness. To cite just a few examples: A study published in 1982 (19) found three times greater mortality in the depressed area of Watts and the skid row areas of Los Angeles than in any other place in the country. Another study (20) revealed that one district in Boston had the highest numbers of deaths in the Commonwealth. Such a district was characterized by severe poverty, poor housing with marked overcrowding and homelessness, personal disability and social isolation. Taking into account that 652 more deaths occurred in this small area than would be expected by statewide mortality rates, they came to the conclusion that the number of deaths exceeded that of places declared "natural disaster areas" by the government.

## CAUSES OF DEATH

The reports from the Offices of the Medical Examiner also provide us with some valuable information in regard to the causes of death among homeless people. In this way, the Office of the Fulton County Medical Examiner (21) found 40 deaths among homeless adults in Atlanta in a review of the 2,380 deaths reported in a one-year period. The median age of the homeless who had died was 44 years old. 44% of these deaths were due to natural causes (disease or normal aging process). 56% of the deaths were due to External causes (injury, drug ingestion, unintentional accidents or intentional deaths due to suicide or homicide). 48% of the deaths due to external causes were caused by unintentional accidents (alcohol intoxication, injuries caused by fire, hypothermia, falls...). There were also 4 homicides and 1 suicide. The Medical Examiner determined that the 70% of these homeless had died owing to a condition related to alcohol.

A subsequent report by The Fulton County Medical Examiner's Office (22) investigated 128 homeless deaths in the three-year period from 1988 through 1990 and found similar results. The average age of death was 46 years old and almost all of the decedents (125) were men. 42% of the homeless deaths resulted from external causes (including 10 homicides and 4 suicides).

The records of homeless deaths reported to the ME´s office in San Francisco revealed that the average age of death was 41 years. The 53% of the deaths were due to external causes. One-third of the decedents were legally intoxicated from alcohol at the time of death, and either drugs or alcohol were detected in the 78% of those who died.

The patterns of death in Atlanta and San Francisco were very similar in the studies cited above. The two major limitations of such an approach are the failure to document deaths that occur outside the jurisdiction of the ME and the tendency to miss the deaths of homeless persons who die of natural causes in hospitals. A further limitation of these reports is the inability to calculate standard mortality ratios, which require an estimate of the size of the homeless population during a given time period in each of those cities.

## STANDARD MORTALITY RATIOS

The risk for death among homeless persons when compared to the general population depends on the calculation of standard mortality ratios (SMR). An SMR of 1.0 means that homeless persons have the same risk of dying as the general population; greater than 1.0 indicates a higher risk of dying, and less than 1.0 indicates a reduced risk of death. The calculation of the SMR for homeless persons requires two critical factors. The numerator is an accurate count of the number of homeless deaths per year, and the denominator is a reasonable estimate of the size of the homeless population in a given city or county.

In Stockholm, Sweden, it was conducted one of the first studies of mortality among homeless persons (23). The cohort included 6,032 men. In comparison with the national death registry the authors found a mortality rate ratio of 4 times that of the Swedish population. The authors noted that this cohort included men who had been homeless for many years, and most of the deaths were related to alcohol.

The first data on mortality in a well-defined cohort of homeless persons in America were published in 1994 (24). It was found that homeless adults in Philadelphia had an age adjusted mortality rate of almost 4 times that of the city´s general population. The study followed 6308 homeless people between 15 and 74 years of age. They were followed in the four-year period from 1985 through 1988. The authors also found that homeless persons lost 3.6 times more years than the general population.

Another study carried out in Boston (25) demonstrated that many homeless persons with HIV infection were dying prematurely and before the disease had progressed to frank AIDS.

In New York a cohort of 949 homeless men and 311 homeless women was studied (26). This sample was interviewed to determine a baseline profile and to identify predictors of mortality. One fifth reported a disability or medical impairment that limited daily functioning. 54% of the men and 38% of the women had substance abuse problems. A third of the cohort reported no mental health or substance abuse problems. Age-adjusted mortality rates for the homeless cohort was approximately 4 times that of the general US population (SMR= 3.9 for men and 4.7 for women). Regarding the predictors, it is noteworthy that those who died reported poorer health (they were more likely to have a disease such as cancer, hypertension...).

A three-year cohort study was conducted in Toronto (27). The most striking finding of this study is that the total mortality rate for homeless men in Toronto was significantly lower than seen in the U.S. cities of Philadelphia, Boston and New York. The findings suggest that men in the middle age groups in Toronto have about half the risk of dying in comparison with the risk of dying in these U.S. cities.

In a study which took place in Copenhagen (28), the SMR obtained for the entire cohort was 3.8., 2.8 for men and 5.6 for women. Mortality was especially high in younger men and women 15–34 years of age. Suicide was six times more common in the cohort than in the general population. Predictors of early death were the misuse of alcohol and sedatives.

## STUDIES OF SUB-GROUPS OF HOMELESS PERSONS

A 10-year study (29) examined mortality among homeless persons with schizophrenia in Sidney, Australia. The authors assessed a cohort of 708 homeless persons referred to psychiatric outreach clinics. 506 were diagnosed with schizophrenia. 12% in the cohort died, with a mean age of death of 50 for men and 57 for women. The 36% of the deaths were not due to natural causes. Most of these deaths were due to suicide, injuries or overdoses. No deaths were due to homicide, in contrast to studies from American cities. AIDS was an uncommon cause of death. The SMR was 3.8 for homeless men and 3.1 for homeless women, with excess mortality highest among the younger age groups. The authors also found a trend toward higher excess mortality among men without schizophrenia compared to men with schizophrenia.

A retrospective cohort study (30) assessed mortality over a 9-year period (1989–1998) in 6714 homeless and 1715 non-homeless male veterans who received care in specialized mental health programs in the Department of Veteran Affairs (DVA). The SMR for veterans of 35-54 years of age who had been homeless less than one year was 4.2 and it was 4.13 for those homeless more than one year. Non-homeless veterans of 35-54 years of age had an SMR of 3.16.This study found no clear relationship between mortality and the length of time being homeless.

A prospective cohort study (31) was conducted in Montreal (Canada) in order to examine the mortality of homeless between 14 and 25 years of age. The SMR for this age group was 11.4. The authors note that this finding is consistent with age-related mortality ratios in Boston, Toronto, New York, and Copenhagen. One half of the deaths were due to suicide. Independent predictors of mortality included HIV infection, daily alcohol use in the last month, homelessness in the last 6 months and drug injection in the last month.

### THE STREET POPULATION

The studies above identified cohorts of homeless persons who utilized shelters or specialized clinics for homeless persons. Few studies have been able to assess mortality in the sub-group of homeless individuals who live on the streets. These rough sleepers may have higher mortality rates than homeless persons who utilize shelters.

Since 2000, the Boston Health Care for the Homeless Program has prospectively followed a cohort of 119 chronically homeless persons who had been living on the streets for at least six consecutive months (32). 75% of the cohort was male, and the mean age was 47 years. At the end of 5 years, 33 individuals (28%) had died and 6 (7%) were in nursing homes. The average age at death was 51 years. The most common causes of death were cancer and cirrhosis, and only one person died of hypothermia. During the five years from 1999 through 2003, this group had a total of 18,384 emergency room visits.24 Further analysis of the data from this cohort study is in progress (33), but the observation that more than a quarter of these individuals died in the five-year observation period from 2000 through 2004 suggests a significantly increased risk of death for homeless persons living on the streets.

## Conclusions

Several studies in major cities across the United States, Canada, Europe, Asia, and Australia have confirmed a persistent relationship between a lack of housing and excess mortality. Despite a diversity of methodologies utilized across multiple continents, the current literature reviewed in this paper demonstrates a remarkable consistency that transcends borders: **homeless persons are 3–4 times more likely to die than the general population.**

* Age-related mortality ratios reveal that homeless persons in all age groups have a higher risk of death than people of similar ages in the general population of the cities cited in this paper.

* The most glaring discrepancies in mortality ratios are seen in the younger and middle-aged groups from 18 to 34 years and from 35 to 54 years of age. While elderly homeless persons have a greater risk of dying than their housed counterparts, the standard mortality ratios across these cities are not as dramatic as for the younger age groups.

* Younger homeless women have from 4–31 times the risk of dying when compared to housed women, and younger homeless women have similar risks of premature death than younger homeless men. The usual competitive advantage of women over men, with increased life expectancy even in impoverished areas, appears to disappear in these studies, a finding that requires further investigation.

* The average age of death in the studies reviewed is between 42 and 52 years, despite an average life expectancy of almost 80 years in this county. The potential years of life lost are incalculable.

* The “tri-morbidity” of substance abuse and mental illness together with one or more chronic medical illnesses appears to increase the risk of early death.

* Health care utilization prior to death is variable and remains poorly understood, although several studies show high numbers of emergency room visits as well as multiple contacts with medical, mental health, and substance abuse services and facilities in the days and weeks before death.

* Many sub-groups of homeless persons appear particularly vulnerable, especially those living with AIDS, street youth, mentally ill veterans, and those who live chronically on the streets.

* Most studies to date have been based on cohorts of homeless persons utilizing the shelter or clinic systems, and further study of those “sleeping rough” is required.

## THE CAUSES OF HOMELESSNESS

The lessons learned from fifteen years of observation of the characteristics of homeless people are that there is not only a great variety in the people and the paths they have followed, but there is also the crushing weight of poverty to explain this situation together with other factors such as mental disorders alcoholism and drug abuse which also appear as "immediate causes". In an attempt to understand why some people in poverty experience homelessness, and why some don’t, both structural and personal dynamics must be considered.

Among the structural factors, employment opportunities should be taken into consideration. The job opportunities are dwindling for those on the low end of the employment spectrum in terms of wages, skills, and education. On the other hand, the purchasing power of low wages is decreasing. The housing opportunities is another structural factors that should not be overlooked. The housing costs are rising drastically.The government housing-assistance programs are massively over-burdened. Currently, only one-fourth of all eligible families receive any federal housing assistance due to program funding constraints (35) and the average wait for Section 8 vouchers is 35 months (3).

From our point of view, health care opportunities are essential in the struggle against homelessness. In 2004, 45.8 million Americans (or 15.7% of the population) were without heath insurance, which was an increase from the year before, and was disproportionately represented by poor households (36). The U.S. spends 16% of its GDP on health care, more than any other industrialized nation, and those countries provide health insurance to all of their citizens (37). Heath care costs are skyrocketing. In 2004, total national health expenditures rose 7.9 percent—over three times the rate of inflation—and since 2000, employment-based health insurance premiums have increased 73%.(37).

People working low wage jobs, even if they work full-time, are less likely to be provided with health insurance. Without health insurance and under increasing medical costs, unexpected health emergencies or serious chronic illnesses can quickly overburden the resources of poor households.

Among the personal factors, it is noteworthy that untreated mental illness can make it difficult or impossible to maintain employment, pay bills or keep supportive social relationships. People with substance use disorder can drain financial resources, cause job or housing lose, and also erode supportive social relationships. Individuals with co-occurring mental illnesses and substance use disorders are among the most susceptible to the above mentioned loses.

In summary, there are a variety of ways that individuals become homeless and many of them occur simultaneously. Economically speaking, the job, housing, and health care markets pose formidable challenges to people without many resources. Politically speaking, in the U.S., dramatic reductions in federally supported housing over the past 25 years coupled with the current reductions in safety net programs leave poor households susceptible to homelessness. Individually speaking, people who have substance abuse problems, mental health issues dramatically increase their likelihood of experiencing homelessness.

In a review of some studies carried out in the U.S. (38), the main causes of remaining homeless were examined. The main conclusions of such a review were:

- 81% of homeless people were unemployed.
- 38% of the homeless surveyed stated that their poor health was the reason of remaining homeless.
- 33% considered mental illness as the main reason.
- 27% regarded alcoholism as the main reason.
- 31% thought that it was the lack of family contact that explained their situation.

If homelessness is inextricably linked to poverty then without alleviation of the most crippling aspects of poverty, homelessness can never be effectively ended. In particular, three main concerns are the focus of both governmental and non-governmental efforts to end homelessness: more affordable housing, livable wages and comprehensive health care.

Both mental illness and drug abuse problems should be treated simultaneously. Although many medical, psychiatric, and counseling services exist to address these needs, it is commonly believed that without the support of reliable and stable housing such treatments remain ineffective. Furthermore, in the absence of a universal health-care plan, many of those in need cannot afford such services.

The present difficultly is to address these root issues while at the same time providing for the real and immediate needs of people experiencing . Lastly, many critics of social policy assert that a failure to live responsibly and a lack of determination are what place and keep people in homeless situations. Such thinking is largely accredited with fueling a stigmatization of homelessness. It is not uncommon for Americans to think of homeless individuals as lazy, apathetic, immoral, irresponsible, unintelligent, or worthless. Such people typically believe it is only by choice that people are homeless and therefore they can choose not to be if they so desire. As such, there often exists considerable tension and resentment between those that are housed and those that are not. Many Americans complain about the presence of homeless people, and feel that their requests for money or support (usually via begging) are unjustified. Likewise, many homeless people feel they are ignored, despised, or even hated. Most who experience such treatment report low self-esteem, depression, and anger. It is often thought that such feelings encourage substance abuse and/or exacerbate mental-health issues, which in turn increase the difficultly of functioning within mainstream society (i.e. holding a job, paying bills, maintaining relationships). In this way, the series of events—whether substance abuse/mental illness caused, or resulted from, homelessness—is contested and inconclusive. Any attempt to truly end homelessness will have to deal with these pervasive social stigmas.

The problems encountered by the homeless often have their origins in childhood. In a comparison of the probability of having suffered childhood problems between the homeless and those having a place to live in the county of Los Angeles, the rates of placing outside the family that were noted were much greater among the homeless, especially Whites, as a much higher proportion of people who had been poor and had even sometimes already been homeless in their childhood, and of those who had been abused or had been victims of rape.

In relation to their backgrounds, in the U.S., 23% are veterans (compared to 13% of general population); 25% were physically or sexually abused as children; 27% were in foster care or similar institutions as children; 21% were homeless at some point during their childhood and 54% were incarcerated at some point in their lives.

Furthermore, the reactions of the population towards the homeless can also be a cause of problems, such as the "Nimby syndrome" (rejection of public shelters). It is with this term, Nimby, that the Americans designate the attitude which consists in refusing to allow services intended for the homeless to be set up in a person's neighborhood: "not in my backyard". These reactions from the public are now the subject of specific studies (39) in relation to the recent development of public policies towards making cuts in the budgets allocated to helping the poorest and the raising of the eligibility conditions. The study also show a hierarchical ranking of degrees of acceptance, based on the characteristics of the persons likely to be sheltered, those of the neighborhood, those of the planned shelter, and the proximity of the shelter to the inhabitants of the district and the corporations located there: "The users will tend to be less acceptable particularly if they are more distinguishable from the inhabitants in terms of their demographic characteristics, if they are perceived as being stigmatized in some way and dangerous, and if they attract a considerable amount of attention because of their physical appearance and behavior." (39)

Apparently, not only are the homeless mentally ill persons being discriminated against due to their mental illness, but also because of the fact of being homeless. As we are examining in the next two parts of our study, homeless mentally ill people are at risk for dying prematurely because of the mental illness they are suffering from and also owing to their homeless situation.

## FIGHTING AGAINST HOMELESSNESS: Recommendations for best practices

The “Pressure Points” report (8) published in the U.K. praises some examples of good practices, such as floating housing support teams, which combine health, housing and social services staff.

Many programs that are designed to assist the homeless population have incorporated some type of housing program for their clients In the United States each year, there are around 3.5million people who live their lives without shelter or a stable occupation. For 2006 alone, $28.5 billion is being allotted to homeless programs ran through HUD (Housing and Urban Development). $1 billion is being given for Section 8 housing, and $1.4 billion is being used for Homeless Assistance Grants.

For a significant number of homeless Americans with mental or physical impairments, often coupled with drug and/or alcohol use issues, long-term homelessness can only be ended by providing permanent housing coupled with intensive supportive services. Permanent housing provides a “base” for people to move out of poverty.

Homeless shelters operated by government, churches, or charities work to provide temporary housing to the homeless. Types of shelters include overnight shelters, warming shelters, transitional shelters, and subsidized housing.

However, without a comprehensive health care program, housing is not often enough to end homelessness. Various agencies, in fact all homeless prevention agencies and programs include substance abuse recovery and prevention programs. For a significant number of homeless Americans with mental or physical impairments, often coupled with drug and/or alcohol use issues, long-term homelessness can only be ended by providing permanent housing coupled with intensive supportive services.

It should be a major goal for all the programs that fight against poverty to improve the quality of life and diminish the risk of early dying life for persons who are homeless due to mental illness or substance abuse. Experts agree that the latter two groups tend to comprise the majority of persistent homeless persons. Therefore, treatment for mental illness and substance abuse disorders should be provided unarguably.

## COST-EFFECTIVENESS OF SUPPORTED HOUSING

Several studies have proved the cost-effectiveness of supported housing programs for this population. The Culhane study (40) assessed the costs for clients placed in the New York/New York (NY/NY) supported housing initiative and a matched control group. The authors of such a study found substancially greater reductions in hospital use among NY/NY clients than controls, offsetting almost the entire $19,000 annual program cost. Although most experts find these findings encouraging, the Culhane study has been criticized due to methodological deficits. Specifically, the absence of random assignment.

The research conducted by Rosenheck et al. (41) is a 3-year prospective experimental study. Therefore it is more statistically powerful than the previous one. This study examined the cost-effectiveness of supported housing (integrating clinical and housing services) for homeless persons with mental illness. The sample consisted of 460 homeless people with psychiatric and/or substance abuse disorders. The study took place at VA (Veteran Affairs) medical centers in San Francisco, Calif (n = 107); San Diego, Calif (n = 91); New Orleans, La (n = 165); and Cleveland, Ohio (n = 97). Veterans were eligible if they were literally homeless at the time of outreach assessment (ie, living in a homeless shelter or on the streets), had been homeless for 1 month or longer, and had received a diagnosis of a major psychiatric disorder (schizophrenia, bipolar disorder, major affective disorder, or posttraumatic stress disorder) or an alcohol or drug abuse disorder or both. They were randomly assigned to 1 of 3 groups:

1* HUD-VASH, with Section 8 vouchers (rent subsidies) and intensive case management (n = 182). The participants of the HUD-VASH (Department of Housing and Urban Development and the Department of Veteran Affairs) program were offered priority access to Section 8 housing vouchers administered by local housing authorities. These vouchers authorize payment of a standardized local fair-market rent (established by HUD using surveys of local rents) less 30% of the individual beneficiary's income.

2* Case management only, without special access to Section 8 vouchers (n = 90). The case management model used in HUD-VASH was modified from the Assertive Community Treatment (ACT) model Most of the case managers were experienced social workers and nurses. They also provided substance abuse and employment counseling.

3* Standard VA care (n = 188).

Primary outcomes were days housed and days homeless. Secondary outcomes were mental health status, community adjustment, and costs from 4 perspectives:
The VA health care costs were estimated by multiplying the number of units of service consumed by each patient by the estimated unit cost of each type of service.

and encouraged at least weekly face-to-face contact, community-based service delivery, and more intensive involvement in crisis situations.

- The VA health service utilization.
- Unit costs for VA inpatient, residential care and outpatint treatment.
- Non-VA health costs.
- Non-health care costs. These costs were used to estimate costs from the perspective of governmental agencies or taxpayers and of society as a whole (total resource consumption): the number of days spent in shelter beds or in jail or prison, cash transfer payments (eg, VA benefits, Supplemental Security Income, and Social Security disability), earnings, and the cost of the Section 8 vouchers. Although cash transfer payments (including housing subsidies) were included in the evaluation of costs from the perspective of governmental agencies, only the administrative cost of these payments was included in societal cost estimates. Productivity (employment earnings) was also included in the societal cost estimate, as a negative cost.

The authors hypothesized that HUD-VASH would generate sufficient savings in hospital, halfway house, criminal justice, and emergency shelter costs to offset the additional costs of intensive case management services but that case management alone would be almost as expensive as HUD-VASH but less effective.

- The main outcomes were: During a 3-year follow-up, HUD-VASH veterans had 16% more days housed than the case management–only group and 25% more days housed than the standard care group (P<.001 for both).
- The case management–only group had only 7% more days housed than the standard care group (P = .29).
- The HUD-VASH group also experienced 35% and 36% fewer days homeless than each of the control groups (P<.005 for both).
- From the societal perspective, HUD-VASH was $6200 (15%) more costly than standard care.

The policy implications of these results were:

- The absence of differences between case management only and standard care in this study raises the question of whether housing vouchers could be provided to homeless clients without being linked to intensive case management services. No study or program has offered vouchers to people with serious mental illness without some special program supports, so no answer to this question is available. To evaluate case management in an absolute sense, one would have to compare outcomes for recipients of those services with outcomes for clients who were kept from using such services at all, which is not a feasible alternative.
- However, as we comment later on, some studies suggest that case management services might be effectively delivered on a time-limited basis (7.2) as in the critical time intervention (7.3) reducing total health care costs while ensuring access to necessary services and supports.
- This study demonstrates the potential benefit of housing vouchers for this population.

The overall conclusion of this study (41) is that supported housing for homeless people with mental illness results in superior housing outcomes than intensive case management alone or standard care and modestly increases societal costs.

## CASE MANAGEMENT SERVICES DELIVERED ON A TIME-LIMITED BASIS

It has been widely documented that persons with serious mental illness experience higher rates of residential instability and homelessness than in general population. Most homeless mentally ill people are capable of living in the community when they are given appropriate services that meet their needs. In spite of this encouraging fact, research has shown difficulties in engaging this population in treatment. Therefore, this is a major factor that should not be overlooked.

Over the past three decades, several programs have attempted to decrease homelessness by linking homeless mentally ill people with ongoing mental health services through assertive outreach and case management. One of the most large-scale effort was Access to Community Care and Effective Services and Supports (ACCESS): a 18-site national project that lasted from 1993 to 1998 (42). An essential strategy of ACCESS was to enhance access to mainstream mental health services by adopting the assertive community treatment model of intensive case management. During the ACCESS program a multidisciplinary case management teat that included psychiatrists, nurses, and substance abuse and other support specialists.

It was conducted a longitudinal epidemiological study between 1989 and 1995. The data were drawn from the Suffolk County Mental Health Project (43). The authors of the study came to the conclusion that linking interventions that enhance the continuation of aftercare in outpatient settings after the discharge and focused case management have shown promising results. The authors also emphasized the prominent role of families, so they called for greater attention to supportive and educational family interventions.

It was also examined the extent to which the use of care management services predicted public shelter use among the homeless mentally ill who took part in the Community Care and Effective Services and Supports (ACCESS) (42). The sample consisted of 475 Philadelphia ACCESS program participants. The study found that the use of specific types of services such as vocational and psychosocial rehabilitation services led to an important reduction of the use of homeless shelters and, thus posed an important contribution in the reduction of the risk of recurrent homelessness.

## CRITICAL TIME INTERVENTIONS

A study of Susser et al. (44) examined a strategy to prevent recurrent homelessness among mentally ill people. They provided an intervention of transition between institutional and community care. The sample consisted of 96 men. Over a 18-month follow-up period the average number of homeless nights for the "critical intervention" group was 30 and 91 for the usual services groups.

## PREVENTIVE INTERVENTIONS

A study carried out in New York City (45) meant to identify risk factors for long-term homelessness among first-time literally homeless people. 377 people took part in this research. They were evaluated with standardized assessments of psychiatric diagnosis, symptoms and coping skills, social and family history, and service use. 81% of subjects returned to community housing during the follow-up period (18 months).

The analysis of the data revealed that a shorter duration of homelessness was related to younger age, current or recent employment, earned income, good coping skills, adequate family support, the absence of a substance abuse treatment history, and the absence of an arrest history. The regression analysis found that older age group ($p<0.05$) and arrest history ($p<0.01$) were the strongest predictors of a longer duration of homelessness. The identification of risk factors for long-term homelessness might guide efforts to reduce lengths of stay in homeless shelters and develop new preventive interventions.

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# Making Meaning in a 'Post-Institutional' Age: Reflections on the Experience of (De) institutionalization

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## Abstract

This article examines the narratives of people diagnosed with psychiatric illness about their experiences of institutionalization in the context of mental health reform and deinstitutionalization in British Columbia, Canada. Listening to the stories of psychiatric patients reveals that their experiences of care are not shaped so much by changing models of care but rather by the degree to which they experience the ability to have control over their lives. The authors conclude that finding ways to listen to and interpret the experiences of people with mental illness is critically important in the context of mental health reforms and the development of new models of care.
**Key words:** deinstitutionalization, recovery, narratives of psychiatric survivors.

## Objectives

The study and analysis of narratives of disease, disability and trauma is a burgeoning field with a range of disciplinary adherents (Frank, 1995; Raoul, Canam, Henderson & Paterson, 2007; Clarke, Febbraro, Hatzipantelis & Nelson, 2005, Appelton, 2000). In the foregoing discussion we contribute to this growing body of multidisciplinary literature through the examination of the narratives of people diagnosed with psychiatric illnesses who shared with us their experiences of institutionalization. We concur with narrative scholars that examining the life stories of stigmatized individuals can be a catalyst for advocacy and social change (Raoul, et al., 2007; Dossa, 2002; Rodrigues del Barrio, 2007).

The history of psychiatry and treatment of people with serious mental illness has been told as one of progress fueled by newer drugs and better models of care. Yet, this history of linear progress has also been contested (Moran & Wright, 2006) making it imperative to give voice to the "objects" of psychiatry both for what this can reveal in terms of cultural meta-narratives and counter-narratives of psychiatry and for how these stories can inform improved social responses to people in mental distress.

Psychiatric discourse obscures contextual factors that may contribute to people's experiences of distress, including the ways in which social determinants like gender, race, ethnicity, sexuality and poverty disadvantage psychiatric survivors. Further, within this paradigm there is little space for recognizing the experiences of people with mental illnesses. This is the case despite the fact Canadian policy documents emphasize the need for involving consumers in the planning of mental health care (BC Ministry of Health, 2002, Kirby, 2006, BC Ministry of Health, 1998).

In the current Canadian context, listening to the stories of people with experiences of long-term institutionalization is meant to contribute to the ongoing dialogue about how to foster recovery for people and to add to the body of literature that details the ways in which mental illness may be experienced differently by women and men in their various social locations.

The subject of our analysis is the experiences of individuals who have recently (since 2002) been transferred from British Columbia's large provincial psychiatric institution (Riverview Psychiatric Hospital-RVH) to smaller tertiary and other supported living arrangements throughout BC. Although psychiatric deinstitutionalization is a process which began in Europe and North America in the late 1950s and peaked in the 70s, the process was slowed, in part, because of the abysmal failure on the part of governments to provide community based supports to people leaving institutions, including adequate housing and sources of income.

These limitations, notwithstanding, deinstitutionalization held out the promise of a new approach to mental illness- one that would 'return' individuals to citizenship and independent lives. Deinstitutionalization in the Canadian context has continued to unfold but with new resources and new models of care in place. In BC individuals and financial resources are now transferred from RVH to a variety of levels of housing and care across the province.

In this shift, custodial care models are being replaced with psycho-social rehabilitation models of care (PSR). These "new" models of care have been lauded by the government, policy makers and those overseeing and implementing the changes as 'visionary' (Interior Health, 2006; BC Mental Health and Addictions Services, 2007). Indeed, preliminary findings from a tracking study of patients suggest that individuals' quality of life has generally improved in the new facilities (Groden, Lesage, Ohana, Goldner, 2006). However, these findings are derived primarily from clinical data rather than from an understanding of the process and how it is experienced by patients.

Research which honours the voices and range of interests and abilities of people living with mental illness has been rare and provides an opportunity to reflect on current changes in care with the goal of further advancing recovery models which have at their centre the goal that people regain control over their life choices.

This paper draws on interviews with seventeen mental health care recipients (nine women and eight men) about their experiences of being transferred from RVH. We show that attending to these experiences reveals a disjuncture between the views of the architects of care and those for whom the care is designed. Listening to the stories of psychiatric patients reveals that their experiences of care are not shaped so much by changing models of care and newer and more pleasing facilities but rather by the degree to which they experience the ability to have control over their lives. Thus, these stories contain important lessons about the unintended consequences of care and how care is taken up or experienced by people with mental illness (Rodrigues del Barrio, 2007).

In particular, the voices of people diagnosed with mental illness are often not taken into account because of the difficulty in making sense of their narratives which may be fragmented and non-linear (Clarke, et al., 2005). Here we provide an analytic frame for making sense of fragmentation in order to respond to the practical and political imperative of involving psychiatric survivor voices. Fragmentation in this instance, illuminates the nature of lived experiences, that is, the fragmentation of the lives of people with mental illness is reflected in how they talk about their lives (Appleton, 2000).

# Methods

First person accounts of mental illness in the North American literature are common (Blackbridge 1996. 1997; Capponi, 2003; Millet 1990; Nana-Ama Danquah 1999) most often written during periods of wellness, these stories serve the purpose of providing insights into the experience of mental illness and in some cases stand as critiques of psychiatry and institutional care.

A further approach is that taken by people who have not been ‘psychiatrized’ but who analyze narratives of mental illness second hand (Schneider, 2007; Schneider, 2003; Rodriguez del Barrio, 2007; Clarke, et al., 2005). This work is varied in its focus, but for our purposes Rodriquez del Barrio’s (2007) project is most pertinent. Through the examination of one individual’s narrative of their experience of psychosis her intent is to discover the meaning that support systems take on in relation to the inner worlds of people and to illustrate how they are multifaceted and contradictory. In an effort to make sense of the narrative Rodriquez del Barrio (2007) contrasts chronological narrative discourse with ‘space discourse’ that prioritizes the use of metaphors and defies narrative logic (p. 139).

The recognition that the narratives of people with mental illness do not always proceed in chronological story-telling fashion also inspired Clark, et al., (2005) to reexamine narratives about psychiatric survivors’ experiences of supportive housing that they had originally analyzed using a standard qualitative categorical framework (Nelson, Clarke, Febbraro & Hatzipantelis, 2005). These authors ‘trouble’ the use of categorical frameworks because of the ways in which the narratives of the people they spoke with defied easy classification. Specifically, they note that the chronology shared by their participants “was frequently circular and fragmented” which upset their assumptions that people will tell stories in a linear, rational and systematic fashion (Clarke, et al, 2005, p. 924).

Clarke et al., (2005) use the concept of ‘braided’ time to capture how in the stories of the psychiatric survivors they interviewed, “…the beginning, the middle, and the end are wound around and circle back onto one another the way that braided hair does” (p. 924). Further, Clarke, et al., (2005) note that in their initial analysis they assumed that lives “are describable and explainable through certain common stages beginning with childhood, moving through adulthood and then after supportive housing” (p. 925) what they discovered instead, was that their participants’ had much more idiosyncratic ideas about connections between events. In the end Clarke, et al., (2005) discuss the possible uses of a poetic representation of social experience to better represent “…individuals’ experiences of human suffering, strengths and hope” (p. 928).

The work of these scholars resonates with our own experiences of interviewing people with psychiatric illness and with our struggle to give voice to our participants’ experiences while at the same time wanting those experiences to have utility with respect to informing mental health care. As such, in our analysis we adopt an analytic frame which appreciates the fragmentation of our participants' narratives and sees emergent meaning in the ways in which people tell their stories as much as in what people say.

In what follows we present sections of the narratives of the individual's we interviewed, where they spoke about their experiences of moving from RVH to their current care facility. Individuals reflected on their experience of the move and their current housing situation. The interview included questions about safety/security, privacy, meal preparation and household chores, relationships with family and friends, outside work or activities and community interactions. Each interview was conducted in person by a member of the research team and participants were offered an honorarium for their participation. Interviews ranged in length from fifteen to sixty minutes. Data was organized into twenty one categories and eventually collapsed into four clusters: Internal States of Being, Experiencing the Move, Activities, and Relationships, which formed the foundation for the following analysis. In our work we understand gender and other social locations (class, race, ethnicity, culture and sexuality) to be critical to understanding individual experiences in a larger social context. Thus in our analysis we applied an intersectional framework when examining the transcripts (Cuádraz, Holguín, Uttal, 1999; Varcoe, Hankivsky, Morrow, 2007).

# Background

## Life in the Institution

In order to set the stage for a more in-depth discussion of the stories we gathered in the course of our research, we begin this section by painting a picture of what contemporary institutional care in new and newly renovated facilities in BC looks like. We provide this context, in part, to counter pervasive beliefs about institutional care that may no longer accurately reflect the reality of current care models.

Historical documentation in Canada about asylum care reveals that the experience of institutional care is complex and sometimes contradictory and that what has been missing are detailed accounts from the perspectives of patients themselves (Moran & Wright, 2006).

Prior to the deinstitutionalization movement of the 50s and 60s large psychiatric hospitals had mostly become warehouses for people with mental illness and worked primarily from a custodial model of care in which patients' lives were subject to institutional routines and patients were given little control over decision making and goal setting. Contemporarily, models of rehabilitative care continue to be experimented with and now most practitioners concur that large asylums are ill-suited to PSR models both because of the ways in which they are physically configured and because staff training may not be adequate.

In BC, individuals leaving RVH are housed in an array of possible living situations. Most patients have been transferred to smaller tertiary units, existing nursing homes and/or other forms of supported living . Decisions about where people would be moved were based on a number of considerations but one of the primary ones was whether a move would bring people closer to their families .

The two facilities in which we conducted most of our interviews include a new tertiary care facility (Facility X) that houses up to 40 people. The design of the facility is meant to optimize patient and staff interaction and the open door policy means that residents can freely leave to activities in the community and family and friends can visit easily. Each floor of this facility is set up in 'pods' centered around a kitchen facility, where residents have their own bedrooms are expected to take responsibility for meals and other household chores. Although few rehabilitative opportunities outside of learning to cope with basic daily activities exist in this facility, residents do have access to a garden program onsite where they are paid for their contributions.

The second facility (Facility Y) is a newly renovated 14 bed facility that has a lower level of staffing than facility X. In this facility individuals are meant to be self-sufficient in all of their activities of daily living. There are no onsite rehabilitative activities, although residents have access to an occupational therapist and to activities in the community.

Managers of the facilities describe their model of care as PSR and emphasize that their care fosters autonomy and independence. Patients are encouraged to interact as much as possible with the surrounding community and to go outside of the institution for all services. Although these institutions provide standard, traditional psychiatric treatment (symptom management through psychotropic drugs) they do not use seclusion rooms or physical restraints. Staff and management emphasized that the care provided stands in stark contrast to the care model in RVH, which was described as custodial.

# Findings

## Internal States of Being

We begin the discussion of our findings with an excerpt from an interview with Tyler which illustrates the fragmented nature of the stories we gathered and provides insight into how he experiences his illness:

> T: I just don’t want to slide. You know, like go down a hill. Once you’re all the way up at the top, don’t fall down
> I: Ohh. Is that a little bit how sometimes it feels?
> T: That’s how schizophrenia is. You go up there and then you fall back down. You’ve got to be careful.
> I: Do you know what helps you from sliding back down?
> T: I don’t know. Just being aware of your surroundings, watch out what people do to you, yeah. (Tyler)

This kind of awareness was also reflected in Quinn’s narrative where he expresses frustration about workers who were trying to engage him in rehabilitative activities:

Yeah. We’re in a different world. And it’s hard for us to…sometimes our worlds, they sort of come together. It peeves me even when, I’ll say world end, normal world, even when you try to show us in our best light, they insult us. Without meaning to, you know, they don’t mean to, but they’re looking up and saying ‘See, look what you can do with your life, even if you have a mental illness?’ Well, I am sorry buddy, I’m the one with the mental illness, you know, not you. It really is a ….sadness. (Quinn)

These passages say something about the inner life worlds of people with psychiatric illness and emphasize the distance felt between the individual and the so-called ‘normal’ world.

## Experiences of the Move

The move from RVH to newly designed and renovated facilities were not meant to be permanent moves for most individuals. In the new model of deinstitutionalization people are meant to ‘move through’ facilities to increasing levels of independence. Reflecting this, more than half of the people we interviewed have lived in more than one residence, with two women moving at least three times.

People are moved according to the level of care required and the types of services available. Thus care is organized around facilities, rather than individuals. While this fits in with the mandate of facilities, frequent moves were sometimes experienced by people as highly stressful.

In reflecting on their new residences most (three quarters) indicated that they like where they live currently, although almost one third commented on ways in which they found even this new form of institutional life difficult, focusing on the ways in which their freedoms continued to be curtailed.

In reflecting on their experiences of the transfer process people emphasized different things, Beth, for example, describes how, despite the move to a new facility with more privacy and ostensibly more opportunities to make autonomous decisions, having a mental illness limits her freedom and makes her vigilant:

So, based on privileges I think, like it's a privilege for me to be able to sit out here on this bench right now, because if I did something too wrong, I could be hauled back inside, transported away from here, you know, and put locked up in a little cell. And you know, no possessions, no nothing, you know. And it's crazy to think that that's possible, but anything's possible... (Beth)

Beth's comment shows her awareness of how tenuous her circumstances are and how little control she has over her day to day life. If she does something 'too wrong' her rights will be removed and she could be transported away to somewhere with even fewer freedoms.

In the transition from RVH, many individuals that we spoke to were experiencing, for the first time in many years, the opportunity to make decisions and carry out day to day routine tasks on their own. One man notes the complexity of how he experienced the change. He describes missing what he is familiar with, the routine of RVH and knowing how the system works, while at the same time acknowledging that given a choice, he would prefer to grow beyond his current level of functioning:

I don't know if I noticed how they're treated at X facility or versus Riverview, but I know for my own self, when I first got here I kind of missed Riverview in a way, because I was that close to becoming institutionalized, you know, like being totally dependent on the system, eh. I really didn't want to end up that way. (William)

Overall in reflecting on their new living situations it was clear that individuals were looking forward to a time when they were able to have a 'real' home, one that allowed them to live outside of institutional care. This was particularly significant for respondents who had been isolated from their cultural communities for long periods of time. Mary, an Aboriginal woman, had this wish for her future:

> I: What about, and if you were to think from five years from now, what would you like to be doing?
> M: Going home.
> I: Going home. Going back to X [name of Aboriginal community].
> M: Going home.
> I: Yeah. Do you have family there still?
> M: Yeah, my brother, my mum's brother is the Chief. (Mary)

These passages take on a particular poignancy in view of the fact that despite the intention that people move through facilities the reality is that there are limited housing options for people with mental illness in their communities and so many will remain in institutional forms of care even after they are capable of living independently. Ultimately, changing models of care and more aesthetically pleasing facilities may have less of an impact on individuals than the degree to which they experience the ability to have control over their lives and their choices.

## Activities

The emphasis in the facilities where we interviewed individuals was on assisting people with basic activities of daily living (cooking, cleaning, hygiene, money management, etc.,). Most individuals seemed to spend the better part of each day accomplishing these activities. However, they also had access to volunteer and paid work in specialized settings and to a range of recreational activities and outings on a regular basis. Activities mentioned were diverse and included: going to the local clubhouse, swimming, camping, playing volleyball, pub nights, social dinners, smoking, watching TV and bingo.

In our interaction with respondents and in our observations, we found that the degree to which individuals were engaged in activities was in part dependent on their overall level of mental well-being. Thus, some individuals appeared very listless, confused and lethargic, while others seemed to be more highly engaged in activities and socializing. Gendered differences did not always predictably follow traditional gendered roles. For example, in some instances it seemed that women were more engaged in household chores like cooking and laundry than men, but staff reports suggest that participation in these activities may have had more to do with level of wellness than gender per se.

A theme running through the interviews was a desire to have meaningful activity and especially paid work opportunities. Robert indicated:

> Oh, I've had all slavery jobs and you know, when I was out in Coquitlam, and I've never really had like a full-time on the outside (job), because I've never had chances to have one, if you understand what I'm saying. (Robert)

Those who did have paid work opportunities spoke positively about them. Sylvester had this to say about himself:

> I: Oh, okay, alright. So one of the things that we usually just start with is if you could just tell me what a typical day looks like for you here?
> S: A typical day is a workday on Monday, Wednesday and Friday. I love working with that.
> I: Okay. Loves working. I am getting it on tape as well.
> S: That's okay. Sylvester loves working as much as he can.
> I: Oh that's great! And could you work at X more if you wanted to?
> S: No, just Monday, Wednesday and Friday. (Sylvester)

The desire for work was tied to concerns about having enough money or feeling limited or controlled regarding the use of their money:

> I: Why is Riverview better?
> L: Well, I got a package of cigarettes every day and $34 a week.
> I: Right.
> L: Here I get $200 a month. That's not enough to smoke on.
> I: Oh, I see. Do you get it all at the end of the month kind of thing?
> L: I get $25 on Tuesday and $25 on Friday. I can't even buy the carton and get it cheaper. (Lucas)

Overall, most of our respondents reported that they liked the flexibility they have in their new facilities and enjoy getting up when they want, eating when and what they want, and being able to go to local businesses and shops. However, this was attenuated by stories that illustrated the lack of concrete opportunities for meaningful activity, especially paid work and the ability to attain higher levels of autonomy.

### Relationships with Others

In this category we clustered themes that referenced intimacy with family, friends, staff, and discussion about community contacts. Sixteen people had answers coded here, nine of whom were women. Fully one third of mental health care recipients that we spoke with indicated that they do not have contact with their family or with visitors. In their transfer from RVH, contrary to transfer guidelines, some appear to have been moved further away from family, while others had been long estranged from family members and friends.

Four people describe family relationships that seemed quite close. More women (9) than men (3) seem to have connections with family, particularly children, whereas men seemed to express more longing for sex and intimate partner relationships. Themes in several individual's stories revealed a strengthening of connection with their ethnic communities as a result of the move.

Beth was an example of a woman who was struggling hard to maintain a relationship with her children. In the following passage she expresses her desire to be with her children and how this is motivating her to get better:

Yeah, yeah. I'm not going to cling to anybody to get me through this life, you know. I want my kids, you know, be able to talk to me and not feel like something's wrong, I don't want them to feel like yeah, this person's just a chronic, you know, sad person. (Beth)

Two women and two men seem to have good friends and yet only one man described comfort with the quality of his friendships. Instead several of the men talked longingly about their desire for intimate female companionship. Terry's interview, for example, had numerous references to his interest in women but also his concerns about being sexually appropriate. In contrast Sylvester spoke mostly about missing his wife whom he described himself as estranged from. In the following excerpt the interviewer probes at to why Sylvester misses RVH:

> S: I loved it there.
> I: You loved it at Riverview?
> S: Yeah, because I got to see my wife at Riverview, she's out in ___________.
> I: Oh, and where is your wife now?
> S: She's in __________.
> I: Okay
> S: And I haven't seen her, I haven't seen [wife's name] here now in nearly four years. (Sylvester)

In some instances men indicated they enjoyed having female staff care for them because this fulfilled some of their need for female connection.

> I: Okay. So who takes care of you the most here? Is it a man or a woman?
> R: Well, I prefer a female rather than a male.
> I: How come?
> R: Because I've never been married in my life, and I've never had a chance to. (Robert)

It was clear that relationships for the individuals we interviewed were often fraught because of long-term estrangement from family and friends and/or significant disruptions because of the person's institutionalization. Estrangement was also sometimes due to the person's problematic behaviours in family interactions due to the complex experience of mental illness. Despite this there was evidence that some individuals, especially the women we interviewed, were maintaining or rebuilding relationships with children and other family members as a result of their move.

# Discussion

To find ourselves in the other and the other in us are in contrast with psychiatry with its emphasis on difference
(Jenkins (1994) in Appleton, 2000)

We began our paper with a discussion of how to make sense of the fragmented narratives of people with mental illness as they tell their stories of institutionalization. Like Rodriquez del Barrio (2007) and the work of Clarke, et al., (2005) we found that the stories of psychiatric patients were rarely told in a chronological fashion and thus the concepts of 'space discourse' and 'braided time' resonated with our findings. Further, we assert that how people tell their stories is, in part, a reflection of their mental distress and potentially, the complex experiences of the many moves and disruptions in care they have experienced.

Psychiatric deinstitutionalization in most Western industrialized nations (Italy being the exception) is an ongoing process, continually prompting new discussions and debates about mental health care in the community and about how to provide care in ways that foster maximum autonomy and recovery for people. People's experiences of institutionalization and their needs and desires post-institutionalization are rarely taken into account in these discussions. What the stories of the people we interviewed reveal, however, is that the experience of mental health care is shaped by a variety of factors, including the degree to which people experience their new settings as a 'home' and the degree to which they are assisted to find meaningful life activity.

In BC deinstitutionalization is taking place in the context of severe housing shortages, especially in large urban centres. This has created barriers for individuals ready to move into the community and live more independently. Further, community-based supports for people with mental illness are still under-resourced and little has been done to augment services that provide important supports to assist people gain access to the aspects of citizenship to which we are all entitled- housing, income and education (Morrow, 2006, Trainor, Pomeroy & Pape, 2004). Other Canadian studies (e.g., the Provincial Psychiatric Hospital and Community Comprehensive Assessments Project – CAP in Ontario) have found that while medical needs are largely being met for people with mental illness there is a dearth of vocational, social recreational and educational services and supports (Koegl, Durbin and Goering, 2004). In addition, the supports that are there do not take into account social and systemic issues like gender, culture and ethnicity. All of this prompts us to be mindful of the fact that the provision of mental health services is just one aspect of a continuum of care that includes social supports and appreciates that men and women and non-dominant ethnic groups may have differing needs.

# Conclusion

As communities throughout BC address how best to support residents living with mental illness, it is our hope that this paper illuminates the diverse ways in which institutional care is experienced. We want to emphasize that finding ways to listen to and interpret the experiences of people with mental illness is critically important in the context of mental health reforms and the development of new models of care. As evidenced in the stories of the people we interviewed even the best intentioned care cannot substitute for the recognition that loss is integral to living with mental illness. These are losses that are related to illness (the inability to concentrate, to differentiate at times between reality and illusion) but perhaps more significantly losses that accrue because of the lack of supports for people, the absence of control over their lives and of access to meaningful activities.

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# *IJPR*

# *Feature Articles*

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# Towards Promoting Recovery in Vancouver Community Mental Health Services

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## Abstract

The concept of recovery has moved to the centre of mental health policy and service delivery for persons who have been diagnosed with a mental illness in Vancouver BC Canada. This article provides a review of the literature on recovery in mental health. A brief definition of recovery is given, followed by a historical review of the development of the philosophy of recovery with emphasis on the cultural implications of recovery for different countries and organizations. Much like other community mental health systems Vancouver Community Mental Health Services (VCMHS) has not yet identified a specific model or framework to guide the development of recovery-oriented services. To that end three models and a framework of recovery are presented and possible next steps in integrating recovery are highlighted for VCMHS. The discussion on model development with a focus on the cultural implications and the process of implementing recovery has relevance for the development of mental health services internationally (Schinkel & Dorrer, 2007).

**Key words**: Recovery, Models, Implementation

# Background

The aim of this paper is to provide an overview of the literature with a particular focus on recovery-oriented models in mental health, as a way of contributing to the dialogue on how Vancouver Community Mental Health Services (VCMHS) in Vancouver BC Canada can continue to implement relevant key concepts of recovery within the system (VCMHS, 2006a, 2006b; VCMHS, 2007a, 2007b). For more details on VCMHS see the section on the Canadian perspective on page nine. As indicated by the current literature, recovery is presented as an outcome, a process and a philosophical approach. As well, this paper briefly discusses the concept of recovery as both a model and a framework for service delivery. Finally, consideration is given to applying the concept of recovery to the Canadian context and in particular within the local VCMHS context. The review begins with a definition, history and background of recovery.

## Definition of recovery

Despite two decades of discussion and debate around the word recovery, and what it means in mental health, much confusion still exists regarding its definition (Davidson, O'Connell, Tondora, Styron, & Kangas, 2006). However, there is considerable agreement that recovery in mental health may be defined in terms of an outcome (Onken, Craig, Ridgeway, Ralph & Cook, 2006), such as the ability to lead a good and satisfying life despite the illness or presence of symptoms (Deegan, 1993; 1988). With respect to the notion of process, recovery is frequently described as being a non-linear lived experience involving both self-discovery and transformation and culminating in an understanding that symptoms of the illness are not definitive in terms of one's self-identity (Davidson, Sells, Sangster, & O'Connell, 2005). A third common theme in the literature is the philosophical underpinnings of recovery, such as hope, connection, healing, empowerment (Jacobson and Greenly, 2001) self-help, mutual-help, self-determination, family involvement, resiliency, choice, justice, responsibility, skill building, a positive culture for healing, a focus on strengths and possibilities, community involvement, education and role development (Mental Health Commission, New Zealand, 2006; Ohio Mental Health Commission, 2001).

Not surprisingly, the lack of a consistent definition adds to the complexity of developing empirical evidence and engaging in research on the subject (Jacobson & Greenley, 2001; Liberman & Kopelowicz, 2005). Despite the challenge of multifaceted approaches and the lack of consistency, Barker (2003) offers what he refers to as the tidal model of recovery for nursing staff. The model aims to protect the ever-evolving story, language, and understanding of each individual and has been used to study outcomes with some success in several countries (Buchanan-Barker & Barker, 2006).

## Other perspectives of recovery

Mary O' Hagan, commissioner for mental health services in New Zealand (NZ), articulates some of the criticisms of recovery as both a word and concept, from service users' and providers' points of view. For instance, some service users say that the word recovery implies being restored to a place where they were prior to their illness when in fact they feel they been transformed by the experience. Other service users disregard the need for recovery as they feel that either they do not have an illness in the first place, or they do not find the madness undesirable. O'Hagan notes that some providers criticize recovery as being "'esoteric nonsense … hard to grasp and … lacking in evidence base'" (2004, p. 1). Importantly, O' Hagan discusses the difficulty that recovery originated in the United States (US), whose individualistic approach may be less useful in a more socially oriented society such as New Zealand. The individualistic approach may lead to a belief that "the problem" and its solution lies with the individual in contrast, a socially orientated approach may foster society assuming some responsibility. A final criticism is that in the US, recovery grew more from professional literature and therefore has a slightly different emphasis. Further discussion regarding the cultural implications of recovery is presented below.

In addition, a comprehensive review of recovery perspectives would not be complete without referring to the critical psychiatry movement, described by consultant psychiatrist Phil Thomas from the UK, as being "part academic, part practical" (n.d., n.p.). The main thrust of this influential organization and others like it is to promote careful consideration regarding how society and mental health stakeholders think about the concept of mental illness. Critical psychiatry emphasizes "social and cultural contexts, places ethics before technology, and works to minimize the control of medical interventions" (Braken & Thomas, 2001, p. 724). Indeed, critical psychiatry can challenge the traditional biopsychosocial approach of mental health systems and aims to make "experiences of psychosis meaningful rather than psychopathological" (p. 727). The ultimate aim of the movement is to move toward collaboration (Roberts & Wolfson, 2004). As with the recovery approach, critical psychiatry seeks to democratize mental health systems so that the "voices of service users and survivors … move centre stage" (p. 727). However, the level to which our systems include or collaborate with service users is generally on a continuum and remains an area for further study (Casey 2006; Schinkel & Dorrer, 2007).

Surprisingly, the recovery literature rarely refers to the health promotion framework, which could potentially offer a scientific structure for evaluating recovery from the perspective of the social determinants of health. The World Health Organization [WHO] defines health through its promotion when it states that "health is created and lived by people within the settings of their everyday life; where they learn, work play and love … by being able to take decisions and have control over ones life circumstances" (WHO, 1986, n.p.). Similarly, two prominent researchers in the recovery field propose a shared decision making model between consumers and staff for effective medication usage as a means to promote autonomy and wellness (Deegan and Drake, 2006). In addition, Onken et al's (2006) framework for recovery, outlined below, seems to lend itself well to a health promotion approach and yet makes no reference to the crucial founding document the Ottawa Charter (WHO, 1986). Authors Lando, Williams, Williams and Sturgis (2006) offer a logic model defined as a visual representation of "inputs, activities and desired outcomes" (p. 1). Further, Lando et al. propose integrating mental health into chronic disease prevention and health promotion; the underlying message is that here is "no health without mental health" (p. 4). Stated goals of this model are to improve service utilization, create more supportive social and work environments, deepen our understanding of the link between physical and mental health and promote service user empowerment. In this model, the focus on chronic disease prevention and illness continuum may seem somewhat at odds with the espoused values of hope and optimism of recovery, often described as a separate wellness and health continuum (Health and Welfare Canada, 1998).

### How recovery evolved

In the US, according to Allott, Loganathan & Fulford (2002), the recovery movement emerged as a result of the civil rights movement of the 60s and 70s, as marginalized groups developed an awareness of their rights and found their voice. The result was a belief that self-determination (defined as people having the right to make their own decisions regarding their psychiatric disability) became a central concept in recovery (Holland & Johnson, 2005; Onken, Dumont, Ridgway, Dornan, & Ralph, 2002). Schinkel and Dorrer (2007) add that interest in the recovery movement was fuelled by the disability movement and deinstitutionalization in the 1990s and was further supported by peer support movements such as Alcoholics Anonymous (AA). The discipline of psychosocial rehabilitation grew with emphasis on utilizing a recovery approach, and as no national implementation system existed, differing frameworks for implementing recovery emerged within each state. Interestingly, these frameworks were complex and developed primarily by professionals and academics rather than by users of service as was the case in New Zealand (Kane, 2007). It is observed that in the US the culture of recovery was influenced by a number of forces and further impacted by federal documents such as the American Declaration of Independence, resulting in a strong emphasis on self-determination which Schinkel and Dorrer caution could lead to neglecting the larger societal factors at play in recovery (2007).

Of interest, the UK mental health transformation, based largely on health reforms both in the US and New Zealand, was introduced to policy in England and Wales in 2001 (Schinkel & Dorrer, 2007). Schinkel &

Dorrer note that the recovery approach fit well with was happening in Europe regarding approaches to mental health, in particular the document released by the World Health Organization in 2005 titled The Mental Health Declaration for Europe: Facing the Challenges, Building Solutions which advocated a strengths-based approach and the inclusion of service users and providers in developing our mental health systems.

In a parallel jurisdiction, recovery in Scotland is currently driven by the Scottish Executive's National Program for Improving Mental Health and Wellbeing which centers on "social justice and inclusion" (Schinkel & Dorrer, 2007, p. 12). Further, the Scottish Recovery Network aims to advance the implementation of recovery by learning and sharing ideas. For example, the tidal model of mental health recovery, discussed further below, is being used in Glasgow as a pilot in acute settings. Shinkel & Dorrer (2007) outline some of the challenges in implementing recovery, such as skepticism on the part of service providers and service users and a culture of inertia and hopelessness. A key recommendation is to develop a "context-specific" recovery approach in collaboration with stakeholders rather than "imposing a framework developed elsewhere" (p. 14). Such content-specific research is evident in the work undertaken by the Mental Health Commission of New Zealand in 1988, in its efforts to understand how to adjust the US recovery approach in order to meet the needs of New Zealanders (Kane, 2007; Schinkel & Dorrer, 2007). It seems this process of understanding the cultural and contextual mental health needs of New Zealand took approximately one and a half years and uniquely employed a number of service users in the process (D. Kane, personal communication, June 6, 2007). Interestingly, Nayar & Tse (2006) contend that learning how to meet the cultural needs of a growing New Zealanders Asian population is an ongoing challenge requiring attention to the cultural competence on behalf of mental health employees, policy makers and researchers who build theory.

O'Hagan (2004) says that since 1988, all mental health services in NZ are mandated by government to use a recovery approach and have a national policy to support the implementation. She clarifies that a small group of service users were given the challenge of defining the concept of recovery for the NZ cultural setting in the following areas: social, economic, political processes, citizenship, stigma, cultural diversity and were to include consumer survivor movements such as the critical psychiatry mentioned above (Mental Health Commission, 1998). In 1993 (later than in other places), the deinstitutionalization movement began in NZ, and consumers were employed at various levels and positions throughout the mental health system. Three such distinct positions available in NZ at present include consumer advisors (who hear the concerns regarding service or policy and can negotiate with managers), consumer advocacy positions and mental health support workers. Mental health support workers have relevant coursework and training and are viewed as an integral part of the multi-disciplinary team along with other professionals in mainstream roles (D. Kane, personal communication June 6, 2007).

Important and relevant key points of difference in how recovery is conceptualized, such as various models, frameworks and systems in countries mentioned above include: the reflection of historical and cultural context of a country (for instance in New Zealand [NZ] there is a strong emphasis on including the Maori culture); the understanding and weighting of elements such as service user involvement (in NZ the concept of recovery was articulated by users of service, not professionals); the acceptance of a mental health diagnosis as opposed to what service users identify as the problem (for instance in Ohio, the acceptance of a diagnosis is an indicator of recovery; in contrast a competency for a mental health professional in NZ is to accept and understand the person's view of their illness); the balance between personal responsibility versus social and environmental causation for example in NZ social factors such as housing are ameliorated prior to the recovery journey in contrast to other models of recovery that propose focusing on the individual's motivation for change early in the recovery process); the knowledge to facilitate various treatment choices; and finally the emphasis on developing and utilizing a range of credible peer support services (Schinkel & Dorrer, 2007). These enlightening differences regarding how systems interpret recovery may prove to be excellent material for VCMHS, and perhaps other organizations, to reflect on during future discussions regarding the meaning of recovery within the specific culture.

## The Canadian perspective and Background on VCMHS

Notably, Canada is as yet without a mental health plan (Kirby and Keon, 2006), and unlike other countries such as New Zealand or Britain, Canada has no legislation indicating the expectation to implement a recovery approach to service delivery. In Canada Legislation in this field is mostly within provincial jurisdiction however, the new federally funded mental health commission, whose mandate it is to "become a national focal point for making progress on mental health issues", will assist in the development of a "national mental health strategy" (Kirby, 2007, p. 4). The commission will build on the recommendations of an earlier report titled Out Of The Shadows At Last (Kirby & Keon, 2006) which calls for radical system transformation to make Canadian mental health systems recovery-oriented. At the local level, in April 2000, VCMHS (designed to provide services for people with mental health issues) became part of the larger Vancouver Coastal Health Authority (VCHA). The larger VCHA serves 1, 044, 750 people which is 25% of the population of BC, and employs over 21, 000 staff with a budget of 21 billion (VCH, n.d.). The smaller VCMHS employs 800 staff, operates out of eight multidisciplinary teams, and serves approximately 9,000 Vancouver residents. In terms of recovery, VCHA states its strategic direction is to engage "the voices of our patients, clients, and residents into VCH policies and procedures" (VCH, 2006a, n.p.). VCMHS (2006b) recently released an operational plan for mental health service delivery that firmly puts recovery at the heart of service planning, delivery, evaluation and research. Interestingly, many staff members feel that becoming part of the larger organization has slowed the implementation of the recovery approach (VCMHS, 2007a). For instance, it seems that becoming part of the larger organization may have been an impediment to promoting consumer involvement. Specifically, in the past people who used services also served on the board of the organization; this is no longer what happens (Casey, 2006). As an organization we are struggling to understand how best to implement recovery in VCMHS (Casey, 2006; VCMHS, 2006a, 2006b; 2007a, 2007b, 2007c), and have began a number of important dialogues regarding what recovery means to stakeholders. In preliminary discussions people who use VCMHS services currently, staff, users of service who are employed in the system, families, and management have been thoughtful in considering how recovery may best meet our specific cultural needs.

How do models and theories of recovery apply?

An initial review of the literature indicates that recovery is described as a process (Deegan 1998), a vision, (Anthony 1993), a set of values (Anthony, 2004), and as an end goal or outcome (Liberman, & Kopelowicz, 2005). This section of the paper discusses recovery as a model (Barker 2003; Jacobson & Greenly, 2001; Roberts & Wolfson, 2004; Rogers, Farkus & Anthony, 2005). For Rodgers et al., the term recovery is "critically in need of a multifaceted theoretical model informed by both mental health and behavioural (sinc) science" (2005, p. 1999). Additionally, in terms of research design recovery is generally deemed well served by using a qualitative approach to data collection and interpretation (Roberts & Wolfson, 2004). On the other hand, some researchers may propose that qualitative research methods impede the development of traditional more theoretical kinds of models. However, according to Roberts and Wolfson, both qualitative and quantitative research approaches and their respective "different kinds of data" are needed (2004, p. 38). While acknowledging these observations and challenges, the question remains: is it possible to describe recovery as a theory, or a model of practice, and if so what is the evidence for such a claim? Another brief review of the terminology in this area may be helpful despite the fact that such terminology is frequently inconsistent and complex.

To begin with, theories pose and answer large questions and provide a way to organize empirical findings about phenomena (Krefting, 1985). Humanistic and behavioral theories, for example, contribute to our understanding of human behavior. Fawcett and Downs (1992) identify three components of a theory. First, the existence of concepts and or constructs is required, (concepts are concrete and directly observable building blocks; constructs are indirectly observable are more complex and difficult to measure). An example of a concept in the area of recovery in mental health is consumer involvement in service delivery and an example of a construct is hope. The second component of a theory includes propositions (statements about concepts or the relationship between concepts). A hypothesis can be developed when the variables of concepts can be measured. The final component of a theory is the construction of a diagram of a theory. The diagram is completed only after the concepts, definitions and propositions have been articulated. It may be argued that recovery has not reached this stage in its development at this time as specific tested empirical evidence is scarce at this level.

On the other hand, a model forms the basis of a theory. Models are not fully tested but generate an organized way of clarifying phenomena and have a smaller scope and level of abstraction than a theory. As Krefting suggests “One might say that a model is a ‘“theory in training”’ (1985, p. 174). Krefting also notes that models can be generic or specific depending on the level of particularity of application. The models described below could be described as specific since they apply to mental health. One early conceptual model of recovery was proposed by Jacobson and Greenly in 2001. Conceptual models identify what should be studied and why (Krefting, 1985). In the conceptual model proposed by Jacobson and Greenly (2001) the what is to “link the abstract concepts that define recovery with” the why of identifying the “specific strategies that systems, agencies, and individuals can use to facilitate it” (Jacobson & Greeenly, 2001, p. 482). A criticism of this model is that the reciprocal relationship between the internal and external conditions of recovery … [is] implicit” in their presentation of the model (p. 485). Making these connections explicit through the use of a diagram could provide much needed insight into systematically evaluating which internal and external factors are more efficacious for recovery.

A later, more developed example of a recovery model comes from Rodgers et al., (2005). These authors propose an “initial conceptual framework and model of recovery processes and outcomes” (p. 209) that may be useful for service delivery, development, evaluation and research. The model is grounded in both a positive psychology approach and behavioral science research. It is based on seven assumptions that emerged from the Centre of Psychiatric Rehabilitation in Boston over the past 30 years and contribute to the credibility of the model. Of note, an underlying belief system or frame of reference is essential for model development (Krefting, 1985). The central construct of the model is that there are “environmental, sociocultural, and individual factors that affect both the processes and outcome of recovery” (p, 210). The model aims to promote discussion of what recovery means, why some people recover, those people’s characteristics and the ideal circumstances for recovery to occur. Helpfully, Rodgers et al. (2005) provide a visual diagram that includes external and internal factors relating to recovery and also objective and subjective components of recovery outcomes. The authors employ a qualitative approach in this research and make mention of studying individual role performance and subjective outcomes such as quality of life, self-esteem, and subjective wellbeing. Given the information above, Krefting (1995) would assert that the rigor of this model of practice is assured as it contains the three required components: a philosophical base, key concepts and their inter-relationships and has implications for further practice. Also, though there are 77 concepts and constructs in the model they are well laid out, structurally clear (Chinn & Kramer, 1995), flexible, easy to understand, complementary, and that represent a wide scope (Chinn & Kramer, 1995) of specialist areas of the person’s life such as social welfare, criminal justice, education, health and employment systems. This model appears easy to transfer to practice as it outlines both objective and subjective measures for success. However, while this model may be important and helpful to clients, families and practitioners, no actual illustrative case study accompanies it as it is presented.

A final model of recovery comes from Barker, who offers a radical (Brookes, 2006) values-based person-centered, universally applicable model for recovery and empowerment, from a nursing perspective (Buchanan-Barker & Barker 2006). This humanistic model developed in the mid-1990s is based on constructs such as “caring processes” (Barker, 2001, p. 235), being human, the concept of helping one another (Barker & Buchanan-Barker, 1999), and the philosophy that change is constant. The model was developed using an “expert nurse” focus group that attempts to understand the person’s story from their perspective through use of metaphor and is designed to be complementary to care provided by other disciplines. The model was also validated by a group of former "psychiatric patients led by Barker's colleagues of many years" (Brookes, 2006).

In the tidal model of recovery the person is approached via three separate dimensions that interact as a system, the self, the world and others. The model requires mental health staff to believe that recovery is possible; that the person has the ability to begin their journey and knows what they need; and that staff need to learn from the person what needs to occur happen at this time – in this way, staff act as a pupil in an ever-changing environment (Barker, 2001, 2003; Buchanan-Barker & Barker, 2006). The concept of mental illness itself is viewed as a disturbance of everyday living and is indicated by the actions or stories these disturbances illicit. Uniquely, the tidal model asserts that "mental illness is a symbolic force, which is known only, in phenomenological terms, to the person involved" (Brooks, 2006, p. 708).

The final portion of the model is based on ten values or commitments, including, valuing the person's voice and their language choice, demonstrating a genuine interest in the person and learning from them, understanding that people are experts in their own story and demonstrating transparency in decision-making both as a staff and as a recipient of service, listening to the person's story for clues, and understanding what needs to be done in the present. Finally, staff need to demonstrate an understanding that time facilitates change (Barker, 2001, 2003; Buchanan-Barker & Barker, 2006). Essential guiding principles include developing the persons curiosity and resourcefulness, having respect for the persons wishes, that crises should be viewed as an opportunity, that small initial goals are desirable and that simple elegant solutions are best (Brookes, 2006).

Consistency, an essential element for model development according to Chinn and Kramer, is evident though consistency of semantics apparent in the above terminology (1999). Certainly, compassion and mutual influence seem to be at the heart of the model. In order to promote consistency training is available and a network has been established to help new projects around the world. Barker also notes that this model is not intended to be prescriptive but rather should be adapted to meet the specific cultural and operational needs of the setting (Brooks, 2006).

Interestingly, this model is being implemented in the UK, Ireland, New Zealand, Canada, Japan, Scotland, Wales and Australia (Buchanan-Barker & Barker, 2006), which speaks to its ability to cross cultural and diagnostic boundaries and adds to its importance and generalizability. The authors acknowledge difficulties in providing proof of the relationship between recovery outcomes and the tidal model (hypothesis); however, improved nursing morale and client satisfaction, as well as a reduction in self-harm, suicide attempts and absconding incidents and decreased aggression were cited as positive outcomes for using the model (Cook as cited in Buchanan-Barker & Barker, 2006). These cited outcomes indicate that the relationships between concepts can be empirically measured, substantiating the theoretical soundness of the model that is, its utility, precision and accessibility.

Aptly, Dr Nancy Brookes (2006) of Ottawa recently described the tidal model as an important middle range theory for "any setting, [and] relevant to any discipline" (2006, p. 715). Middle range theories attempt to bridge the gap between grand intellectual theory and empirical knowledge. These theories are described as having a number of related concepts, used in limited settings that can be represented by a model. According to Brooks, concepts within the tidal model provide a helpful solution-focused "philosophical approach to recovery versus a model of care or treatment of mental illness" (2006, p. 698).

In terms of model clarity, the concepts are defined and the relationships between those concepts are defined which promotes new theory development. One such development is the reframing of the original term "logic of experience" which developed into "practice based evidence" (Brookes, 2006, p. 711). The term logic of experience is defined as what might work in this particular situation and may contribute to our learning in other situations. Concepts and relationships are presented parsimoniously or elegantly in the holistic assessment of the person fro instance. The visual representation of this assessment is titled “Structure of Care” (Brooks, 2006, p. 713). The person’s story is represented as a heart at the centre of three concentric circles and influencing the first two innermost circles. The central circle is titled the care plan based on holistic assessment and the next outer circle is titled the security plan. The largest circle surrounds the heart and is titled multidisciplinary teamwork. This visual demonstrates how important the person’s story is to the development and implementation of care plans. The simplicity of the model is demonstrated through the use of simple terms such as being human and respectful however, the concepts and their relationships are complex (Brooks, 2006). The focus is on the process involved in recovery and I believe is in line with Dr Terry Krupa’s work on complexity theory, (Associate Professor at the School of Rehabilitation Therapy, Queens University in Toronto), is powerful and may prompt further thinking in model development providing a way to study process of change involved in recovery (Krupa, 2007).

As noted in the foregoing discussion of models, recovery can be described both by the internal conditions of someone who is engaged in recovery – conditions such as hope, healing, empowerment, and connection and by a focus on strengths and external conditions, such as the person’s rights and a positive culture of healing. This conceptual perspective generates interest in applying the philosophical underpinnings of recovery (and the development of a model) of recovery to service delivery, development, evaluation and research (Jacobson and Greenley, 2001), enabling mental health systems to generate a foundation of evidence on recovery. The result is a recovery-oriented system based upon evidence-based practice (Farkas, Gagne, Anthony & Chamberlin, 2005).

In recent years Dr William Anthony and Stephen Onken have been leaders in producing a much-needed literature on recovery. A framework based on the principles of recovery that holds enormous promise comes from Stephen Onken, Catherine Craig, Priscilla Ridgway, Ruth O. Ralph and Judith Cook (2006). For the purposes of this paper a framework is described as a basic conceptual set of ideas used to describe a useful course of action. Onken’s “ecological framework” which builds on the person’s strengths and the exchange with the environment, encompasses a number of theoretical approaches and conceptual frameworks resulting in a comprehensive strengths-based person-centered approach to recovery. These approaches and frameworks include but are not limited to positive psychology, the transtheoretical change model, capability approach, social justice and cultural competence (Onken et al. 2006).

In this context the person-centered elements of recovery are hope, as defined by having at least one person who believes in you; a sense of agency, as defined as goal directed action; self-determination, which may not be cohesive; meaning and purpose, as defined by understanding what has happened to the person; and finally an awareness and potentiality. Onken et al. (2006) posit that if people are not aware, they are unable to make necessary changes to promote their own recovery. Re-authoring or telling stories to make sense of what has happened and to uncover strengths and meaning generates energy to move forward and is critical to promoting the culture and energy necessary for recovery. Onken proposes that individuals move from surviving or coping to healing and wellness, and finally to thriving. As with the tidal model, these authors assert that recovery is indeed a change process from both the individual perspective and the systems perspective and propose using the transtheoretical change model developed by Prochaska & DiClemente (1983) to facilitate the change. Significant emphasis is placed on healing from the trauma of having a “psychiatric disorder”.

Further, a connection with others and an opportunity to practice skills is paramount for learning and skill building. Significant emphasis is placed on the relationship between the service user and provider. The service provider’s approach should match the person’s or service user’s coping style, stages of change, expectations, and resistance. Empathy, positive regard, genuineness, feedback, and self-disclosure are used to better understand the person and goal agreement and consensus between service user and provider is essential.

These strategies aim to promote personal learning and adaptation through problem solving. Cultural competence is deemed essential for person-centered service delivery and responsiveness. The concept of human rights is used to promote equity and accountability. Choice is the final critical component of this framework and is used to promote meaningful options for individuals in terms of risk-taking, social roles, independence, and vital engagement (this last term defined as being involved in something meaningful and absorbing) (Onken et al, 2007). Perhaps the strength of this framework is that it enables service users and systems to think critically and in a broad inclusive way in terms of service delivery, development, evaluation and research.

# Summary

It is suggested that users of service, providers, family members and researchers continue the quest to define recovery in more scientific ways. As noted above, one of the critiques of the recovery approach is that empirical knowledge on the subject is lacking (Buchnan-Barker, 2006; Davidson et al., 2006; VCMHS, 2007a, 2007b). Further, the Ohio Mental Health Commission notes that “Historically, there has been inadequate testing of service models and even less testing in improving quality …however interest is now improving” (2001, p. 33). Importantly, with regard to knowledge translation and the implementation of the recovery approach, Anthony (2004) says that the delay in incorporating recovery into our systems is due not to a lack of science underlying practices but rather as a result of the lack of articulated values underlying those same practices.

## Next steps for VCMHS

It is apparent that VCMHS will need to continue to involve users of services, staff, families and researchers in formulating the organization’s specific, evolving values, definition, and framework or model of recovery in our mental health system. Involving stakeholders in this way may further develop new partnerships with individuals who hold diverse perspectives and thus promote new learning. As an organization we will need to pay careful attention to the cultural implications of recovery for British Columbia and more specifically for Vancouver Community Mental Health Services (VCMHS, 2007a). As a city comprised of individuals from a variety of different ethnic backgrounds a significant challenge may arise in the need for a continuum regarding self-determination and the range of culturally relevant social supports offered in service delivery. Measuring the promise: A Compendium of Recovery Measures provides a number of tools that may help to measure recovery outcomes within our system (Campbell-Orde, Chamberlin, Carpernter, & Leff, 2005). Articulating a model or framework to guide thinking may also be a helpful process. To conclude from a series of recent dialogues, it seems clear that VCHS plans to build on past successes as we walk the path ahead to develop more evidence-based recovery-oriented service delivery (VCMHS, 2007a, VCMHS, 2007b).

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# Reference Group Focused Therapy for Schizophrenics (RGFT-S) - A New Rehabilitation-Oriented Approach in Schizophrenia.

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## Abstract

'Reference Group Focused Therapy for patients with Schizophrenia' (RGFT-S) is presented. This therapy is designed to modify patients' social networks, spanning a continuum from rearranging contacts among members of existing social networks to creating entire new social networks. Based on the holistic, contextualized view of ill persons within social systems it is an extension of the established psycho-educational approach as defined by Expressed Emotion (EE). The focus of this therapy is the patient's re-socialization through the assessment of the patient's social matrix and providing patient-tailored social problem solving, based on Trigger Event Analysis (TEA). A series of case-reports illustrating the specific therapeutic interventions is presented.

**Key words:** Schizophrenia, Reference Group, Relapse, Rehabilitation, Trigger Event

"The 'core' of a schizophrenic is not schizophrenia. The core is a human core, a divine core, with all the attributes and facets of any other human being. Building a relationship of integrity with the client is to be willing to be with all of who they are; the sane and the insane aspects of their experience."
***Tanina Davanzo*** (inspired by the movie "A Beautiful Mind") http://www.schizophrenia-help.com/Schizophrenia__Trauma/schizophrenia__trauma.htm

"Over half century of psychodynamic research has proved that schizophrenia is not only a medical disorder, but a biographical facet of the human being-it is a challenge to the whole of society to understand, accept and reintegrate the psychotic patient amongst us."(Ninth International Symposium on the Psychotherapy of Schizophrenia)

"It is in the psychotic's suffering that the most serious problems of the human mind are encountered. Tackling them means illuminating the human being with signification and sense, gaining a better understanding of the human being in general, not only of the psychotic person."(Tenth International Symposium for the Psychotherapy of Schizophrenia)
***Professor Gaetano Benedetti***

# Introduction

Schizophrenia inflicts immense suffering on patients and their relatives and is a leading cause of disability (Geddes, 2002) with less than 20 percent of patients maintaining full recovery after the first episode (Cannon & Jones, 1996). The monthly relapse rates are estimated to be 3.5 percent per month for patients on maintenance neuroleptics and 11.0 percent per month for patients who have discontinued their medication (Weiden & Oltson, 1995). Psychosocial interventions such as family therapy, supportive, cognitive and other type of psychotherapies (McIntosh & Lawrie, 2001), are additional common approaches in preventing relapses. One of the important contributions to psychosocial management of relapse prevention is the concept of expressed emotion (EE) that refers to the inner dynamics of patient's families (Brown, Birley, Wing, 1972; Vaughn & Leff, 1976). A meta-analysis which analyzed data from numerous studies showed a 48% median annual relapse rate in a high-EE environment, versus 21% in a low-EE environment (Kavanagh, 1992). Marom et al studied the influence of EE with a follow up of 7 years. They demonstrated prolonged predictive validity of EE and emphasized the role of therapies aimed at lowering high EE as a long-term preventive approach (Marom, Munitz, Jones et al, 2005). Since these studies generally measure the expressed emotion in the subject's family, this may serve as evidence for the decisive influence of a single specific group upon a schizophrenic patient. Extrapolating from this it may be inferred that the impact of the entirety of a patient's social groups may be yet more profound.

In social psychology a person is regarded as a member of one or more social group(s). Thus, schizophrenic relapse may be analyzed, apart of biological causes, within the context of social trigger events that are specific for the patient and his/her interactions with the group.

# Theoretical Background

In this paper, we attempt to investigate the contribution that Reference Group Theory (Hyman, 1942; Sherif, 1948; Deutsch &, 1955; Hyman & Singer, 1991) and other social-psychological approaches makes to the understanding and treatment of schizophrenic relapse (SR).
SR is commonly seen as an event with multi-factorial cause. Biological vulnerability, substance abuse, conflict, confusion and frustration, environmental stress, and social isolation are regarded as possible precipitating factors (Geddes, 2002).

These factors, excluding biological vulnerability and, to a lesser extent, substance abuse, may be better understood if seen in the context of the person's reference groups. Reference group theory has been widely used in various cultural settings (Cochran et al., 2004; Hurtado et al., 1994; Schlaupitz et al., 2000), including Israel (Murell Dawson & Chatman, 2001). Reference group theory has shown that sociocultural differences transmitted through interpersonal relations affect beliefs and practices (Erickson, 1988). The use of theories exploring the social matrix with mental patients was discussed in an article on social psychology of illness support groups (Davison et al., 2000).

Reference group (RG) is defined as a group whose presumed perspectives or values are being used by an individual as the basis for his or her current behavior (Hyman, 1942).

In the framework of RG theory, a group influences an individual through specific control mechanisms (Hyman, 1942; Hyman & Singer, 1991). Complying with these controls promises wellbeing, non-compliance leads to strain. This strain is especially likely to occur within the normative RG (a group in which individuals are motivated to gain or maintain acceptance – (Hyman, 1942; Sherif, 1948; Deutsch &, 1955), and in which an individual is especially sensitive to withdrawal of group acceptance. This acceptance might be withdrawn, for example, due to a violation of the RG norms.

A primary RG, in Tonnies terms (a social system in which an individual's basic roles are integrated – (Tonnies, 1940) is viewed here as a prime candidate to contribute to normative function. The quantity and quality of an individual’s RGs is seen to serve as another important factor in affecting his or her reaction to the stressor.

Social mobility – exchange of the RGs – is an additional factor that is reported to contribute to strain put upon a person’s adaptive mechanisms, particularly when a conflict takes place between the former and the new RGs (Merton & Kitt, 1950).

A special problem for schizophrenic patient arises when there is a conflict between his imaginary RG and other RGs:

Definition: a person’s RG is described as imaginary if the members of this group, or the type of their interactions with the person, or both, do not exist in reality but solely in the person’s imagination. In the case of a psychotic patient, an imaginary RG may take the form of psychotic systematic delusion(s) and/or hallucination(s).

Inaccurate perception of the RG norms and behaviors - as a part of compromised social perception - can be a frequent source of considerable emotional strain in a schizophrenic patient (Corrigan & Green, 1993). Difficulties in adaptation to group norms because of misperception of emotional and social cues of the group, may play a crucial role for schizophrenic patients - the issue generally addressed in Social Norms Theory - (Knight Lapinski & Rimal ,2005; Rimal & Real, 2005). Uncritical transfer of the “norms” of the imaginary RG to the real RGs has a potential for creating conflicts in its own right.

Absolute deprivation (person’s disease per se, loss of important others, stigmatization) as well as relative deprivation (failure to get promoted at work) may well be highly probable triggers for schizophrenic relapse (SR) (Groudace et al., 2000; Wilkinson & Marmot, 2000).
Cognitive dissonance (Festinger, 1957) in schizophrenic patient may develop as a result of frequent hospitalizations, stigmatization, degradation into low social status role, and lack of social contacts. It may negatively influence his/her emotions, thinking, and behavior and place a considerable strain on the patient’s most vulnerable adaptive mechanisms and thus contribute to SR.

Self-esteem is clearly dependent on the corresponding RG (Korman, 1970.) and can be modified as a result of functional or structural change within the RGs or change in the hierarchy of individual’s RGs (Pratt et al, 2005).

Changes in the quality and significance of a patient’s imaginary RG may be of specific importance for schizophrenic patients. No less important are changes in the patient’s status in real groups as a result of changes in his/her mental state.

# Suggestions for intervention

We propose a newly developed classification of triggers, Trigger Event Analysis (TEA). Trigger is defined as an event that produces a change in the individual's mental state linked to changes in both temporal and causal relationships. The classification is a result of examining the range of triggers associated with mental breakdowns in both outpatients and inpatients (Kuppuswamy, 1962; Holmes & Rahe, 1967; Hudgens et al., 1970; Cochrane & Robertson, 1973; Brown et al., 1973; Cochrane & Robertson, 1975; Singhet et al., 1981; Turner et al., 1995).

TEA divides all triggers leading to some kind of mental breakdown into 6 categories: Status, Norms, Attachment, Threat, Routine, Energy. These triggers have either explicit or implicit social characteristics, which means that they are associated with patients' reference groups. The given context of mental deterioration leads to the conclusion that they have to be regarded as negative triggers - events that precipitate deterioration in mental states.

Here is a more detailed definition:

## 1. Change of status within RG

Examples of these triggers include changes in work position, deterioration in marital relations, significant lottery wins, etc.

## 2. Conflict with RG associated norms

Examples are RG pressure on a person to perform an action inconsistent with the person's moral norms; inability to comply with RG norms (because of a decline in the intellectual level for example); unwillingness to accept RG norms; consequences of a violation of RG norms (that result in some punitive response by the RG), etc.

## 3. Alteration (or the threat of alteration) of important personal attachments

Included are such events as loss or changes in social structures. Examples of the former are the death of a significant other, the break-up of relations with a lover, the loss of face-to-face contact with a significant other (drafted into the army, admission to a boarding school). Examples of the latter are events such as marriage, child birth, entering a new RG group (new job, beginning of studies), etc. Included here are personal attachments to a pet or a highly valued object (e.g. collector's item), or idea.

## 4. Threats to an individual's survival (physical or economical)

In this category belongs life-threatening illness, financial problems, etc.

## 5. Rapid change in daily routine

Examples include moving to a new location, vacation, changes in work routine, and changes in roles and role identity (becoming a parent, going to pension, drafted into the army), etc.

## 6. Deterioration of a person's energy resources

Overwork, lack of sleep, unbalanced meals or under eating, or disease and illness are examples of factors which reduce a person's energy.

Some of the above mentioned examples can be indexed into more than just one category. In addition, a number of triggers can occur in close temporal proximity resulting in a cumulative effect.

It is hypothesized that an individual reacts to all possible triggers in a unique and specific way. The same trigger that has a profound impact upon one particular individual may leave another totally unaffected. The personal sensitivity to specific triggers is categorized in exactly the same way as the triggers themselves. This means that each person will exhibit sensitivity (or lack of it) to such issues as changes in status, RG norms, attachments, threats, routine, and energy resources in a specific way. We call the corresponding personal sensitivities – sensitivity channels. This implies that provided that a person is sensitive to changes in his /her status (for example) within the RG and that such changes take place in reality, there will be a high probability for aversive mental response.

While considering only non-biological (psychological and social) causes for SR, we can infer that SR will result when specific personal sensitivities are matched by some corresponding RG impact. In other words, SR will be the consequence of interaction between the given person and his/her RGs.

The Reference Group Focused Therapy For Schizophrenics (RGFT-S) aims at producing one or a combination of the following changes:

1. Reducing the significance to the individual of the RG that impinges upon the vulnerable sensitivity channel(s).
2. Enhancing the significance of the RG that ameliorates the vulnerable sensitivity channel.
3. Improving the patient's position within a pathogenic RG.
4. Creating a new, empathic RG that ameliorates vulnerable sensitivity channel (s).
5. Removing a pathogenic RG that hurts vulnerable sensitivity channel(s).
6. Mediating (bridging) between specific RGs in order to reduce intergroup conflicts.
7. Modifying Social Perception in order to reduce pathogenic influences on vulnerable sensitivity channels.

We define a certain RG as pathogenic for a person when in his/her case it exerts a profound negative emotional impact (causes significant mental distress) upon this person. We assume, in the context of TEA, that this negative impact will be at one or more vulnerable sensitivity channels.

In contrast, a certain RG is defined as an empathic group for a person if it has a profound positive emotional impact upon this person. Again, this influence will be mediated through one or more sensitivity channels involved.

## Intervention Recommendations :

Patient selection criteria:

1. An analysis of the patient's relapse makes it probable that there is a major problem associated with his RGs which comprises one or more of the following:
   a) Paucity of the number of RG's
   b) One or more of his/her RG's has a pathogenic influence on his/her vulnerable sensitivity channels (in other words, is a pathogenic RG)
   c) One or more of his/her empathic RG's has undergone a recent functional or structural change.
2. Before a patient is eligible for RGFT-S, he/she has to undergo proper psychopharmacological

and/or other biological treatment to enable him/her to enter the rehabilitation program.
3. A patient has to agree to the rehabilitation program and be capable of comprehending its goals.
4. A patient has to possess basic social skills such as communication, problem solving, decision-making, self-management, and peer relations abilities that allow him/her to initiate and maintain positive social relationships with others.

## Intervention modalities:

The RGFT-S comprises three stages and is conducted according to the Manual of RGFT-S (available from the authors):

## Stage 1 - Assessment.

TEA (Trigger Event Analysis) is completed both for the patient himself and for his/her RGs
In the diagnostic interview, in addition to the usual intake data, information is gathered about his/her history of trigger events (Trigger Event History – TEH) as well as mapping the patient's RGs including their subjective significance for him/her (RG-map). The personal impact of a trigger upon the patient's sensitivity channels is evaluated through the Trigger Event Impact questionnaire (TEI). Individual sensitivity to specific triggers is assessed through the Trigger Event Proneness for Individual questionnaire (TEP-I). The proneness of each RG to serve as a potential trigger is assessed through the Trigger Event Proneness for Reference Group questionnaire (TEP-RG) – (questionnaires can be obtained from the authors).

The data collected in the assessment stage serves as the basis for intervention planning.

## Stage 2 - Intervention Design

The primary goal of the intervention is to reduce negative impacts on the vulnerable sensitivity channel(s) on the one hand and/or to enhance positive impacts on the same channels on the other.
Another goal is to create a new empathic RG when the current number is not sufficient.

Real RGs and imaginary RGs are treated differently.

### Real RGs:

The subjective significance of the patient's RGs is most important for intervention planning. In the case of pathogenic RGs three possible interventions are available. The first is improving the patient's position within the group, e.g. reducing the negative impact on the patient's vulnerable sensitivity channels. The second focuses on reducing the pathogenic RG's significance for the patient. The third is the most extreme measure – removing the pathogenic RG.

The significance of the empathic RG may be increased in order to enhance its positive effect on the patient's vulnerable sensitivity channel(s).
A new empathic RG may be created when the total number of the patient's RGs is insufficient; another indication for this intervention is to enrich the network of empathic RGs. Examples of such new groups include protective living settings such as rehabilitation facilities or halfway houses, therapeutic settings such as out-patient clinics, psychiatric wards, or group psychotherapy, and social settings such as friends, clubs, etc.

### Imaginary (delusional) RG:

Initially, it has to be determined whether the imaginary RG is acute in nature or chronic where it has become

an integral part of the patient's inner world.
If it is clearly of acute character, the main intervention has to focus on reducing the personal significance of this group or removing it altogether. This can be accomplished by means of the proper biological therapy (psychopharmacological, ECT, etc.).

In case of chronic delusions that are resistant to modern biological interventions, including higher risk therapies such as clozapine and other compounds, a patient has lived with his/her delusions for an extended period during which they have become an integral part of his/her life experience. The removal of such delusions is unlikely, at least until more effective biological therapies become available. The imaginary RG may have a positive effect (delusions and hallucinations of a supportive character). In this case, the main therapeutic effect has to be focused on reducing the patient's tendency to incorporate his/her imaginary RG norms in real RGs. If, for example, the patient's delusion is that he/she is the messiah with a special relation to God , it is plausible that he/she will tend to translate his/her inner belief into corresponding behaviors and, hence, encounter conflict situations. A therapeutic intervention could be directed towards identifying the borders between various RGs and the discrepancies within their group norms – by means of mediation technique (see Case 2). In the case of pathogenic imaginary RG (e.g., imperative hallucinations and/or delusions with negative content), the main goal of the intervention is to reduce the personal significance of this group - if removal doesn't seem feasible. Creation of real empathic RGs (rehabilitation facility, half way house, therapeutic group) may serve this purpose (see Case 3).

Stage 3. Intervention.
Interventions begin at the assessment stage as the patient becomes familiar with the concept of the RG. After the assessment and planning stages have been completed, a patient is introduced in a positive way to the RG focused approach and the influence of the RG on aspects of his life such as self-esteem, status and self-efficacy. Interventions that are expected to lead to the most significant changes (increase in the patient's subjectively perceived importance within the empathic group, increase of the relevance of the empathic group for the patient, decrease of the pathogenic group's relevance, change of the group's type from pathogenic to less pathogenic) are closely scrutinized.

The final treatment plan is developed together with the patient. One or more of the seven possible RGFT-S interventions is then applied.

We now present three cases to demonstrate some possible forms of intervention.

## Case 1:

H, male, 51, single, 2nd of 3 siblings, works as a clerk, diagnosed as suffering from residual schizophrenia. He became highly anxious, developed overvalued ideas of inadequacy, disturbed sleep and manifested a severe drop in functioning after he felt that he was intimidated by his superior at his working place. He is a resident of halfway house, has quite a few friends and a girl friend. His remissions are stable, lacking any secondary production. H. was on a low dosage anti-psychotic medication regimen.

On admission the patient was evaluated through a standard battery of RGFT-S related questionnaires (TEH, RG-map, TEI, TEP-I, and TEP-RG). His TEH disclosed three psychotic episodes with corresponding high TEI scores for Status sensitivity channel for each of the episodes. His TEP-I demonstrated (see graph) high vulnerability of the Status channel: 8 (out of 10). TEP-RG for the present RGs (working place, family, girl friend, and friends) has showed mostly positive influence from the side of his girlfriend on the Status sensitivity channel.

On the RG-map the patient stated that he evaluated his work group (colleagues, carrier) as 10 (out of 10) for personal significance. He had few contacts with his family which was evaluated as 1 (out of 10) and his relevant social groups - friends and his girl friend were evaluated as 3 (out of 10).

It was obvious that a patient evaluated his professional life much higher than other RGs. It was also clear that while his girl friend could potentially play a desirable supportive role, since the patient attributed a relatively low personal importance to his relation with her, it would likely not be fruitful.

The rehabilitation effort concentrated on two of the seven possible RGFT-S interventions:

a) increase the significance of the particular RG that enhances the vulnerable sensitivity channel;

b) Social Perception Modification – for the Status sensitivity channel.

It was decided to assist the patient in strengthening his emotional involvement with the girl friend. Four couple sessions were conducted where his girl friend was exposed to the patient's feelings about his superior and provided the necessary support. It turned out that a patient perceived a joke produced by his superior as an attempt to intimidate him though it was apparent that the joke had been misinterpreted. The patient was given a course of Social Perception Modification (basically techniques of Social Skill Training (Bellack et al., 2004) adapted to specific sensitivity channels) that was aimed at correcting the distorted perceptions in the social sphere (this approach is to be discussed elsewhere). The patient's girl friend's supportive role was greatly enhanced by the therapeutic process. The patient was encouraged to increase his involvement in the relationship with his girl friend: new shared activities such as trips, going to the movies, etc. were discussed.

At the conclusion of the therapeutic intervention, the RG-map assessment was repeated and showed an increase in the couple's perceived relevance to 6 (out of 10) while other groups remained unchanged. He was discharged in a state of good remission.

## Case 2:

D, male, 53, single, dairy equipment technician, diagnosed as suffering from paranoid schizophrenia. He lives on a kibbutz and has a married older sister. D. regards himself as the historian of the kibbutz, and lives in an imaginary nostalgic world of the former kibbutz life. This idea has reached the dimensions of a psychotic delusion that has persisted for about 30 years notwithstanding various antipsychotic medications. As a result of his delusion he attempts to transfer the norms of his imaginary group to real kibbutz life. He persistently criticizes the way of life of kibbutz members and tries to "convert" them into accepting the norms he believes in. He wrote a "hymn" about "his" kibbutz and sings it aloud at any occasion. He also tries to impose his beliefs upon the kibbutz children, sometimes in a rather aggressive manner. His interactions led to conflicts which culminated in a worsening of his mental state and consequently led to his psychiatric hospitalization.

After a decrease in his psychotic anxiety subsequent to antipsychotic medication, the patient was assessed using a standard set of RGFT-S questionnaires.

The patient's TEH demonstrated that in all four psychotic exacerbations that preceded the current episode, his corresponding TEI scores were high for the Norms sensitivity channel due to conflicts between the inner norms (in this case the norms of his delusional group) and the norms of the kibbutz. This same tendency was evidenced by the patient's TEP-I: 9 (out of 10) on the Norms sensitivity channel. The TEP-RG for the present RGs (kibbutz, family, imaginary (delusional) group) showed strong and incompatible norms both on the part of the kibbutz and the imaginary group.

The RG-map showed that the patient's imaginary group was judged 10 (out of 10), followed by the kibbutz: 5 (out of 10) and his sister: 4 (out of 10) in their significance to the patient. It was obvious that the imaginary group plays a major role in the patient's life and that problems arise when his imaginary group norms clash with the real group norms of the kibbutz.

The applied RGFT-S approach was mediation between the patient's imaginary group and the kibbutz that aimed for a clear delineation of the group norms within each and every group. The patient was assured of the importance of his inner group values but, on another hand, the issue of respecting other group norms, even if personally unacceptable, was discussed, and examples of inappropriate role behavior and the transfer of group norms from one group to another were presented (e.g., general manager of a big firm trying to act as a "big boss" in a hospital setting where he was admitted as a patient). Some representatives of the kibbutz management were invited to a number of therapeutic sessions where these issues were discussed.

As a result, the patient learned to differentiate between the norms of his imaginary group and the norms of the kibbutz more effectively. The kibbutz management, on the other hand, learned to accept the patient's peculiarities as potentially valuable for the enrichment of the kibbutz's local tradition. The patient was involved in creating an exhibition devoted to the history of the kibbutz thus generating a socially acceptable platform between his imaginary group and the real kibbutz. Additionally, it helped him to gain better acceptance by the kibbutz community.

## Case 3:

J., female, 28, single, painter, diagnosed as suffering from paranoid schizophrenia in good remission, developed an acute psychotic episode after an art gallery owner cancelled his agreement to sell her paintings. She describes her work as of major importance to her, supporting her both emotionally and financially. She developed persecutory ideas about the gallery owner as wanting to kill her, plotting with the owner of the local grocery shop where the patient bought her food and to whom she owed some money. She was involuntarily committed after an attempt to hang herself.

Following a course of medication therapy with 20 mg/day of olanzapine, her mental state stabilized sufficiently to enable her to take part in the rehabilitation program.

The evaluation showed that her TEH revealed two previous psychotic episodes for which the major trigger on the TEI was the Threat sensitivity channel with the Status sensitivity channel playing a lesser role. This impression was supported by the TEP-I with 8 (out of 10) for the Threat sensitivity channel and 5 (out of 10) for the Status sensitivity channel.

The TEP-RG for the present RGs (gallery, imaginary group) revealed a high level of stress on her vulnerable Threat sensitivity channels both in her real and imaginary groups.
The RG-map demonstrated a significant decrease in the imaginary group's significance as a result of pharmacological therapy: from 10 (out of 10) down to 3 (out of 10), the real group (gallery) was evaluated as being of 8 (out of 10) significance.

She reported to have only sparse contacts with her family and siblings; the perceived relevance of this group was 1 (out of 10). She had a boy friend; this relation was rated as 3 (out of 10) in importance, but the boy friend broke up with her after she developed the psychotic episode. She has only a few friends, whom she evaluated to be of 2 (out of 10) in importance. After completing the RG assessment, it turned out that the most important real RG for the patient had been her work group and that this RG suffered a major blow. She no longer had a relationship with her boy friend and her parents and friends seemed unable to compensate as support groups. It was also obvious that the imaginary group was pathogenic and only of temporary influence since it nearly disappeared within the short time she was receiving psychopharmacotherapy and hence it didn't require inclusion in the intervention. It was suggested that the creation of a new support group might be of major importance for the patient. Social Service assisted by connecting her to a sponsor who was interested in promoting mentally ill individuals. The sponsor was impressed by the patient's paintings and committed himself to provide support in organizing exhibitions on a regular basis. This has encouraged the patient significantly: she reported further improvement in her mental state and her delusions ceased completely. On the follow-up assessment with the RG assessment table (RG-map) she rated the impact of the new RG (new gallery) as 9 (out of 10) while her former gallery was rated as 1 (out of 10).

# Discussion and Conclusion

The RGFT-S is a rehabilitation-oriented approach that takes into account the profound socialization problems of the schizophrenic patient. It's goal is his/her re-socialization through analyzing the patient's social matrix and promoting patient-tailored social problem solving.

Currently the main treatment approaches that face the problems of social adaptation in schizophrenic patient are as follows:

- Supportive psychoeducational intervention provides the patients with support, information and management strategies. The relevant studies (Adams et al., 2000) suggested that even one year after the termination of the program the relapse rates were still lower than before its application. This is one of the more established methods in lowering EE.

- Social skills training uses behaviorally-based assessments of a range of social and interpersonal skills, stressing the role of both verbal and non-verbal communication, as well as the individual's ability to perceive and process relevant social cues and to respond to and provide appropriate social reinforcement. A number of study results suggest that some reductions in psychopathology, when they occur, may be time limited in duration and restricted to only certain categories of symptoms ( Hogarty et al.,1991; Eckman et al., 1992; Overall & Gorham 1962).

- Problem/symptom focused therapies include Cognitive behavioural therapy (CBT), Cognitive remediation therapy (CRT), and token economy. In CBT the participant is encouraged to take an active part by examining the evidence for and against the distressing belief, challenging the habitual patterns of thinking about the belief, and using reasoning abilities and personal experience to develop rational and personally acceptable alternatives. Current studies show mixed results regarding the improvement in the relapse rate in schizophrenic patients subjected to CBT (Trower et al., 2004; Startup et al., 2004; Sensky et al., 2000; Lewis et al., 2002; Rector et al., 2003). Cognitive remediation therapy in schizophrenia is focusing on the specific cognitive deficits of the illness such as poor memory and difficulties in planning and decision-making. A study that used computer-assisted cognitive rehabilitation to treat 16 patients with schizophrenia and 18 patients with schizoaffective disorder with chronic course, showed significant improvement on several measures of cognitive functioning, most noticeable being in verbal/conceptual learning and memory, and concentration ( Bellucci et al., 2003). A token economy is a behavioral therapy technique in which the desired change is achieved by means of tokens administered for the performance of pre-defined behaviors according to a program. This technique shows statistically significant improvement in negative symptoms of schizophrenia (McMonagle & Sultana, 2000; Bark et al., 2003).

As opposed to above mentioned therapies, RGFT-S conceptualizes a holistic approach to the re-socialization problem of a schizophrenic patient. It takes into consideration both the individual parameters of a patient as well as the qualities of his social matrix - in his/her own perception. The use of psychophysical variables that assist in quantifying the patient's subjective experiences provides a basis for rational therapeutic planning.

Complementary to other approaches, RGFT-S addresses the patient's current problems and is aimed at their solution with the patient's full participation at all stages of treatment. It encourages the patient's responsibility for change and growth and provides him/her with the tools necessary to deal with similar problems in the future. It assists the patient to identify, elaborate and reinforce his/her progress towards goals. It takes into account not only real RGs but also the patient's long-standing imaginary RGs and assists him/her to integrate delusional experiences within the demands of reality thus improving the patient's adaptation to the real world.

The RGFT-S extends the therapeutic impact of the well-established EE-oriented approach by taking into consideration not just an isolated RG but the entirety of the patient's relevant RGs. Established therapeutic techniques such as CBT for schizophrenic patients, CRT, family therapy, behavior therapy and others can be easily implemented within the RGFT-S approach.

The impact of this approach on the improvement of long-term prognosis and relapse prevention has yet to be evaluated.

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# Using Psychological Formulation As A Means Of Intervention In A Psychiatric Rehabilitation Setting

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## Abstract

This report describes an intervention undertaken by a trainee clinical psychologist, whilst working with people with severe and enduring mental health problems in the United Kingdom. It describes an innovative piece of work that helped to shift a difficult situation in which the staff and client were feeling ‘stuck’. The intervention described included a full assessment of the client’s background and current situation. Following this, a psychological formulation was drawn up, focusing on attachment theory, and was shared with the staff team. This then allowed a series of interventions to take place, including systemic work with the staff team. Implications for maintaining change and a critical review of the work are described.

# Background Information

Following the closure of the local psychiatric hospital in 2003, twelve people with chronic psychiatric difficulties were re-housed in a private hospital staffed 24 hours a day. The residents remained under the care of a local multidisciplinary rehabilitation team, which includes psychiatrists, psychologists, nurses and occupational therapists.

## Reason for Referral

Anita was referred to this multidisciplinary team (MDT) by the staff team of her residential home. She had previously received diagnoses of schizophrenia and obsessive compulsive disorder. The staff team were experiencing difficulty in managing Anita's behavioural compulsions in a coordinated manner. They felt the frequency of her compulsions was increasing, and disagreements over managing these was causing tensions within the staff team. Therefore the home manger asked the MDT for advice on managing this behaviour. The MDT had supervised Anita's care for many years, and felt psychology would provide the most helpful intervention for the staff team.

## Aims

Following the referral several aims were identified:

- Obtaining informed consent from Anita to use psychological theory to help with her current difficulties
- Understanding more about Anita's difficulties
- Increasing the staff's understanding and psychological thinking around Anita's difficulties
- Empowering the staff to manage Anita's behaviour

## Informed Consent

Anita and her key worker met to discuss psychological involvement, and to obtain consent for this. The psychologists within the MDT were well known to Anita through their involvement with care programme approach meetings. Anita gave consent for the various stages of this piece of work, such as consenting for me to communicate with her mother, or to look at her medical notes.

## Initial Assessment

An extended assessment gathered information from:

- Anita,
- discussion with the staff,
- medical notes,
- discussion with the MDT,
- informal observations at home,
- interviewing Anita's mother.

# Getting to know Anita

### ***Engagement***

Anita was known to be reluctant to inform professionals about changes in her mental health. Therefore, the process of assessment took place over several weeks, during various activities e.g. shopping. This was explained to Anita as an opportunity to get to know her better and thus find ways of improving the relationship between her and the staff team.

### *Presentation*

Anita was a casually dressed woman in her forties. Her clothes were noticeably stained. Before leaving the house she would brush her hair and put on underwear when prompted by staff. Although Anita had new clothes, she only felt able to wear one large jumper and a pair of jogging bottoms. Anita was overweight at this time.

### *Current Situation*

Anita attends a sheltered work project twice a week, undertaking work such as stuffing envelopes, which pays a small wage. Anita enjoys eating out with members of staff, and sees her mother every other week. Anita cooks her own meals regularly, and shops independently for ingredients. She had recently started a relationship with a man who lives on a local psychiatric rehabilitation ward.

## Discussion with the staff team

I interviewed several staff members including Anita's key worker in order to understand the challenging behaviours, and learn about the relationship between the staff team and Anita. This revealed conflicting theories around managing Anita's behaviour.

Staff did not know how to respond to Anita's compulsive behaviour. These compulsions changed every few weeks, and once one compulsion had been eliminated, another would arise. Examples of compulsions included putting paper towels down the toilet, and touching the plastic pots used to dispense medication a certain number of times. Staff were concerned that she may jeopardise her links with the community through her restricted use of clothes and odd behaviour such as visiting a shop repeatedly to return and purchase the same item.

## Anita's medical notes

Anita had been known to psychiatric services for a number of years, and her clinical notes provided details of past interventions and changes in behaviour. Anita was first admitted to hospital aged 27. She was diagnosed with schizophrenia, and later Obsessive Compulsive Disorder.

Her behaviour in hospital was bizarre at times, for example bathing while fully dressed, and covering drinks to prevent contamination by germs. A range of medications were trialled unsuccessfully. Anita reportedly experienced a severe lack of motivation and engaged in few activities. For several years she did not leave the ward, and her ability to self care was severely impaired.

Following the introduction of clozapine[2], Anita's motivation and engagement with others improved. The clozapine was discontinued due to physical complications, but reintroduced after a rapid deterioration in her mental health. Anita was then able to engage with some social activities. However behaviours such as hoarding food, throwing money away, and being unable to write anything down without subsequently crossing it out persisted throughout her hospital stay to the present time. At the time of referral Anita took several medications including clozapine, and citalopram.

# Interviewing Anita’s mother

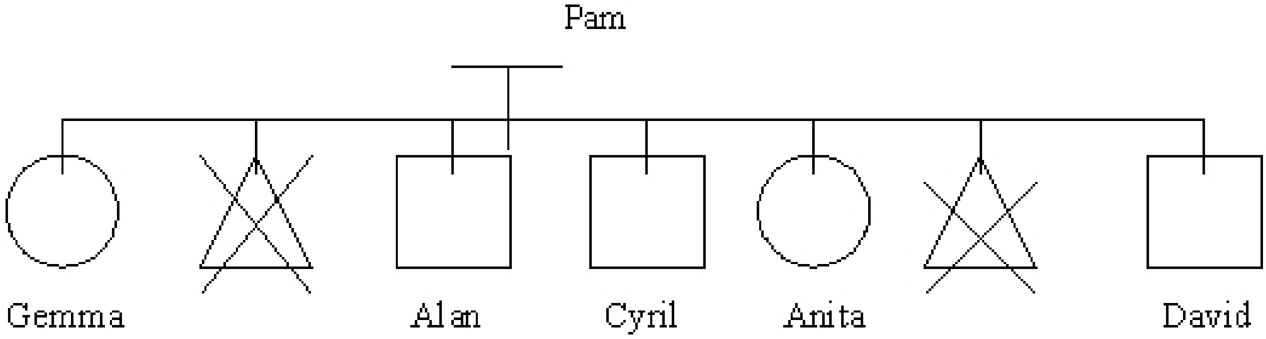
Anita gave consent for me to meet with her mother who provided information about Anita’s history. Anita currently met her mother twice a month although their relationship had been more distant previously.

## *Family History*

Anita’s mother Pam felt she was called by God to be a nurse, and resented her marriage at the age of 21. Pam felt her children prevented continuing with her career, but felt unable to use contraception. Anita’s family tree is given in Figure 1.

Pam “spent her whole life feeling guilty” for conceiving before her wedding. The family struggled financially, at one stage living in a caravan. Anita’s father drank heavily, and the family home was noisy and crowded. Anita cared for her younger siblings while her father was at the pub and her mother was working. Pam said she couldn’t give Anita much attention due to her job, and because her son had a learning disability. The family accommodated several foster children. Pam reported that her husband was abusive to all the children but singled out Anita.

**Figure 1: Genogram of Anita’s family**



Gemma married at 16 and lives in Cornwall. Anita has lost touch with all her siblings except Gemma, who sends occasional cards.

Alan spent time in the same hospital as Anita for alcohol detoxification. Cyril suffered anoxia at birth and has lived in institutions for people with learning disabilities. David is dependent on alcohol, and has no fixed abode. He has Asperger’s syndrome and is considered a dangerous person by the police, having threatened Anita and Pam with a gun in the past.

## *Personal History*

Anita was described as being a very quiet child. She left home at 15, and lived with a family friend until she left school with 2 O levels at 17. She had several jobs including factory worker. At 16 she moved in with her first boyfriend. He sold drugs, and Anita used alcohol and cannabis heavily at these times. Anita and her boyfriend went abroad for several months and lost contact with Anita’s family. Whilst away, she became unwell, experiencing hallucinations and displaying bizarre behaviour such as refusing to remove her raincoat. The couple did not have enough money to return to the UK, and Anita may have been sold for sex in return for their airfare home. On their return Anita became increasingly unwell. She was unable to undress when bathing, and was admitted to a psychiatric institution. Her mother believes Anita’s compulsions as began with this admission.

Anita received psychiatric diagnoses (schizophrenia and OCD) in the past but few attempts had been made to understand her behaviour from a psychological perspective.

# Formulation

A preliminary formulation was drawn up with supervision from my clinical supervisor, and a specialist in systemic formulations using the information gathered. This draws on several approaches including attachment theory and psychodynamic concepts.

As a child Anita lived in a context of danger (violence and bullying from father) and her needs (emotional and physical) were unmet by her parents. Her caregivers were unavailable, unpredictable and unreliable. Anita ignored her own needs in order to care for her siblings. Children whose needs are not met by caregivers may either increase their attachment behaviours in an attempt to get their needs met, or may withdraw and internalise their needs (Bowlby, 1969). From Anita's description as a withdrawn child, she concealed her unmet needs and internalised the resulting feelings of anxiety. Individuals with insecure attachment styles may be at increased risk of developing psychosis (Berry *et al*, 2007). This pattern of withdrawing from others was seen during her hospital stay, when she interacted infrequently with staff and patients.

There was a deficit in caretaking during the early months of Anita's life as her mother was incapacitated through guilt, resentment towards Anita, and the demands of her other children. Anita's father was described as "bullying" Anita, which reportedly included criticising her appearance and behaviour, and accusing her of sexually promiscuity. This may have lead to fundamental developmental damage resulting in distortions to Anita's basic sense of reality and whether the world and others can be experienced as dependable. This critical, negative attention is replayed by the staff team who find themselves "telling her off" for her socially inappropriate behaviour. It may be that negative feedback is ego-syntonic for Anita and that she feels more comfortable receiving this type of attention, than other, more positive interactions with the staff. Children who experience adverse circumstances in childhood (including parental mental illness, and witnessing domestic violence) have lower levels of social functioning in adulthood and are more likely to experience psychiatric illnesses (Rosenberg *et al.*, 2007). Lack of good enough parenting (i.e. empathic attunement to the infants' communications and needs) may fundamentally damage the capacity to relate to others and to regulate one's own emotions (Cassidy, 1994). Anita's anxiety, which she attempts to control through her thoughts and behaviours, cannot be contained or regulated and is experienced as overwhelming and threatening to her self. This anxiety is felt by the staff team and is reflected in their determination to 'do something' to help Anita, and their difficulty in tolerating her anxiety.

Anita's subsequent relationships were with violent, unpredictable men. They were unable to provide Anita with stability, mirroring Anita's childhood experiences of a chaotic household. Anita's involvement with alcohol and drugs may have suppressed her emotional needs and memories of past trauma. Drugs and alcohol are frequently used as substitutes for defence mechanisms (Khantzian & Kaufman, 1994). Defences prevent feelings, ideas, impulses and entire subjective experiences from being consciously articulated or from reaching conscious awareness (Shapiro, 1989 in Khantzian & Kaufman, 1994).

During her hospital stay Anita remained detached from others, feeling unable to join others in activities for many years. The routines and rituals which protected her from perceived danger (e.g. covering drinks to protect herself from germs) may have helped to regulate her emotional distress. They provide a sense of control and predictability that had been missing from her environment, contained her anxiety, and defended against her internal pain. Obsessional checking may be a way of managing unacceptable hostility, which Anita may feel towards her parents who were both unable to meet her needs as a child and as an adult. The damage which Anita fears would result from the hostility requires the constant reassurance of the checking (Leiper, as cited in Vetere & Dallos, 2003).

Anita's current style of relating to staff demands a large amount of staff attention.

# Collaborative Reformulation with staff team

Parts of this formulation could be shared with the staff team to help them understand Anita's challenging behaviours. The formulation was presented as a working hypothesis, and staff were encouraged to contribute further information or hypotheses about Anita's current behaviour and her past experiences. Little was known about her social interactions or what sense she made of her experiences in hospital. Detailed notes about her medication over the years existed, highlighting the predominantly medical model in which Anita lived, perhaps with insufficient attention being paid to her internal world. Many of the staff team had known Anita over several years, and it was hoped they could contribute important detail to the formulation.

This consultancy based session centred on the premise that the client (the staff team) is expert at understanding their own system (Anderson & Goolishan, 1992), and encouraged staff to form a narrative about their own abilities in overcoming the 'problem' (Wilcox & Whittington, 2003). This meeting was attended by five staff members, including Anita's key worker, and a nurse, Brian, who worked with Anita for many years in hospital. Staff were encouraged to try to make links and hypotheses based on the information I had gathered. A number of techniques were used including Socratic and circular questioning to try to increase staff's empathy and understanding of Anita's situation (e.g. Vetere & Dallos, 2003).

Initially the staff team looked to me as an 'expert' to provide guidelines on managing Anita's behaviour. When it became clear that I believed them to be the experts on the situation, several staff members, especially Brain questioned the value of the session. The team appeared to look to the MDT for guidance and felt uncomfortable with the idea of them as 'experts'. I wondered whether the staff team felt pressure to 'cure' Anita, and worried that their continuing difficulties were viewed as a failure by the MDT.

With the acknowledgement of their expertise, and the assurance that they were not being blamed them for 'failing' to manage Anita's behaviour, the atmosphere changed. Staff provided much useful information about Anita's previous behaviour and relationships in the hospital. Examples of changes in her ability to socialise and relate to others were given, and we reflected on the progress Anita had made over the years. I learned about the challenges Anita's behaviour had posed to staff in the past, and the resulting frustration. I highlighted changes between Anita's past and current functioning. Her increased confidence, self-esteem, ability to form and maintain relationships and her job in sheltered employment were all discussed. Contrasts were made between her current level of independence in the home and community, and her previous inability to leave the ward in hospital. Staff also realised that the frequency of her compulsions had greatly reduced since leaving hospital and noted that these behaviours were not causing her subjective distress.

Staff participated enthusiastically in this session, and made hypotheses about Anita's behaviour. Brian wondered whether Anita's difficulties in self regulation may contribute to her current over eating, and considered the effect her current body shape on her self-esteem. Another staff member had noticed that Anita's mother also crosses through her signature in the home's visitor's book, and wondered whether Anita had learned this behaviour. Most significant was a shift in attitude from Anita being, in Brian's words "just really annoying", to someone who had faced significant difficulties throughout her life, and who had made much progress.

Removing possibilities of blame allowed the team to let go of their defensive feelings, and approach the exercise with curiosity. At the end of the session, I asked the team about the implications of this session. They felt they lacked training around OCD, and would welcome a teaching session on this. Service providers should know about the impact of serious psychiatric disability such as psychiatric symptoms and the course of disorders (Corrigan *et al.,* 2001)

A number of ideas were generated by the staff team, which linked areas of Anita's current behaviour with information about her past. These included acknowledging the role of her early upbringing on her subsequent psychiatric difficulties, the sense of control her obsessions and compulsions may have given her in unpredictable environments, and the nature of her interactions with others in the past which have been predominantly negative. Staff suggested that any 'positive' attention may not fit with Anita's view of herself and therefore would be uncomfortable for her.

The staff team drew the following conclusions from the session:

- Anita is happier now than she has ever been previously.

- Staff's responses to Anita's 'bad behaviour' is different from how people would have reacted in the past (e.g. using violence). This is important in changing behaviour.
- Anita's compulsions have given her a sense of control for many years. They have been useful, and will not be quickly changed.
- Anita is asking staff for attention. While this can be frustrating, it is a huge improvement from her behaviour in hospital when she was completely isolated from other people and made no attempts to interact with them.
- Staff need to respond consistently to Anita's behaviour. Anita's behaviour is a product of her past, and further changes will be slow (although significant progress has been made in the last few years)

## Staff Teaching

Following the staff team's request for teaching on OCD, a session was planned at a convenient time. Several MDT members wished to attend the session. The staff team decided MDT members would be welcome at the teaching session, and hoped the MDT would understand more about the day-to-day challenges they faced, and would facilitate a coordinated approach to Anita's management.

This session was conducted in Anita's home, and was attended by MDT members. The home manager, and six members of the staff team, including Brian and Anita's named nurse, also attended.

The session included basic education around the symptoms and diagnostic criteria of OCD. Examples of other people with OCD in both more and less severe instances that Anita were given. The discussion led onto a recent television programme by Professor Salkovskis. This featured three people with severe symptoms of OCD overcoming their difficulties through intensive cognitive behavioural interventions. The staff team wondered whether Anita could be cured by a short-term cognitive behavioural intervention, reflecting a persistent desire to 'cure' Anita. Thinking about the differences between Anita and the people featured in the programme revealed some of the complexities of Anita's behaviour and the complications added by her diagnosis of schizophrenia.

I shared the background information and hypotheses resulting from the reformulation session with the staff team. Time was spend thinking about obsessions and compulsions as occurring along a continuum, with some level of these being in the normal range and experienced by the general population. Some of the traditional interventions for OCD were discussed including the behavioural exposure response prevention strategies that had been unsuccessfully tried with Anita in the past, and more recent cognitive behavioural techniques. The group explored whether these approaches would be suitable to use with Anita. Given our increased understanding of Anita's history, an approach based on this information would be most helpful in containing Anita's anxieties, and helping the home staff team and the MDT work in a mutually supportive way. The group developed some guidelines for working with Anita:

- The staff team to meet regularly and manage Anita's new behaviours in a consistent way e.g. deciding on guidelines that all staff members would adhere to
- Naming one member of staff to be allocated for Anita's care on each shift, ensuring consistency of responding
- Staff to avoid reinforcing Anita's behaviour by telling her off or giving 'negative' attention. Instead staff would respond empathically and refer Anita back to her allocated member of staff

In addition, we reflected on the progress Anita has made over the past 20 years. The MDT commented on the quality of care the staff team had given to Anita over the years. Both teams agreed that Anita was someone with complex and long standing difficulties and that further progress would require patience from all involved in her care. This acknowledgement that the MDT did not expect the staff team to in some way ‘cure’ Anita, and that they appreciated the day to day demands she placed on the service were welcomed by the staff team.

# Evaluation

The process of engaging with Anita over several months gave Anita an experience of a therapeutic relationship in which she was able to discuss some of her difficulties, especially around her relationship with members of the staff team. Anita’s engagement with the therapist was not formally measured, although it was clear that she felt more able to discuss her distress and interpersonal conflicts freely as the therapeutic relationship grew stronger. Anita was keen to spend time with the therapist, and prioritised these sessions above other activities she also enjoyed.

Initially the staff team lacked confidence and felt overwhelmed by Anita’s behavioural difficulties. The team felt an expectation from the MDT to manage or ‘cure’ Anita, which they felt unable to do, and subsequently left them feeling disempowered, frustrated, and critical of Anita. These dynamics were established through extensive discussions with several members of the staff team, discussion with members of the MDT, and through supervision.

One aim of the intervention was to empower staff to manage and contain Anita’s anxieties. The collaborative formulation allowed staff to discover where the anxiety around Anita originated from. It also allowed them to generate strategies around how best to manage this, and how to coordinate their approach to the difficulties both within the staff team and with the MDT. Formal measures of staff morale and locus of control were not taken. However qualitative feedback from the staff team indicated that the collaborative formulation session was helpful and allowed staff members to develop a more detailed picture of Anita’s life. With this additional information came a renewed sense of empathy. When presented over many years, Anita’s progress in many areas including social skills and participation in activities was highlighted. This reportedly countered the feeling that Anita was “stuck” and that the efforts of the staff team made no difference to her quality of life.

The staff reported that the training session allowed them to understand the symptoms of OCD and current theories around treatment. Staff participated and appeared engaged in the teaching session.

One important outcome of this intervention was an improved working relationship between the staff team and the MDT. Both teams indicated that this process had enabled future work to be more coordinated and consistent, and had communicated several important messages to the staff team. These included reassurance that the MDT did not expect the staff team to ‘fix’ their clients, and an appreciation from the MDT of the day-to-day difficulties faced by the staff team.

# Critical Review

The work lacks quantitative evaluation, and relies on qualitative feedback from individuals in the system. A more systematic method of evaluation may have collected more information and allowed stronger conclusions about the efficacy of the work to be made. Standardised measures of change over short periods of time are difficult to obtain for this client group.

One aspect of the work I found particularly valuable was improving the communication between the staff team and the MDT. It was clear how assumptions could be made about what was expected from the staff team, or that indirect messages were being given out by the MDT. If these are not made explicit or challenged openly, the relationship between the two teams could deteriorate, affecting the quality of care for all clients in the service. Through supervision I explored the difficulties from various perspectives including the staff team, members of the MDT, and Anita. This flexibility of thinking and ability to develop empathy for all members of the system allowed me to step outside the system and gain a different perspective, whilst remaining mindful of the challenges faced by each group.

Ethical issues were carefully explored in supervision. Anita had experienced many damaging relationships in the past. The experience of a therapeutic relationship which was non-judgemental, yet curious about her story, may have been novel for Anita. Therefore I thought carefully about the impact of establishing and withdrawing this relationship on Anita. The boundaries of the relationship were explicitly explained at the beginning and throughout the relationship. Towards the end of the work, Anita and I thought together about alternative sources of support.

Alternative models of working could have been used. There is a good evidence base for the effectiveness of an individual cognitive behavioural approach for OCD, based on the cognitive model of OCD proposed by Salkovkis (1985) (e.g. Whittal, 2005). However, Anita's difficulties in accessing her cognitions would make reappraising harm related cognitions difficult. In addition, exposure response prevention may reduce compulsions amongst individuals with OCD (McLean *et al,* 2001). The consistent and coordinated approach it requires from the staff team made it difficult to implement practically. This approach had reportedly been used in the past, but was unsuccessful, due to Anita's fluctuating motivation to comply with the response prevention.

It may have been useful to use a reflecting team approach (e.g. Vetere & Dallos, 2003) to support the development of the team's confidence, and to help with the concept of problem externalisation (White, 1989).

One challenge of working within rehabilitation settings can be the maintenance of progress. This intervention endeavoured to transfer the mechanisms and responsibility for change from an external locus (the MDT) to a more internally located locus. In order for change to be maintained, the dynamics between the two teams needs to shift, so that the staff team can feel empowered to work confidently with Anita. In turn, the MDT need to understand more about the skill mix of the staff team, and ensure that each team has a clearly defined role within Anita's care (Firth-Cozens, 2001).

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# Rehabilitation for Children with Cerebral Palsy: Seeing Through the Looking Glass

## --Enhancing Participation and Restoring Self-Image through the Virtual Music Instrument

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## Abstract

This paper presents the results of a qualitative pilot study conducted on an innovative psychosocial rehabilitation technology developed and applied at Bloorview Kids Rehab, Toronto, Ontario, Canada. The Virtual Music Instrument (VMI) developed by Dr. Tom Chau is a video-capture software program that increases music-making opportunities for children and youth and allows children with disabilities to play musical sounds and melodies using gestures. The qualitative study was conducted to identify suitable music therapy interventions and techniques using the VMI with children with cerebral palsy (CP), to categorize areas of benefit that are made possible by the VMI, and to build theory on the role and significance of the VMI in music therapy. The research questions included: (1) What interventions and techniques are best used by the music therapist to promote the therapeutic relationship in application of the VMI? (2) In which domains is there benefit, both during sessions and over the time period of the study, from the use of this instrument within music therapy? Six participants aged 5.5 to 10 were recruited on a cross-disability basis. Each participant received ½-hour individual music therapy sessions, twice per week over 10 weeks, using the VMI. The Music Therapist employed a variety of techniques, including both clinical improvisation and task-oriented activities. The sessions were videotaped, transcribed and reviewed by a multi-disciplinary team. The clinician notes were also transcribed. Using a multiple case study qualitative methodology and grounded theory techniques, the transcribed material was coded and analyzed according to emerged themes using the QSR N6 software program. The results bring better understanding of using the VMI for optimum benefit, and also lead to theoretical and practical advances in the use of gesture recognition technology on music therapy and psychosocial rehabilitation among children with cerebral palsy.

**Keywords:** Cerebral Palsy, psychosocial rehabilitation, Music Therapy, Virtual Music Instrument, Qualitative Research

# Introduction

Children with significant physical challenges such as cerebral palsy (CP) are at risk for developing passivity and learned helplessness. They may feel socially isolated (Blum et al., 1991; LaGreca, 1990; Anderson & Clarke, 1982; Cadman et al., 1987; Law & Dunn, 1993). A lack of participation is ubiquitously reported in the literature for children with special needs. Patterns of social restriction and isolation begin early in life, indicating a need for timely intervention (Blake, 1995; Brown & Gordon, 1987). Preschoolers with disabilities are unable to explore the world around them (Rosenberg et al., 1989) and spend more time passively non-engaged, compared with developmentally age-mated peers (McWilliamet al., 1995). By school age, social contact is diminished (Romer & Haring, 1994), with the majority of free-play time focused on non-play or manipulative activities (Kontos et al., 1998). Observational studies (e.g. Magill & Hurlbut, 1986) note that adolescents with physical disabilities also have a smaller peer network and fewer peer-interactions. Adolescents with physical disabilities experience more emphasis on activities planned by adults than on spontaneous activities with peers (Margalit, 1981). Studies also show that the participation of children and youth with disabilities decreases as they grow up. As adults the participation may be strictly limited (i.e. Pollock & Stewart, 1990; Crapps et al., 1985; Dempsey, 1991). A lack of participation can lead to the development of physical, medical, cognitive, emotional, or psychosocial secondary conditions with adverse outcomes in health, wellness, and quality of life (Hough, 1999). Contributing to the enhanced accessibility of current media and technology is a key aspect of independence, full participation, and achievement of long-range goals. Throughout history, music has been a significant component of health care (Davis et al., 1992). Particularly, in the last decade, effective therapeutic applications of music in many health-related domains of participation have been documented. For example, improvisational music therapy was found to increase communicative behaviours in eleven children with autism (Edgerton, 1994). Similarly, using creative music therapy as a treatment form, Aldridge et al. (1996) reported improvements in hand-eye coordination, personal-social relationships, and hearing and speech tasks in eight children with developmental delay. In studying the impact of music therapy on children with visual impairments, Gourgey (1998) reported increased exploration of the environment, heightened social awareness and interaction with peers. Subsequent studies have recounted therapeutic benefits of music such as enhanced participation, interaction and relationship development in school children (Camilleri, 2000), and acquisition of appropriate social skills among adolescents with behavioural problems (DeCarlo, 2001). Yasuhara & Sugiyama (2001) studied the impact of music therapy on children with Rett Syndrome. They found significant improvements in sustained hand grasp duration and frequency, socialization, language and participation in music activities. In a study of hospitalized pediatric oncology patients, Robb (2000) concluded that the therapeutic music interventions elicited significantly more engaging behaviours from the children than any other hospital activity. Contrary to other therapeutic techniques, engagement in musical tasks does not have physical, cognitive or sensory prerequisites for participation. However, in traditional music therapy practice, acoustic instruments are used to elicit active participation, leaving out some children with special needs due to access issues based on limited fine motor control, co-ordination, strength and endurance. This limits the level of participation and therefore the extent to which they can effect their environment.

Bloorview Research Institute has been at the forefront in developing and applying psychosocial rehabilitation technology. In the music technology area, the Institute has developed four original technologies, and tested a number of other devices and software programs that involve young people with disabilities in new and different ways (Knox, 2004). One of these developments was ListenUp! (Assistivex, 2003), a music software program for remediation of attention deficits of clients with acquired brain injuries. Musical engagement has been encouraged through active participation, enabled by a variety of adaptive technologies such as the MIDImate switch access system (Assistivex, 2003), and automatic movement technologies that convert movement to music are used, such as the Soundbeam (Soundbeam Project, 2003; Swingler, 2003), and the Virtual Musical Instrument (VMI) developed at Bloorview Kid's Rehab by Biomedical Engineer Tom Chau (Lamont et al., 2002). The use of these adaptive technologies has created a paradigm shift in which access to a musical instrument no longer requires physical strength, endurance and fine motor abilities (Ellis, 1995). As a result, participation in musical tasks and the subsequent emotional, psychosocial and therapeutic rewards is no longer restricted by physical barriers (Schwellnus et al., 2002).

The Virtual Music Instrument (VMI) is an instrument that uses a computer and web-camera to capture and display the image of the child on the screen and allows the user to designate musical areas that are outline on the screen by different coloured icons (Chau et al., 2003). The child interacts with the instrument producing pre-determined musical tones or events by moving his or her body into the physical space represented by the icons on the screen (Chau et al., 2002). The VMI has been used extensively in individualized settings and the newer versions of VMI software have proven highly valuable in past years. Usability studies involving the VMI suggest a positive impact on precursors to participation, including learning cause and effect (Chau et al., 2002), and the technology is more engaging for children with more complex physical disabilities (Lamont, et al., 2003). The versatility and ease of use inherent in the VMI system, makes it an ideal music environment in which to assess a children's ability to participate. However, in addition to development and usability study of the VMI system, research on its *efficacy* within music therapy practice was needed. A qualitative study was required to build a knowledge base as to *the potential techniques and varied use of the system* for practical use in the music therapy, and to better understand *areas of benefit* resulting from use of this adaptive technology as a tool within the music therapy environment.

***Figure 1:*** **The Virtual Musical Instrument (VMI)**

## 1. Research Methodology

The objectives of this qualitative pilot study were to identify music therapy interventions and techniques using the VMI that are suitable for young people with disabilities, to categorize areas of benefit over time that are made possible through enhanced participation using the VMI, to build theory on the role and significance of the VMI in music therapy, and to add to the existing literature and practice of music therapy, with the ultimate goal of client self-actualization through active participation.

The research questions included:

1. What *interventions and techniques* are best used by the music therapist to promote the therapeutic relationship in application of the VMI?

2. In which domains is there *benefit*, both during sessions and over the time period of the study, from the use of this instrument within music therapy?

**Participants**

The trials were carried out with six study participants of either sex (between 5.5 and 10 years of age). From previous experience, it was found that the VMI is most effective and of most benefit to lower-functioning children with significant physical challenges including spinal muscular atrophy, cerebral palsy, and chromosomal abnormalities such as Rett Syndrome. The inclusion criteria were that the child: have at least one independent movement that is self-controlled; not knowingly possess any adverse sensory reactions to music (e.g. seizure activity onset by particular frequencies); might be non-speaking but must have identifiable responses to auditory stimuli, specifically musical tones of mid-range frequency; must be able to remain positioned on the floor, in a chair, or in wheelchair for the majority of the session time. Participants were recruited by advertisements and were selected on a cross-disability basis according to inclusion criteria and interest. All sessions took place at the Bloorview site of Bloorview Kids Rehab. They were held in a moderately sized, multi-use clinical space that houses musical instruments (including a piano, several guitars, percussion equipment, and small hand percussion equipment), audio equipment, a computer installed with the VMI system, a webcam, and a large screen television. All children were seen individually. Music therapy sessions were ½ hour in length and were scheduled 2 times per week for 10 weeks, within each of the study's time periods. The child was invited to take his or her place in front of the camera of the VMI. The music therapist made camera adjustments to center the child's image in the television screen. If applicable, the child was encouraged to recognize his/her image in the television screen. From the computer, the music therapist placed circles and/or squares of various colours with corresponding tones around or on the child's image according to each child's physical abilities. The child was then engaged in a music therapy session employing a variety of music therapy techniques including clinical improvisation and task-oriented activities to encourage active participation on the VMI. Verbal, gestural, and physical prompting (hand over hand) was employed in sessions to ensure comprehension and appropriate access of the system. The therapist monitored the child's fatigue (physical and emotional) through observation and verbal inquiry to ensure participant safety.

**Research Design**

The research was based on the qualitative paradigm (Denzin & Lincoln, 2000; Coffey & Atkinson, 1996) and its nature was abductive (Peirce, 1839-1914) and descriptive (Bruscia, 2005, p. 81). The study employed a multiple case study paradigm, one of the five key methods in qualitative research (Creswell, 1998), grounded theory (Corbin & Strauss, 1998; Glaser & Strauss, 1967/1999; Strauss & Corbin, 1990, 1997, 1998; Glaser, 1998), and narrative inquiry (Ceglowski, 1997; Glesne, 1997; Hollway & Jefferson, 1997; Frank, 1995.) The aim was to look deeply into the characteristics and processes of six children in their music therapy sessions. The study was designed to characterise the individual; however, cases often show precedence and build up a body of evidence on which to build theory. In this study we also took a comparative approach to examining the six children's case data.

**Qualitative Data Collection**

Two types of data were collected: (1) Field notes (indexed session notes, case studies, and reflections) on all sessions from the therapist's observations, and (2) video observation notes on all sessions. All sessions were videotaped and reviewed by two music therapists but only meaningful moments (Amir, 1996) chosen by them were analysed by the occupational therapist. Reviewers justified their selections by saying why the examples illustrate what they say they do. Those moments were first described as narratives and transcribed, followed by further reflection. The field notes then combined with the video narratives (see Table 1).

During the research process there was a cycle of observing-describing-interpreting completed several times; not always followed in a linear fashion (Ansdell & Pavlicevic, 2001). Sometimes the different stages of the cycle interacted and circled back on each other. The task was to get the material into a form where closer analysis was possible, in view of the research questions. Once field notes of the therapist and videotape notes had been transcribed, the two researchers coded data into themes for content analysis using QSR N6 software. The aspects or events that were relevant to the research questions were labelled, while not excluding the possibility of unveiling new questions. The material was then organized into categories and subcategories. The robustness of the categories was tested in addressing the research questions, and the researchers firmed up boundaries by looking for overlaps and discarding weak categories.

One of the chief characteristics of this qualitative inquiry was the evolving nature of the design, methods and analytic procedures used. The theory evolved as the data was being analyzed and the descriptive categories were formed. It was not straightforward to separate out description from interpretation. The research process included a series of dialogues; with the data, with the ideas, with colleagues and with oneself. All of those interactions led to reflections and different decisions. The results developed through these various transactions (Coffey and Atkinson, 1996).

## Results: Therapeutic Benefits

The therapeutic benefits of the VMI are introduced in the form of the following descriptive categories *(Table 1).* The core category — the grounded theory — is articulated as: "*Enhancing Participation and Restoring Self-Image Through the Virtual Musical Instrument — Seeing Through the Looking Glass.*" The main category growing out of the core category is: *"Knowing through creative musical expression."* The four sub-categories include:*" To see and to be seen through reflective mirroring," "Learning and building concepts through a musical framework," "Enhancing full body participation through multi-sensory musical expression," and "Restoring self-image and expressing feelings through containing musical experience."*(In the following, participants' names have been changed to maintain confidentiality.)

***Table 1*****: Seeing Through the Looking Glass**
**Enhancing participation and Restoring Self-mage through the Virtual Musical Instrument**

| **1**<br>**Visual Awareness** | **2**<br>**Auditory Awareness** | **3**<br>**Kinesthetic Awareness** | **4**<br>**Self Awareness** |
|---|---|---|---|
| **I can see me**<br>**I can see you**<br>**I can see us** | **I can hear it**<br>**I can hear you**<br>**I can hear myself** | **I can touch it**<br>**I can play it**<br>**I can control it** | **I can understand**<br>**I can feel it**<br>**I know** |

| | | | |
|---|---|---|---|
| **I can see it** | **I can hear us** | **I am good at it!** | **I like it**<br>**I did it!**<br>**I can cope**<br>**I can choose**<br>**I believe** |
| **To see and to be seen through reflective mirroring**<br>**experience** | **Learning**<br>**and building concepts through musical framework** | **Enhancing**<br>**full body participation through multi-sensory musical expression** | **Restoring**<br>**self-image**<br>**and expressing feelings through containing musical experience** |
| **Knowing through creative musical expression** | | | |
| **Enhancing Participation and Restoring Self- Image Through the Virtual Musical Instrument**<br>**— Seeing Through the Looking Glass** | | | |

Dr. H. Ahonen-Eerikäinen and A. Lamont

## *Category 1* — "To see and to be seen through reflective mirroring experience"

*I can see me*

*I can see you*

*I can see us*

*I can see it*

According to Hobson, (1987) "The face is the mirror of the emotions and the eyes are the windows of the soul. In a simultaneous expression and communication, we give and receive, as our eyes convey and register the emotions of joy, interest, curiosity, anger, fear, and many complex combinations of these and other affects." (p. 123).

We all need to belong. We need a sense of self, other and belonging (Stern, 1985). "The sense of community and belonging can be related to empathy itself" (Shapiro, 1998, p. 52). "The earlier in life an individual experiences that the need for a relationship is *not* being met, and the more consistent that experience is, the greater and more disruptive its effects…" (Erskine, Moursund & Trautmann, 1999, p. 11). There is only one thing that can cure isolation. "Contact… is the key. Contact, contact, and more contact" (Erskine, Moursund, & Trautmann, 1999, p. 12). An infant can feel what her mother is feeling if she is imitating her mother's facial expression (Lee and Martin, 1991). "Without the *dance* that takes place between mother and child, growth and development are constricted" (Shapiro, 1998, p. 51).

> *"The visual feedback of her own image in the VMI allowed X to make eye contact with herself and with the music therapist on a regular basis… Also, the visual feedback permitted X the opportunity to play "dress-up" as the diva (bowing in front of the camera and saying "thank you, thank you!"), or as the leapfrog. When the camera was not focused on her face, X could become confused, occasionally moving to the floor to see her face in the television if working on a "dancing" screen."*

According to the research results VMI provides a sense of relationship. Participating in VMI as a form of creativity and play is a benefit in and of itself. Play is one of the main occupations of children and play for play itself is satisfying. It also gives the opportunity for empowerment, to control objects in their environment, which children with CP may not have in other typical play activities. VMI sessions were full of feelings and laughter. According to Chain-West (1998, p. 101) playfulness spreads within a developing therapeutic process and laughter is therapeutic. It reduces tension and anxiety and establishes cohesiveness as an outcome from shared experiences. Winnicott (1971a) explains that if the therapist cannot be playful he/she will not be capable of doing successful therapy. Stern (1985) noticed that only a *securely* attached baby plays, and only a *very* secure baby can *tease*. Chain-West (1998) compared play with therapy and found the level of comfort and security of the clients was reflected in their playfulness within the psychotherapeutic process. "If the therapist can be teased, in a benevolent way, he is less likely to be either feared or defensively idealized and is experienced as *more human* and, thereby, more understanding of his patients and compassionate towards them" (Chain-West, 1998, p. 101).

## Category 2 — "Learning and building concepts through musical framework"

*I can hear it*

*I can hear you*

*I can hear myself*

*I can hear us*

Cognitive behavioural therapy focuses on correcting a vicious cycle of thought distortions, negative emotional responses to these thoughts, and the resultant maladaptive behaviour (Beck, 1975). In the context of this study, challenges faced by children in previous music experiences, such as unsuccessful traditional music lessons or a lack of physical strength and/or dexterity, left a sense of failure. This can leave the child with little motivation to embrace music-making and distort a sense of musicianship. The use of VMI seemed to motivate children:

> *"The use of the pentatonic scale, specifically, appeared to be a motivator for Bill to move his body. As this scale was used in previous therapy, it was easily recognizable to Bill evidenced by the immediate use of his voice and engagement with the VMI system... No matter what icon was fired, Bill could be assured that his music would sound correct and sonorous."*

Bill's tune contained within the pentatonic scale provided a secure base from which he could explore musically in a safe manner. Success-oriented client experiences in the music making can work to challenge thought distortions. This is encouraged through the music therapist's ability to establish a therapeutic relationship with the client through the provision of an appropriate music aesthetic (Lee, 2003) within communication accentuated music therapy practice (Ahonen-Eerikäinen, 1999) in which child can then hear his or her successful communication in the music making.

The results show the VMI, as a music therapy tool, offers the potential for positive, reinforcing musical experiences. The use of the VMI provides a new learning experience and one that focuses on the ability of the child versus the child's inadequacy. The music therapist has the opportunity to design screens that focus on accessible modes such as the pentatonic. The pentatonic offers a developmentally-appropriate, comforting and stable aesthetic that ensures no harmonic mistakes can be made by the child, allowing the child a success-oriented musical experience. This resembles communication accentuated music therapy as an upper level of all music therapy approaches (Ahonen-Eerikäinen, 1999). Communication must be encouraged within a safe musical atmosphere before an issue may be "worked through" (Ibid).

Once this is achieved, learning a theoretically accentuated music therapy approach in which "music conditions and works on behaviour or stimulates learning" (Ibid, p.159) is possible. In this approach, positive reinforcement through song lyrics and/or social praise confronts previous emotional responses. Maladaptive behaviours in response to initial distorted musical experiences can then be reshaped into more productive music making, thereby reinforcing the new thought process.

> *"In the final period, Bill demonstrated a different child; one that could "play" in the music with the more subtle awareness evident in the ability to top his own music, explore silence with another person, and to express a complex musical thought understanding that he would hear another and would be heard in his place."*

The use of imitation is crucial to the process of reshaping associated feelings and behaviours. The child begins to understand his/her music through the auditory recognition of his/her movements causing the effect of music ("I can hear it"), of his/her music played on the VMI or imitated by the therapist ("I can hear myself"), imitation of the music therapist's music ("I can hear you") and musical interplay ("I can hear us"). This, of course, then feeds back to reinforce the formerly distorted thought regarding musicianship and leads to potential success in other areas:

> *"...may develop physical skills to access an augmentative communication device. The VMI could be a motivating method to practice physical and perceptual motor skills."*

## Category 3— "Enhancing full body participation through multi-sensory musical expression"

*I can touch it*

*I can play it*

*I can control it*

*I am good at it!*

Sensory integration refers to the body's ability to receive input from the senses, integrate this information to what is already known by means of sorting and screening, and interpret this information with respect to the individual's experiences and understanding of the world (Hatch-Rasmussen, 1995). It is known that sensory modulation, an aspect of sensory integrative dysfunction, is often a critical issue within developmental disability (Riesman, 1993). This refers to the nervous system's over-efficiency or lack thereof when processing information from the senses resulting in hypo-reactivity or hyper-reactivity to the stimulus (Stephens, 1997). In the practice of sensory integration therapy, as developed by Ayrs (Spitzer et al. 1996), the occupational therapist strives to provide the client with a stimulating environment with physical activity (both gross and fine motor) that is reasonable in expectation (known as the "Just Right Challenge"), promotes adaptive behavioural responses to tasks presented, allows the child to be active in participation, and is client-directed or centered (Dabrowski, K., 1967).

In recent literature, it has been suggested that there is a link between the practice of sensory integration therapy and music therapy (Hooper et al., 2004). Music therapy provides a context in which a client can interact with his/her environment in a variety of ways with purpose and success (Berger as cited in Hooper, 2004). Specific techniques involving the pairing of movement with music (pre-composed and improvised) are of particular interest for the integration of the auditory sense to the vestibular (information from the head in relation to gravity and the inner ear) and proprioceptive (as sense of self in space) systems (Ibid). This dovetails well with the idea of neuropsychologically accentuated music therapy in which "music serves as multisensory experience, contributes to the automatisation of working, [and] initiates association and memory functions and stimulates verbalization" (Ahonen-Eerikäinen, 1999, p. 159).

> *"The VMI provided the opportunity for full body musical expression. This emphasis on gross motor skills may have better spoken to Bill's abilities rather than his inability to correctly grasp or articulate his fine motor movement. This instrument also addressed Bill's energy and attention span. It did not require compliance to sit or maintain a specific posture, but could be adapted to Bill's unique movement."*

The results of this study show how the use of the VMI provides a number of opportunities for sensory integration within the music therapy environment. Specifically, it meets all criterion listed above for successful practice with an added dimension of potentially positive visual feedback.
Adequate stimulation within the environment is clear:

> *"The VMI may be a good way to promote movement, physical fitness and exercise. For example, it may help to increase strength, coordination and balance. Large movements of the body may help to stimulate muscle tone of the trunk and increase her ability to sit in a stable position for activities that require more precise motor control of the arms."*

> *"Most outstanding was motivation the VMI provided X to move both in novel ways and clearly outside of her normal ranges. She was rewarded both musically and visually in the jumping tasks. With the success of tasks such as jumping out the tune of "Twinkle, Twinkle Little Star", it suggests that music education could be conceived as a full body experience promoting not only musical skills but also physical fitness and gross motor strength and agility."*

Physical activity was promoted:

> *"Used right hand to access VMI icons most frequently and was observed to cross midline. Was able to target and activate specific icons when asked."*
>
> *"The physical nature of the VMI may improve joint range of motion, muscle strength, eye-hand coordination and body awareness. These skills may transfer to other activities in her daily life such as participating in dressing, bathing, etc. It may make it easier to move her body and rely less on caregivers to move/stretch her body parts"*
>
> *"X demonstrated twisting at his waist and clapping to the side and overhead"*
>
> *"For the masking tape activity, he worked on directionality, front/back, side to side"*
>
> *"The VMI could be used to introduce new movements, therefore increasing strength, coordination and balance."*
>
> *As a result of this study…. "X increased the number of times he crossed his midline with both arms…increased his ability to target specific icons to make musical sounds and phrases"*

Activity was reasonable in its expectation, fitting the "Just Right Challenge":

> *"X could alternate hand movements on the drum. Holding the drumsticks may give him a tactile, concrete clue to improve his accuracy to activating the icons (tactile feedback to his hand that guides movement)."*
>
> *"X improved bilateral hand skills. He increased the use of a hand that he does not normally use."*
>
> *"X increased ability to dissociate body movements i.e. he will be able to move his arm without his whole trunk moving"*

Adaptive behaviour was promoted:

> *"X may develop physical skills to access an augmentative communication device. The VMI could be a motivating method to practice and develop physical and perceptual motor skills."*

> *“X demonstrated the ability to separate movements i.e. he could play the drum and VMI together and separately (demonstrated bilateral hand skills)*

> *“X created new movements on his own such as twirling, walking on all 4’s, and taking little steps. Jumping seemed challenging for him.”*

Active participation was clear:

> *“X developed a ‘boxing’ move to activate icons and said it was like getting exercise on a bike.”*

> *“X appeared to increase her repertoire of movements from session 2. This could be used to improve her balance, coordination, physical stamina and endurance, and body and spatial awareness. She was able to explore different body movements to activate the VMI icons i.e. jump like a frog, flap like a bird.”*

> *“X was able to follow a simple beat. Following the music beats may improve the fluidity & quality of his movements. He was able to respond to increased speed of beats with increased speed of movements.”*

> *“X demonstrated cause & effect by crouching on the ground to stop the music, then popped up to activate the icons.”*

Music making was client-directed:

> *”The activation of his voice also appeared to be influenced by the whole tone scale, although this could not be confirmed with so few sessions. It would suggest that the stretching nature of the scale could be influencing the end points of his vocal range. In this case, there is very much a safe base for the whole tone, but it is elongated vertically, not laterally which may encourage a smaller voice like Bills to slide slightly higher or lower than normally would be seen.”*

> *“During the dancing/making bird sounds activity, X initiated jumping, flapping arms like a bird, moved right arm to hit icon”*

## Category 4 —“*Restoring self-image* and *expressing feelings* through *containing* musical experience”

*I can understand*

*I can feel it*

*I know*

*I like it*

*I did it!*

*I can cope*

*I can choose*

*I believe*

It was Donald Winnicott (1971) who first asked "What does the new born baby see when he or she looks at the mother's face?" Mother is looking at the baby, and how she looks at the baby is somehow related to what the baby sees in her. If the mother "looks with love and with tenderness, the baby experiences him or herself as joyfully alive. If, however, she is depressed and unsmiling, even more so if she does not look back and cannot maintain the reciprocity of looking, the baby experiences him-or herself as joyless, unlikely, even absent" (Pines, 1998, p. 47). Winnicott (1947/1964) discovered how the baby begins to see him- or herself in the mother's look, and how babies begin their lifetime search of "creating a sense of self. That sense of self could, for example be: 'I am good or bad to see and/or to hold.' Or the response could be empty of feeling" (Pines, 1998, p. 144–145). Can the cerebral palsy experience be an "empty mirror" for the baby or toddler, who may adopt a non-reflective image and incompetence and bad self-esteem through to the core of the self?

VMI could be compared to a hall of mirrors where each client is confronted with aspects of his or her psychological, social or body image (Foulkes and Anthony, 1990, p. 150–51). Children discover themselves, seeing who they are in a new light through their experiences in the VMI screen. For many children with CP this is crucial as their environments may not have provided that "magical" or good mirror all human beings need to see themselves in a healthy light. These children may have been seeing themselves only through distorting mirrors that have been reflecting only ugly images or freezing images (Behr, 2000, p. 175–76).

> *"Period 3 is a time in which X is able to process many of his feelings around strong emotions such as violence and sadness. It is in the acknowledgement of sadness that X opens up emotions forbidden in the past. Like other children with disabilities, X is not denying his own capacity or understanding of sadness, but is sensitive to exposing others to what might be additional sadness or worry; especially his parents."*

> *"Creating music and incorporating emotional content may help him to express his own feelings and explore emotional expression…"*

The results show that through the VMI the children with CP find their new identity. It is like the voiding a spell of an old distorted image: something that made them freeze, did not allow them to be visible, audible, livable, motorically talented, musical, or competent. It gives them permission to feel equal. It gives them permission to show their *true self*, instead of a false self, to become visible and audible. In VMI children with CP have different ways of dealing with their issues, and expressing their feelings. It becomes acceptable to be different, "to be one's own person" (Chazan, 2001, p. 55), to be individual.

The use of song-writing appeared to contain feelings in a more effective way than improvisations with instruments on the subject of anger. The inclusion of text may have helped to contain and address the topic in a more concrete and therefore satisfying manner.

> *"X was able to explore emotions by matching sounds to the emotions. He followed the verbal cue of 'sad' in the song to change instruments."*

> *"Repetition of key words such as yes or no allowed the song to be accessible to X. These were words that were well practiced and easily understood in his vocabulary allowing to express some of these feelings, in some ways, to the "empty chair" containing different family members."*

The *holding environment* (Winnicott, 1965) is a further idea that describes VMI experience and the *container (*Bion, 1959) is another. A VMI is a *safe* container and holding environment. It holds feelings of anger or pain. It holds feelings children were not able to express without music. If the music can *contain* those feelings, if the music can *hold* the child, it will be a *corrective* and *compensative* — something that perhaps was missing during their formative years. Having cerebral palsy may be quite traumatizing experience. The VMI is often the container for hurting feelings, anger, depression and anxiety.

## Main Category —"Mastery of knowing through creative musical expression"

> *"It was often noted that Luke appeared to be watching himself in the television or computer screen. This seemed to be a point of investigation or reflection as he played. ... a sense of musical mastery was achieved and Luke enjoyed viewing the results of his hard work."*

> *"This therapeutic relationship developed in the music seemed to permit X to not only learn to praise herself, but to explore the limits of her social, communication, and motor boundaries through active participation in the music."*

Results show that VMI engages the children with CP in the occupation of play, which is a normal activity for their age. VMI also gives them the opportunity to be an active participant and indicator of play rather than having less control as a passive recipient. This could benefit feelings of competence, confidence and self-esteem. Engaging in cooperative song writing and improvisations may provide feelings of pride or mastery, which is positive for building sense of competence and self-esteem i.e. "*look what I can do!"* This may help build confidence in self and in interactions with others. Children know they can succeed at VMI. "*I like it because I know I can do it.*" For example, Jennifer verbalized her own positive reinforcement by saying "*I did a good thing*" and "*I did it"* after each stop during VMI play.

> *"X demonstrated increased competence in making something happen (making musical sounds)…He seemed to have increased confidence that he could produce/create music. He was doing something that made him feel good."*

> *"A smile on his face indicated enjoyment of making music. He appeared to be proud of himself in completing the whole song and said "I may have a little party when I come home."*

The search for competence and mastery is basic motivation for behavior (Basch, 1988, p. 25). The following lower level categories illustrate that in VMI, children with CP find enjoyment with music and the multi-sensory stimulation it provides. They find mastery in various areas when playing music with the VMI. They begin to communicate, build concepts, enhance full body participation, restore self-images and express feelings. They begin to share their stories through improvisations and song-writing. It is remarkable that if people feel they cannot share their stories, they feel isolated, invisible, lonely, unimportant and incompetent. Only after their stories have been heard, shared, and witnessed do they begin feeling validated.

## Core Category: Seeing Through the Looking Glass —Enhancing participation and Restoring Self-Image through the Virtual Musical Instrument

*"How would you like to live in Looking-glass House, Kitty?*
*I wonder if they'd give you milk in there?*
*Perhaps Looking-glass milk isn't good to drink -- But oh, Kitty!*
*Now we come to the passage.*
*You can just see a little peep of the passage in Looking-glass House,*
*if you leave the door of our drawing-room wide open:*
*and it's very like our passage as far as you can see,*
*only you know it may be quite different on beyond.*
*Oh, Kitty! how nice it would be if we could only get through into Looking-glass House!*
*I'm sure it's got, oh! such beautiful things in it!*
*Let's pretend there's a way of getting through into it, somehow, Kitty.*
*Let's pretend the glass has got all soft like gauze, so that we can get through.*
*Why, it's turning into a sort of mist now, I declare!*
*It'll be easy enough to get through –*
*' She was up on the chimney-piece while she said this,*
*Though she hardly knew how she had got there.*
*And certainly the glass was beginning to melt away, just like a bright silvery mist."*

The multiple case studies included 6 children with a diagnosis of cerebral palsy who restored their self-image and found and owned a new identity during the VMI Therapy experience. During the narrative case study analysis (Ceglowski, 1997; Glesne, 1997; Hollway & Jefferson, 1997; Frank, 1995) the following titles became apparent. Matthew became *The Boxer*. Jennifer became *The Performer*. Bill became *The Conductor*. Steven became *The Acrobat*. Maddie became *The Scout*. Luke became *The Rebel*.

## MATTHEW—The Boxer

*Matthew* is looking through the glass but he can't see *himself* —he only sees his disability. He feels sadness and anger but locks the forbidden emotions inside. He doesn't want to upset anybody as they've been through enough… Gradually, music opens the door for Matthew to reach out and explore an extreme character. He becomes a boxer, rapper, a crocodile hunter… He expresses anger, sadness, frustration, violence… Multi-sensory combination of music and the physical manipulation of the mirroring experience make the self-process and new identity possible. He declares he will have a little party for himself!

### THE BOXER
Song composed
by Matthew

*There was a boxer - there was a boxer*

*There was a boxer who wasn't in the ring*

*So he boxed - and he boxed*

*And he boxed the television in*

*BOXING ACTIONS & INSTRUMENTAL CHORUS*

*First he gave it the left hook*

*Then he gave it the right hook*

*And then he gave it the noggin*

*And the TV fell down*

*BOXING ACTIONS & INSTRUMENTAL CHORUS*

*There was a boxer – there was a boxer*

*There was a boxer who wasn't in the ring*

*So one day he boxed the TV*

*And his parents came in*

*BOXING ACTIONS & INSTRUMENTAL CHORUS*

### The Long Way Home

Song composed

by Matthew

There were two crocks that liked to eat humans

*[3x djembe, tom drum right hand then left]*

But I'm already too far into the story.  Let me go back

*[chime]*

One day a man goes for a walkabout and becomes very, very hot

[bongos]

So he decides to go for a swim in the lake

*[2 black, one red, one green icon on VMI]*

But he doesn't know that there are 2 crocks in the lake.

*[2 black VMI icons and cymbal]*

So he tries to throw a fish to trick them

*[VMI icon arch]*

But then they fought

*[VMI/piano fighting music with arch ending in an accelerando]*

And fought – but then the man died

[bell tree music with Aeolian scale on piano]

There was a funeral for the man.  Everyone was sad, but especially his cousin.  His cousin was very sad

*[improvisation con't]*

He went from being sad to being mad

*[Improvisation with snare drum and piano in dual tonality]*

To being angry

*[improvisation con't]*

And he went from angry back to being sad again

*[Snare changes to bell tree, piano changes to Aeolian mode]*

He couldn't get over it.  He began to have feeling about the crocks.  He started to think about how he wanted to shoot them

*[black square VMI icon]*

Then he thought no, he wanted to poison them

[*blue circle icon]*

Then he thought he wanted to club them

*[black circle icon]*

Then he thought, “That’s even too good – I’m going to leave them in the water.”

*[silence]*

One day the cousin discovers that music helps to fill the hole in his heart. While he was playing, he realized something about life. He began to sing: “Live Your Life”

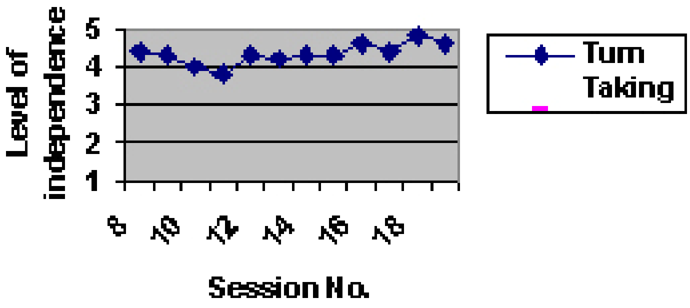
and he lived happily ever after

*[Guitar with vocal line “live your life”]*

## JENNIFER—The Performer

*Jennifer* is looking through the glass and only sees herself. Me, me, ME!!!! MY MUSIC! She’s afraid of the mist because she can’t see anyone else… she can’t find them. She’s there by herself. It’s a lonely place to be, filled with anxiety. It’s like she’s desperately trying to control her environment but she can never see very far ahead. New sound, new person, new demands would break down her safety. Music clears the mist. Jennifer first recognizes connections in music and gradually with another human being. She integrates the “we-ness”, dance between two people. She learns to dialogue. She becomes brave—exploring novel movements, crossing her physical comfort level.

Figure 2: Level of independence acheived in turn taking tasks



Level of independence: 5=Independent 4=verbal prompting required 3=gestural prompting required 2=physical prompting required 1=no performance

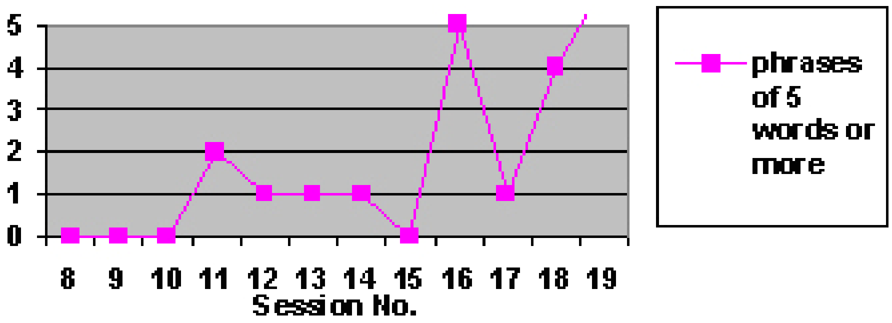


Figure 3: Use of phrases containing 5 words or more

### BILL—The Conductor

*Bill* is looking through the glass and only sees the glass, its beauty, its colours, its shapes, its music…its chaos. He does not see himself. He does not see another person. He's thrilled, however, like being inside a kaleidoscope. Every turn produces beautiful sounds. *He controls them*. He owns them. There's empowerment but music stretches him … his body, his voice, his abilities. Music helps him to differentiate himself from the chaos and have intentional communication with another person. And certainly the chaos was beginning to melt away, just like a bright silvery mist.

### MADDIE—The Scout

*Maddie* is looking through the glass but doesn't like what she sees. She turns away. She's resistant. She tries to control but there's too many things going on… She tries to trust but why bother as she may not come back next week. Music gave her a glimpse of an old Megan, the playful one, without so many worries… Although she has explored before through the looking glass her footing was no longer secure. It's like she's looking at the frame and not the mirror… and taking glimpses of herself when she can. *Let's pretend there's a way of getting through into it, somehow, Kitty…*

### STEVEN—The Acrobat

*Steven* is looking through the glass and is looking for something particular…to be excited. There are many fascinating things in the glass but he only plays with his favourites. You can just see a little peep of him in Looking-glass House, even if you leave the door wide open and offer him all the possible opportunities. He's caught and knows only a few ways to get out. Music helps him to expand his musical expression. Enticing music brought him to life.

### LUKE—The Rebel

*Luke* is looking through the glass and sees everything taking away from him. He sees an angry boy! He's blaming his disability. He's blaming his family. He feels his life is unfair. He feels nobody's listening. He's beating himself on a glass. Music allows constructive expression and control over the feelings. The song is empowering. It validates his opinions and feelings about his life. Music gives him a voice. It allows him to be articulate, respected. It gives permission to rebel. Music restores his self-image, re-constructs his identity.

**The following song was composed**

***1.***

***Your Mom or Dad says: "No more TV!" but you want it…so you sing:***

*YA, YA, YA, YA! I want TV!*

*YA, YA, YA, YA! I want TV!*

***2.***

***Your Mom or Dad says: "It's time to get in the car to go for an appointment far, far away!" but you don't want to go…so you sing:***

*NO, NO, NO, NO! I don't want to go!*

*NO, NO, NO, NO! I don't want to go!*

***3.***

***Your Mom or Dad says: "It's time to go to school" but you don't want to go…so you sing:***

*NO, NO, NO, NO! I don't want to go!*

*NO, NO, NO, NO! I don't want to go!*

*4.*

***Your Mom or Dad says: "It's time to go to bed!" but you don't want to go…so you sing:***

*NO, NO, NO, NO! I don't want to go!*

*NO, NO, NO, NO! I don't want to go!*

*5.*

*Your brother comes and takes your piano and says: "NO! MINE!"*

*but it belongs to you…so you sing:*

*YA, YA, YA, YA! That's my piano!*

*YA, YA, YA, YA! That's my piano!*

These multiple case studies and narratives characterize the school aged child with cerebral palsy— their daily life challenges, joys and sorrows, preferences, motivations, inner realities and main obstacles, and psychosocial therapeutic needs. The categories presented as results of this study represent the multi-sensory benefits of VMI in the therapeutic setting with these children. The results show clearly that music is a motivator for participation in life. This will decrease the learned helplessness and restore the damaged self-image.

# Conclusion

*Participation is "the nature and extent of a person's involvement in life situations" (WHO, 1997).* Participation “includes the activities of personal maintenance, mobility, social relationships, education, leisure, spirituality, and community life.” (King, Law, King, Rosenbaum, Kertoy, & Young, 1999).

One of the main aims of psychosocial rehabilitation of children with CP is to help them to promote participation. Active participation is the key. Through participation children develop various skills and competencies, reach psychological and physiological challenges, accomplish mental and physical health, express themselves, and establish their own purpose in life. Participation is associated to better social and intellectual capability and to resilience (Werner, 1989). Contentment with various activities is a central interpreter of life happiness among adults with various physical disabilities and is linked with adjustment and over all well-being (Kinney & Coyle, 1992; Lyons, 1993; Brown & Gordon, 1987).

King, Law, King, Rosenbaum, Kertoy & Young (1999, 2005) and other literature (i.e. Anderson, & Clarke, 1982; Blum, Resnick, Nelson, & Germaine, 1991; Brown & Gordon, 1987; Cadman, Boyle, Szatmari, & Offord, 1987; Dempsey, 1991; LaGreca, 1990; Law, & Dunn, 1993;Lyons,1993) indicate that some of the most important factors to enhance participation may be to enhance children’s *feelings of competence*, to enhance their physical, cognitive, communicative, emotional, behavioral, and social functioning.

The results of this research project addressed the whole child with CP, not only their disability—offering new knowledge to rehabilitation teams, families, challenging social and musical barriers, and allowing ample opportunity for the child’s participation and creative development. The results show that the VMI enhances children’s feelings of competence. It also enhances their physical, cognitive, communicative, emotional, behavioral, and social functioning. It helped children with CP to see beyond their disabilities.

Keeping in mind the whole child, in music therapy it is standard to consider more than one area of benefit, both when assessing areas of need (Boxill, 1985), and designing music therapy programs (Davis, 1992; Bunt & Hoskyns, 2002; Wigram, Nygard, Pedersen & Bonde, 2002). This consideration is well suited to the clientele of Bloorview Kids Rehab, where the mandate includes addressing the unique individual in a family context. This study considered the following areas of potential benefit from music therapy: The VMI experience enhances participation and restores self-image of the child with Cerebral Palsy. Visual, auditory, kinesthetic, and self-awareness is developed and increased during the therapeutic process.

According to research results the VMI creates an environment that is developmentally appropriate and fosters active exploration and engagement, which is key to facilitating social-communicative skills, motor skills and kinesthetic abilities, cognitive development and socio-emotional growth. According to the child’s therapeutic needs the VMI can be used as a tool of music therapy but also as a tool of physiotherapy, occupational therapy, speech therapy and psychotherapy when working with the psychosocial and physiological rehabilitation needs of children with CP. Various theories, such as sensory integration theory, cognitive-behavioural theory, Winnicot’s psychotherapeutic approach, or Stern’s mother-baby interaction findings, can be applied as eclectic theoretical foundations of VMI rehabilitation.

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Dr. Roger Knox, Music Research Coordinator, Bloorview Kids Rehab, contributed to the preparation of the grant proposal and coordination of the budget.

This article explores the findings from the second research question only.

This article focuses on results generated on the second research question only.

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Results generated from the first research question discuss musical interventions in the following non-musical goal areas: **(1.) Motor and physical Skills** (1.1 Instructional Lyrics: Identification and/or emphasis of specific targets; 1.2 Enhancement of Physical Experience: Utilization of parallel musical elements such as up/down; 1.3 Theme Creation/Improvisation: Distillation of the whole person: creation of themes using various elements of music; 1.4 Repetition and/or Fragmentation of Music: Establishment or re-establishment of structure & Complimentary music to movement; 1..5 Pre-Composed Music: Relaxation & Encouragement of specific movement; 1.6 Hide & Seek: Imitation of contrasting elements, Motivation & Mastery; 1.7 Combination of "real" instruments and VMI: Enhancement of drum set & Use of jingle bells/egg shaker for grasp) **(2.) Communication, Speech, and Cognitive Skills** (2.1 *Receptive Communication:* 2.1.1 Instructional lyrics: Directions; 2.1.2 Musical interaction/conversation: "Is the child imitating what he is hearing?" "Does he understand me?"; 2.1.3 Pre-composed music: target actions; 2.2 *Expressive Communication;* 2.2.1 Enhancement of communication: reinforcement of expression or tone; 2.2.2 Musical Reflection: observation of client's actions/behaviour (therapist is saying "I see, hear, and accept you); 2.2.3 Theme Creation/Improvisation: distillation of the whole person: creation of themes using various elements of music, Repetition/fragmentation: can include vocal themes to distil anxiety, reference earlier material for integration or anticipation, or re-establishment of structure, Pre-composed music: for familiarity, trust, and relaxation, Hide & Seek: to establish non-verbal, humorous musical exchanges (mother/baby) & Character Development.) **(3.) Sensory and Auditory Skills** (3.1 Instructional Lyrics: Identifies specific target with emphasis, repetition, and lengthening of words; 3.2 Enhancement of Sensory/Auditory Skills: Utilization of Musical Element; 3.3 Theme Creation/Improvisation: Distillation of the moment of the whole person; 3.4 Repetition/Fragmentation: Re-establishing structure & Modelling target consonants/vowels; 3.5 Pre-composed Music: Sense of structure; 3.6 Hide & Seek: Mastery & Cause & effect; 3.7 Combination of "real" instruments & VMI: orientation.) **(4.) Socialization Skills** (4.1 Instructional Lyrics: Target action emphasized,Orientation to social structure, Sequencing events, transitions, turn taking & Leadership initiation; 4.2 Enhancement of socialization: Use of musical elements to emphasize social structure, direction, etc.; 4.3 Musical Conversation: Musical interactions that are based on client's expression building to a more complex musical environment; 4.4 Theme Creation: Distillation of the moment of the whole person; 4.5 Repetition/Fragmentation: Re-establishment of the structure; 4.6 Pre-composed Music: Familiarity, Trust & Structure; 4.7 Hide & Seek: Establishing non-verbal, humorous musical exchange (mother-baby).) **(5.) Psycho-Social and Emotional Skills** (5.1 Enhancement: Spotlight on the experience, Establishment of tone & Acknowledgement of feelings; 5.2 Musical Reflection: observation of client's actions/behaviour (therapist is saying "I see, hear, and accept you); 5.3 Musical Conversation: Reflection of child's feelings & Reflection of child's verbalizations in song writing, etc.; 5.4 Theme Creation/Improvisation: Distillation of the moment of the whole person; 5.5 Pre-composed Music: Exploration of feelings, Familiarity, Trust & Relaxation; 5.6 Hide & Seek: Establishing non-verbal, humorous musical exchange (mother-baby); 5.7 Empowerment or "being the boss"; 5.8 Character Development: Song writing, Improvisation, development of themes & Development of alternate personalities (the boxer, rock star, etc.): Song Writing: Original compositions, Song arrangements, Lyric replacement & Improvised song.) This article does not, however, explore these findings further but concentrates the results generated from the second research question.

This kind of holistic description "gives the what, when, where, and how, without the whys. It is concerned with discerning what constitutes the phenomenon"(Bruscia, 2005, p. 89).

Grounded theory “is a general approach of comparative analysis linked with data collection that uses a systematically applied set of methods to generate an inductive theory about a substantive area. It’s purpose is to discover theory from data (Glaser & Strauss, 1967, p. 1). The researcher focuses on one area of study, gathers data from a variety of sources such as interviews and field observations, and analyzes the data using coding and theoretical sampling procedures. (Glaser & Strauss,1967, pp. 22-23)” (Amir, 2005, p. 365)

Narrative Inquiry “creates an intersubjective space that reflects a dynamic relationship between researcher, the context of research, and the reader.” (Bruner, 1986 cited in Kenny, 2005, p. 416). It “… is hermeneutic in nature because it is contingent upon the perception and interpretation of the researcher. The writer/researcher selects aspects of a narrative to highlight elements of a research context in order to portray a holistic picture of research participants, issues, and settings. “ (Kenny, 2005, p. 416). The narrative inquiry was used to capture the essence of multiple case studies and the core category and illustrate it in the form of narrative.

The field notes included reactions, thoughts, and analyses either during or after the sessions, and were transcribed.

The ethical review was accepted both by the Wilfrid Laurier Ethics Committee and the Bloorview Research Institute Ethical review board.

The Occupational Therapist was issued an instruction sheet directing her to read a case study, and then observe selected video excerpts for each participant. The Occupational Therapist was then asked to describe beneficial outcome areas of the VMI in the music therapy setting. Any additional comments were welcomed. There were no restrictions for video and/or case study access.

Dr. H. Ahonen-Eerikäinen and A. Lamont

The names assigned are pseudonyms.

For various reasons Maddie attended only 50% of the scheduled session.

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# Psychosocial Correlates in Adolescent Children of Alcoholics-Implications for Intervention

(A Study From India)

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## Abstract

**Introduction:** There has been an increasing focus on children of alcoholics particularly in the West seeking to understand the impact of parental alcoholism on their psychosocial functioning. Indian literature from this perspective is scanty and there is a need for more comprehensive investigation particularly with adolescent children of alcoholics (COAs).
**Objectives**: This comparative study investigated the manifestation of self-esteem and adjustment in a group of fifty adolescent children of alcoholics (COAs) and a matched reference group of adolescent children of non-alcoholics (nCOAs). MATERIAL & METHOD: The Self esteem Index (Mac Kinnon, 1981) and Adjustment Inventory (Srivatsa and Tiwari, 1972) were the instruments administered. An ex-post facto research design was used. Chi square, t-tests and Karl Pearson's correlation coefficients were computed using SPSS for analysis.
**Findings:** The data revealed lower self-esteem and poor adjustment in all domains studied, in the adolescent COAs than the controls. These deficits can be attributed to the increased stress and vitiated alcohol complicated domestic environment of the COAs.
Clinical Implications: This study makes a strong case for psychosocial intervention with COAs who are otherwise neglected in conventional de-addiction programmes in India.

**Key Words**: Adolescent Children of Alcoholics, Self-esteem, Adjustment.

## Introduction

There is a vast body of literature both in India and the West devoted to understanding the marital dynamics involved in alcoholism and ascertaining the deleterious impact that alcoholism could have on the personality and functioning of the spouse. Traits such as neuroticism, higher anxiety levels, depression, low self-esteem and communication apprehension have been reported in wives of alcoholics and attributed to the intense stress and trauma experienced by her in the vitiated domestic environment that she lives in (e.g. Stanley, 2001; Kutty and Sharma, 1988; Rao and Kuruvilla, 1991). Higher levels of marital conflict and aggression have been also documented in couples with an alcoholic spouse when compared to marital relationships which were not complicated by alcohol (Stanley, 2006; Stanley & Anitha, 2007). Of late there has been an increasing focus on children of alcoholics seeking to understand the adverse impact of parental alcoholism on their growth and psychosocial functioning. Indian literature from this perspective is scanty and there is a need for more comprehensive investigation to explore the consequences of parental alcoholism particularly on adolescent children.

Adolescence has been globally accepted to be a period of turbulence and a significant developmental milestone. Parental alcoholism could further compound and create a not so conducive domestic environment significantly impacting the adjustment and personality of the adolescent as he tries to come to grips with this tumultuous phase in his developmental career.

There is strong evidence to suggest that family dysfunction during childhood can negatively influence later life experiences and adjustment (Werner and Broida, 1991). Drinking behavior may interrupt normal family tasks, cause conflict and demand adjustive and adaptive responses from family members who do not know how to appropriately respond. In brief, alcoholism creates a series of escalating crises in family structure and function, which may bring the family to a system crisis. As a result, the members may develop dysfunctional coping behaviors observes Ranganathan (2004). Marital conflict and a lack of coping mechanisms were more frequent in these families and children of alcoholic (COAs) fathers represent a group at risk for the early onset of psychiatric problems observe Furtado et al. (2002).

Roosa et al. (1990), report that COA status was related to higher levels of negative and lower levels of positive events. Hall and Webster (2002) found that adult COAs had more self-reported stress and more difficulty initiating the use of mediating factors in response to life events. More COAs than comparison offspring were experiencing serious problems in the areas of drinking, personality and psychopathology (Casas-Gil and Navarro-Guzman, 2002) and Harter (2000), notes that adult COAs appear at increased risk for a variety of negative outcomes, including substance abuse, antisocial or under-controlled behaviors, depressive symptoms and anxiety disorders.

Sher et al. (1991), found that COAs reported more alcohol and drug problems, had stronger alcohol expectancies, higher levels of behavioural under-control and neuroticism, and more psychiatric distress in relation to nCOAs. Bird and Canino (1991), also found that children of alcoholics when compared to those of non-alcoholics manifested higher levels of behavioural under control, more neuroticism and greater psychiatric distress. Hall et al. (1994), report that adult COAs had lower life satisfaction scores and significantly lower levels of locus of control than nCOAs. Their academic performance is relatively poor (Miller and Krop, 1985) and Casas-Gil and Navarro-Guzman (2002) have identified five variables on which performance by children of alcoholic parents was poorer: intelligence, repeating a grade, low academic performance, skipping school days, and dropping out of school.

The dysfunctional family environment created due to the presence of parental alcoholism has been the focus of several investigations. A recent study by Kelley et al. (2007), reveals that adult children of alcoholics reported more parentification, instrumental caregiving, emotional caregiving, and past unfairness in their families of origin as compared to children of alcoholics. Williams and Corrigan (1992), comment that growing up in a household with alcoholic parents is more likely to produce emotional disorders, increases the child’s risk of health problems, physical abuse and neglect. The single most potent risk factor is their parent's substance-abusing behaviour and this can place children of substance abusers at biologic, psychological, and environmental risk (Johnson and Leff, 1999). Menees and Segrin (2000) observe that COAs are characterised as an at risk population because of the dysfunctional family environment that disrupts their psychosocial development. They often lack guidance and positive role modelling and live in an atmosphere of stress and family conflict. Obot and Anthony (2004), found evidence to favour the hypothesis that adolescent children living with an alcohol dependent parent have more delinquency problems than other adolescents. Mylant et al. (2002) found that adolescent COAs scored significantly lower on all psychosocial factors of family/personal strengths and school bonding and significantly higher on all factors of at-risk temperament, feelings, thoughts, and behaviours than non-COAs and that they were at risk for depression, suicide, eating disorders, chemical dependency, and teen pregnancy.

Hart et al. (2003) interpreted their results as providing partial and preliminary support for the contention that living in an alcoholic environment during childhood and adolescence plays a role in the manifestation of serious medical problems in adulthood. Findings from a longitudinal study by Andreas & O'Farrell (2007) show that fathers' heavy drinking patterns and children's psychosocial problems appear to be closely related to one another over time, waxing and waning in meaningful patterns, such that children's adjustment was improved during times of parental alleviated drinking and was worsened during times of parental exacerbated drinking. Their results thus add additional support to the hypotheses of causal linkages between problematic parental and problematic child functioning.

It is well established that children of problem drinkers have an increased risk of developing mental health problems, not only during childhood but also when they grow up into adolescents and adults observe Cuijpers et al (2006). Children of alcoholic fathers are at high risk for psychopathology and gender-related differences also seem to exist contend Furtado et al. (2006). Depression and anxiety are recurring themes in the literature on COAs (e.g. Callan and Jackson, 1986; Williams and Corrigan, 1992; Steinhausen, 1995; Kelley, 1996; Deborah,1997) However, Reich et al. (1993), report that though children of alcoholics exhibit high rates of psychopathology and may be at risk specifically for oppositional and conduct disorders, they may be not so for depression. Behavioral problems in adolescence have been shown to be associated with the presence of a positive family history of alcoholism and negative parenting practices (Barnow et al., 2004). Jacob and Windle (2000) are of the view that risks for COAs might relate specifically to parental alcoholism and its impact on offspring development and not to the combined effects of various parental psychopathologies and/or extreme forms of family instability. Exposure to marital conflict is associated with children's adjustment problems, including internalization and externalization (Cummings et al., 2000) and the results of Keller et al. (2005) indicate that problem drinking may harm children through its association with marital and parenting difficulties.

However, there is a contention within the alcoholism literature pertaining to children of alcoholics that holds that they manifest no significant differences in terms of psychopathology or other behavioural and personality deficits when compared to children of non-alcoholics. Segrin and Menees (1996), opine that children may exhibit undisturbed psychosocial functioning despite having an alcoholic parent and found no differences between adult children of alcoholic's and controls. Baker and Stephenson (1995), suggest that parental alcoholism does not necessarily result in personality differences in adult children. Morey (1999), found that COAs and nCOAs demonstrate no significant differences on measures of social support and shame while Reich et al. (1993), report few differences between children of alcoholics and controls with respect to self-esteem and achievement tests. Harter (2000) observes that there is little empirical support for "adult COA syndromes" described in the clinical literature since the reported outcomes in them are neither uniformly observed nor are specific to them. He contends that co-morbid parental pathology, childhood abuse, family dysfunction, and other childhood stressors may contribute to or produce similar outcomes.

The brief review of the literature in the field reveals that while a lot of investigations have been carried out with adult children of alcoholics, those with a specific focus on adolescent children are not many. Further there is a dearth of exploration carried out on this issue in the Indian socio-cultural context. This investigation was carried out against this background primarily from the stress perspective associated with co-dependency, which hypothesizes that the heightened stress of living in an alcohol complicated family environment could have adverse consequences on the personality traits of adolescent children and manifest deficits in their psychosocial functioning.

# Objectives

- To study and compare the self-esteem and adjustment in adolescent children of alcoholics (COAs) and those of non-alcoholics (nCOAs).
- To bring out the association if any between socio-demographic factors and the subject dimensions studied.
- To study the relationship if any among the subject dimensions.
- To discuss implications for therapeutic intervention with adolescent COAs and their families in the light of the results obtained.

# Material and Methodology

## Sample and Selection Procedure

### Study Group

The study group consisted of 50 respondents whose fathers were receiving de-addiction treatment at a private psychiatric hospital in Tiruchirappalli, India. Only adolescents between the age group of 13 and 18 years and who were residents of Tiruchirappalli were included in the sample. Their father was registered for in-patient treatment after being diagnosed by the psychiatrist according to ICD-10.

Children of relapsed or recovering alcoholics visiting the de-addiction centre for follow-up services were excluded.

### Reference Group

50 nCOAs were identified from the schools of the study group respondents through their teachers. A child was included in the reference group only if the father did not have a known drinking habit and if the father scored less than seven (indicating non-alcoholic status) on the AUDIT (Alcohol Use Disorders Identification Test; Babor et al., 1983) and if the child had no known history of psychiatric illness. The two groups of respondents thus identified were comparable and matched on the following variables (Table I):

**TABLE I**
**AGE, BIRTH ORDER & FAMILY INCOME OF THE RESPONDENTS**

| S. No | Group |  | S.D. | Statistical* Inference |
|---|---|---|---|---|
| 1 | Age |  |  |  |
|  | nCOA | 14.44 | 0.95 | t = 0.78 |
|  | COA | 14.26 | 1.33 | P > 0.05 |

| | | | | |
|---|---|---|---|---|
| 2. | Birth Order | | | |
| | nCOA | 1.74 | 0.85 | t =1.18 |
| | COA | 1.94 | 0.84 | P > 0.05 |
| 3 | Monthly Family Income **(Rupees per month)** | | | |
| | nCOA | 5508.00 | 2518.57 | t =0.306 |
| | COA | 5368.00 | 2022.87 | P > 0.05 |

*** df = 98**

The choice of same school respondents as the COAs also ensured a near homogenous socio-economic profile for both groups. Their socio-demographic profile is presented in Table No. II and the chi-square values indicate that the difference between the two groups is not significant and that they are also comparable on the variables tabulated.

**TABLE II**
**SOCIO DEMOGRAPHIC BACKGROUND OF RESPONDENTS**

| DIMENSION | CATEGORY | Group | | Total % | **STATISTICAL SIGNIFICANCE |
|---|---|---|---|---|---|
| | | *nCOA | *COA | | |
| **Sex** | Male | 23(46) | 20(40) | 43 | $X^2$ =0.367 |
| | Female | 27(54) | 30(60) | 57 | df=1 |
| **Domicile** | Urban | 9(18) | 17(34) | 26 | $X^2$ =3.407 |
| | Rural | 20(40) | 15(30) | 35 | df=2 |
| | Semi-urban | 21(42) | 18(36) | 39 | |

| | | | | | |
|---|---|---|---|---|---|
| **Type of Family** | Nuclear | 41(82) | 34(68) | 75 | $X^2$ =2.613 |
| | Joint | 9(18) | 16(32) | 25 | df=1 |
| **Fathers Occupation** | Govt employee | 15(30) | 13(26) | 28 | $X^2$ =1.810 |
| | Private | 12(24) | 18(36) | 30 | df=3 |
| | Business | 16(32) | 14(28) | 30 | |
| | Self employed | 7 (14) | 5(10) | 12 | |
| **Medium Of Instruction** | English | 29(58) | 20(40) | 49 | $X^2$ =3.241 |
| | Tamil | 21(42) | 30(60) | 51 | df=1 |

***Figures in parantheses are percentages***
***n=50, **p > 0.05**

## Research Design

This is a comparative study based on the presumption that the effect if any, of living with an alcoholic (study group) or non-alcoholic (reference group) father would have already manifested itself on both groups of respondents. The groups being matched on key socio-demographic variables, the study is only an attempt to determine and compare the levels of self-esteem, and adjustment manifested in these children at the point of data collection. This quasi-experimental study thus uses an ex-post facto research design.

## Tools of Data Collection

1. Self Esteem Index (SEI, Mac Kinnon, 1981) assesses an individual's perception of himself – his potential, worth and competence. It is a twenty-five item five point scale with responses ranging from "strongly agree" to "strongly disagree" and has been widely used for research in India in a variety of settings.

2. Adjustment Inventory (Srivatsa and Tiwari, 1972)
Adjustment inventory is an 80 item, two point scale with yes or no responses and measures four dimensions of adjustment namely:
Home adjustment, Educational adjustment, Emotional and Social adjustment.

3. Self Prepared Interview Schedule to elicit information pertaining to socio-demographic background and father's drinking.

# Results

## Perception of Father's Drinking

Forty per cent of the COAs reported daily drinking by their father while forty two per cent said it was on alternate days, the remaining were not sure of the frequency of drinking.

Regarding the duration of drinking, forty per cent said it was up to three years with the remaining respondents mentioning that it was between three and ten years.

With regard to the behaviour of the father when intoxicated, fifty four per cent said that he became more silent than usual, twenty six per cent said that he became boisterous and shouted at others while the remaining twenty per cent expressed that he scolds and beats up the family members.

**TABLE III**
**MEAN SCORE PROFILE OF RESPONDENTS ON SUBJECT DIMENSIONS**

| S.No. DIMENSIONS | | CHILDREN OF | | STATISTICAL* * SIGNIFICANCE |
|---|---|---|---|---|
| | | Alcoholics * | Non-alcoholiCS * | |
| 1. **SELF-ESTEEM** | MEAN | 81.10 | 97.26 | t =11.41 |
| | SD | 6.60 | 7.53 | **p <0.01** |
| 2. **OVERALL ADJUSTMENT** | | | | |
| | MEAN | 119.88 | 138.28 | t =12.21 |
| | SD | 8.66 | 6.21 | **p <0.01** |
| a. **HOME ADJUSTMENT** | | | | |
| | MEAN | 29.36 | 35.26 | t = 10.29 |
| | SD | 3.38 | 2.24 | **p <0.01** |
| b. **EDUCATION** | | | | |
| | MEAN | 17.36 | 19.66 | t =4.95 |
| | SD | 1.66 | 2.83 | **p <0.01** |
| c. **EMOTIONAL ADJUSTMENT** | | | | |
| | MEAN | 32.08 | 36.08 | t = 7.85 |
| | SD | 2.33 | 2.74 | **p <0.01** |
| d. **SOCIAL ADJUSTMENT** | | | | |
| | MEAN | 40.94 | 47.38 | t = 8.70 |
| | SD | 4.07 | 3.29 | **p <0.01** |

***n = 50; ** df = 98**

## Self Esteem

Data presented in Table No. III show that the two groups of respondents manifest a high statistically significant difference on the scores of this dimension with the children of alcoholics obtaining a lower mean score indicative of poorer self esteem than children of the reference group.

Further it was seen in this study that the self-esteem scores did not show any significant correlations with the age of the child ($r = 0.15$, $p > 0.05$) or his birth order ($r = 0.15$, $p > 0.05$). However a negative correlation was obtained between the self-esteem scores and the number of siblings of the respondent child ($r= - 0.30$, $p <0.01$).

## Adjustment Profile

The data in table III reveals that COAs have obtained lower mean scores on overall adjustment as well as all its component sub-dimensions (Home Education, Emotional and Social adjustment) than the respondents of the reference group and that the difference between them is statistically significant.

## Self Esteem and Adjustment

The self-esteem scores showed a highly significant positive correlation with the overall adjustment score ($r= 0.68$, $p<0.01$) and also with all its component sub-dimensions namely, home adjustment ($r= 0.65$, $p<0.01$), education ($r= 0.42$, $p<0.01$) as well as emotional ($r= 0.59$, $p< 0.001$) and social adjustment ($r= 0.52$, $p<0.01$). It is significant to observe that all the correlations are positive in nature. Though a cause-effect relationship cannot be read into this finding, each dimension studied can be expected to directly influence the other.

# Discussion

The low self-esteem scores obtained by the study group respondents according to Mac Kinnon (1981), indicates feelings of unhappiness with oneself and feelings of not being competent. It reflects a sense of alienation and feelings of meaninglessness and failure.

Cole et al. (1980), observe that emotional maturity manifests in high self-esteem and enhances one's interpersonal ability. Thus the low self-esteem seen in COAs is indicative of poor emotional maturity and may diminish their interpersonal competence. This perhaps is reflected in the poor adjustment scores obtained by the COAs across several domains seen in this study.

The findings of this study do not agree with that of Churchill et al. (1990), who found no significant relationship between parental alcoholism and self-esteem of their children. In contrast, the results are congruent with that of Morey (1999), who reports that self-esteem ratings for COAs were significantly lower in comparison to ratings for nCOAs. Domenico and Windle (1993) also observe that ACOAs reported higher levels of depression and lower levels of self-esteem. In a recent study Hussong and Chassin (2004), found that children of alcoholics showed a statistically significant difference in their emotional and behavioural aspects such as shyness, insecurity and low self-esteem. Williams and Corrigan (1992), observe that growing up in a household with alcoholic parents is likely to produce low self- esteem and Harter (2000) has also reported low self esteem in ACOAs. Drucker and Greco-Vigorito (2002) observe that five separate factors related to Negative Self-concept, Acting-out. Somatic/Disturbed Symptoms, Mood, and Hopelessness and that depressive symptoms displayed by children of substance abusers are related to self-concept and externalization.

The finding of poor adjustment across all domains studied in COAs is consistent with the literature on this issue. Harter (2000), reports that COAs faced difficulties in family relationships, and experienced generalized distress and maladjustment. Hall and Webster (2002) found that ACOA had more symptoms of personal dysfunction than the control group while Casas-Gil and Navarro-Guzman (2002) report that more COAs than comparison offspring were experiencing serious problems in the areas of educational and social functioning. Sher et al. (1991) observe that COAs also evidenced lower academic achievement and less verbal ability than nCOAs. Lower quality of life scores in children of alcoholics has been reported in another study by Oravecz (2002).

Haugland (2003), also reports that children of alcohol abusing fathers were found to have more adjustment problems compared to a general population sample. His findings further suggested that child adjustment in families with paternal alcohol abuse is the result of an accumulation of risk factors rather than the effects of the paternal alcohol abuse alone. Both general environmental risk factors (psychological problems in the fathers, family climate, family health and conflicts) and environmental factors related to the parental alcohol abuse (severity of the alcohol abuse, the child's level of exposure to the alcohol abuse, changes in routines and rituals due to drinking) were related to child adjustment. Adult children of alcoholics have reported more parentification, instrumental caregiving, emotional caregiving, and past unfairness in their families of origin as determined by Kelly et al. (2006). Thus the alcohol complicated domestic environment of the COAs could account for the deficits in self esteem and adjustment seen in them in this study and these findings are in consonance with the bulk of the western literature on these issues.

# Implications for Psychosocial Intervention

The findings of this study have definite implications for intervention in de-addiction settings. It highlights the fact that any effective de-addiction programme must acknowledge the 'need' of adolescent children to overcome and deal with various deficits in their psychosocial functioning. The involvement of children in most de-addiction programmes in India is often peripheral if not totally non-existent. De-addiction counsellors tend to concentrate more on the alcoholic in enabling him overcome his psychological problems and in preparing him to lead a life without alcohol. While the spouse is frequently involved for marital therapy, conflict resolution and antabuse compliance, the therapeutic needs of children trapped in such families are most often ignored.

It is therefore important that the therapeutic needs of these children are addressed through individual psychotherapy and other supportive therapies by providing an opportunity for ventilation of feelings and integrating elements that will boost their self esteem and promote their psychosocial adjustment in deficient areas. Normal difficulties and dilemmas associated with adolescence in general could be worked through in these sessions besides focusing on issues pertaining to parental alcoholism. A study from Korea reports that stress management program helps children of alcoholics by enhancing self-esteem, providing information about alcohol, and improving emotional and problem focused coping abilities, eventually enhancing their mental health (Yang and Lee, 2005). Hence stress management techniques and relaxation modalities could be an important component of working with COAs.

There is evidence to indicate that children show a considerable improvement on various domains when their alcoholic fathers undergo treatment. Andreas et al. (2006), have found that before their fathers' treatment, COAs exhibited greater overall and clinical-level symptomatology than children from a demographically matched comparison sample, but they improved significantly following their fathers' treatment. An effective package to overcome alcoholism should go beyond routine pharmacotherapy and individual psychotherapy for patients. A wholistic intervention package must involve other therapeutic adjuncts such as family therapy, couples therapy for not only the spouse but also the COAs. O'Farrell and Fals-Stewart (2002), have advocated Behavioural Couples Therapy (BCT) since it has been found to reduce social costs and domestic violence and showed indirect benefits for the couple's children, and so BCT ought to be expanded to include family members other than spouses, particularly the COAs. O'Farrell and Feehan (1999), note that BCT with alcoholics and remission after individual alcoholism treatment have been associated with improved family functioning in a variety of domains, including reduced family stressors; improved marital adjustment; reduced domestic violence and verbal conflict; reduced risk of separation and divorce; improvement in important family processes related to cohesion, conflict and caring; and reduced emotional distress in spouses. These family factors have been linked with child mental health and psychosocial functioning in more general child developmental and psychopathology studies. Gains for COAs will hence accrue if they are involved in family therapy sessions. This will facilitate opening up of communication channels and resolution of conflicts within the family and thereby enhance the domestic and emotional adjustment of the children. Ranganathan, (2004), observes that it is imperative to involve family members in treatment and that family therapy ought to be specific, with attainable therapeutic goals.

Children of alcoholic fathers represent a group at risk and are deserving of more attention in prevention and early intervention (Furtado et al., 2002). Erblich et al. (2001) contend that since COAs themselves are at particularly high risk for developing drinking problems, early intervention efforts among COAs need to be initiated. Some of the guidelines that they stress include emphasising the negative consequences of alcohol, developing in youth an increased sense of responsibility for their own success, helping them to identify their talents, motivating them to dedicate their lives to helping society rather than feeling their only purpose in life is to be consumers, providing realistic appraisals and feedback for youth rather than graciously building up their self-esteem, stressing multicultural competence in an ever-shrinking world, encouraging and valuing education and skills training, increasing cooperative solutions to problems rather than competitive or aggressive solutions, and increasing a sense of responsibility for others and caring for others (Kumpfer and Hopkins, 1993). An affectionate father-child bond has a protective effect observe Brook et al. (2003) and so an important focus during the course of family therapy is to strengthen the intimacy between the parent and child, particularly with the alcoholic father since it is likely that these bonds are already exacerbated due to the so called “generation gap”. It is also necessary to confront parents with the effects of their behaviour (intervention, therapy) to develop their possibilities to renovate their parenting functions, which is necessary for effective prevention observes Wojcieszek (2003).

Nespor (2004) holds that prevention at the family level includes appropriate family monitoring and rules, moderate and consistent family discipline and family conflict resolution. Kumpfer et al. (2003), hold that since "substance abuse" is a "family disease" of lifestyle, effective family strengthening prevention programs should be included in all comprehensive substance abuse prevention activities. They advocate dissemination of five highly effective family strengthening approaches (e.g., behavioural parent training, family skills training, in-home family support, brief family therapy, and family education).

Currently, many COAs remain unidentified within schools and may not be receiving the counselling services that they deserve and require. The family dysfunctionality of such children places them at high risk for adverse academic, physiological, emotional, and social consequences observe Lambie and Sias, (2005). It then becomes an important task for the school counsellor to identify such children in distress and to provide them with supportive services besides intervention with families to the extent possible. Knowledge of fathers' alcohol use and its time of onset may be used to determine children who are at added risk of problematic alcohol use later in life and so special guidance, support and treatment can be targeted to these families observe Seljamo et al (2006). In the Indian scenario where the majority of schools do not have a professional counsellor, this important task needs to be addressed by teachers who are in a position to identify such children.

While groups such as ‘Alateen’ function for COAs in the West, such therapeutic self help groups for COAs in the Indian setting are woefully lacking and must be initiated. The common intervention foci for such groups should according to Emshoff and Anyan (1991), include information on alcohol and alcoholism, the dynamics of alcoholic families, common social and emotional reactions (e.g., embarrassment, loneliness, guilt, depression, anger), skill building (e.g., problem solving, communication, expression of feelings), coping strategies for living in an alcoholic home, and general social and emotional support. Kuhns (1997), observes that both group psychotherapy and self-help groups for COAs were effective in decreasing levels of depression while Kingree and Thompson (2000), found that participation in the mutual help group promoted perceived status benefits, which in turn led to reductions in depression and substance use. The need to strengthen the social support available to such children has been highlighted by Werner and Johnson (2004) who’s data showed that individuals who coped effectively with the trauma of growing up in an alcoholic family and who became competent adults relied on a significantly larger number of sources of support in their childhood and youth than did the offspring of alcoholics with coping problems.

Intervention with COAs must hence involve resolution of individualised issues pertaining to adolescence as well as parental alcoholism. Elements to enhance their self esteem and adjustment across various domains need to be consciously included besides involving them in family therapy sessions. Strengthening their social support systems, fortifying familial bonds besides facilitating their participation in self help groups comprising of other COAs, could go a long way in enhancing their mental health. These efforts must be concurrently initiated along with other therapeutic procedures that focus on the alcoholic per se.

# Conclusion

This study has revealed that the majority of COAs manifest lower levels of self-esteem and a lesser degree of adjustment than nCOAs. The two groups of respondents were matched on key socio-demographic variables and the alcoholism of the father of the study group subjects was a major differentiating factor between the two. The author against this background is inclined to concur with the proponents of the stress perspective on co-dependents of alcoholics as the data of this study indicates that the stressful and vitiated domestic environment prevalent in alcohol complicated familial relationships is responsible for the low self-esteem and deficient adjustment seen in adolescent children of alcoholics. There is hence an imperative need for therapeutic intervention with this population. The need of the hour is to develop programmes for COAs with a strong focus on strengthening resilience in them and to inculcate desirable personality traits and enhance their psychosocial functioning through appropriate psychotherapeutic procedures. This study underscores the point that co-dependent adolescent children of alcoholics also merit therapeutic intervention owing to the various deficits in psychosocial functioning manifested in them.

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# Peer Specialists and Carer Consultants Working in Acute Mental Health Units: An Initial Evaluation of Consumers, Carers, and Staff Perspectives

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## Abstract

The purpose of this project was to evaluate the impact of introducing Peer Specialists (PS) and Carer Consultants (CC) as employees in the targeted acute units of CNAHS. A random sample of 30 consumers and 25 carers completed questionnaires as did 58 volunteer pre-existing staff members and 12 newly employed PS and CC. To provide further information, appointed PS and CC mentors also participated in a discussion group. Overall, data indicated that the employment of PS and CC was positively associated with various consumer, carer, organisational, and personal gains. Reported issues are consistent with existing literature and such information is being used to direct future endeavours and positively reorient existing systems.

***Keywords:*** Mental Health, Peer Specialist, Carer Consultant, CNAHS

## Introduction

The effective delivery of mental health services continues to evolve and services often experience both structural and cultural shifts. In Australia and many other countries, the trend to integrate consumers and carers into the development, implementation, delivery, and evaluation of mental health services is articulated through ongoing policy changes (Australian Health Ministers, 1992, 1998, 2003; Commonwealth of Australia, 1997, National Mental Health Working Group, 1996). Furthermore, it is evident that consumers demonstrate an ongoing desire to have greater representation and involvement in all aspects of mental health service provision (Berger, Carter, Casey. & Litchefield, 1996; Meehan, Bergen, Coveney & Thornton, 2002; Connor 1999).

Minimal research has been conducted in the developing area of consumer and/or carer inclusion on acute units. However, an expanding literature consistently indicates that service provision can be improved with the addition of such, "lived experience" staff. An increasing number of people who experienced or continue to experience episodes of mental illness are successfully working as trained staff (e.g., Peer Specialists) within mental health areas. The unique insight gained through being a former client of mental health services is potentially valuable and associated with numerous positive consumer, organisational, and personal, gains (Lawrence, 2004; McAllistster & Walsh, 2004). Research indicates a positive correlation between involvement with a Peer Specialist and gains in both consumer welfare (Soloman, 2004; Voelker, 1994) and the mental health delivery system (Soloman, 2004).

Additionally, research evidence suggests that carer involvement (e.g., Carer Consultants) in the workforce is beneficial to the consumers they are working with, the employing organisations, and to the individuals themselves. For example, the Mental Health Branch, Victorian Government Department of Human Services reported that the involvement of carers in mental health services contributed to overall improvements in consumer's treatment adherence, quality of life, social adjustment, family functioning, and periods of wellness (2004).

Although the additional benefits of employing the services of consumers and carers are evident, researchers have also identified particular barriers that impede effective consumer and carer participation. Such barriers include the negative attitudes of pre-existing professional staff members (Gordan 2005; Happell & Roper, 2006. Lammers & Happell, 2004) and insufficient training/support for newly employed consumers and/or carers (Happell & Roper, 2006; Middleton, Stanton, & Renouf, 2004; Roper, 2003). Research evidence also suggests that consumers may lack the unique knowledge and skills set required of mental health care staff (Campbell, 1990; Miller & Katz, 1992; Pyke et al, 1991). However, such a barrier can be overcome with adequate training and studies also reported that the psychological well-being of appropriately trained consumers providing acute services was not adversely impacted (Meehan, Bergen, Coveney, & Thornton, 2002).

Literature continues to explore strategies for overcoming barriers to consumer and carer participation in service delivery and new mental health initiatives continue to expand service provision to include such strategies. In 2006 as a new mental health service innovation, Central Northern Adelaide Health Service (CNAHS) employed Peer Specialists and Carer Consultants into each permanent acute unit within the region (i.e., Cleland and C3 in the East, 1G and Woodleigh House in the North and Cramond Unit in the West) and several state-wide specialist services (e.g., Forensic).

The general purpose of the current report was to evaluate the impact of introducing Peer Specialists and Carer Consultants as employees on the targeted acute units within CNAHS. The specific aims were to evaluate the impact of newly employed Peer Specialists and Carer Consultants on consumers and carers and to gauge any pre- to post-employment perceptual shifts among existing staff and newly employed Peer Specialists and Carer Consultants.

# Method

## *Participants*

Participants included consumers and carers, pre-existing staff, newly employed staff, and their mentors. To assure anonymity at time of participation, specific demographic details were not obtained from volunteers.

A random sample of 30 consumers and 25 carers who utilised acute services of the targeted units were invited to complete a questionnaire during telephone contact. Each Peer Specialist and Carer Consultant maintained client contact sheets and members of the research team obtained such records at 6-months post-employment for each new staff member. Thus, consumer and carer participants were drawn from a 2-week time period either side of the respective 6-month post-employment client contact pool. The required pool of participants required for adequate research power was based on in-patient and discharge statistics reported by the Clinical Evaluation Unit and the Clinical Nurse Consultants of each targeted acute unit.

Additionally, prior to the formal introduction of the newly employed Peer Specialists and Carer Consultants, 58 pre-existing staff members working on the targeted acute units volunteered to complete pre-questionnaires. For various reasons (e.g., staff absences, resignations) 46 pre-existing staff members completed post-questionnaires. A broad range of professionals participated from each unit (e.g., Psychiatrists, Nurses, Occupational Therapists, Psychologists, and Social Workers).

After screening and interviewing of applicants, the newly employed Peer Specialists and Carer Consultants attended various training and induction workshops (e.g., 2-day Helen Glover Recovery Workshop, 3-day Orientation to CNAHS Workshop). At the time of writing, such staff were reported to continue with ongoing training and development since being employed (e.g., Certificate 3 in Mental Health: Non-Clinical, additional Helen Glover workshops). Twelve of the new employees completed both pre- and 6-month post-employment questionnaires.

Finally, Peer Specialists and Carer Consultants also had a respective staff mentor appointed by Carers SA and Baptist Community Services (i.e., non-government organisations supporting the current initiative). Both mentors were involved in the process of recruiting, training, and sustaining the newly employed staff. Broadly, both mentors conducted monthly small groups with staff to discuss their experiences, associated feelings and issues. However, they were also available for individual support.

Specifically, the mentor program for Carer Consultants commenced with and sustained a strongly educational approach and provided high levels of information on new resources and programmes available to carers. The initial mentor program for Peer Specialists focused on problem solving and support in a group format however evolved to one-on-one mentoring. At approximately six months post-employment of Peer Specialists and Carer Consultants, the appointed mentors participated in an hour-long discussion focus group coordinated by a member of the research team.

### *Design*

The current project utilised a pre- and post non-experimental design. Information was gathered from consumers, carers, and staff mentors at approximately 6-months post-commencement of duties for Peer Specialists and Carer Consultants.

Pre-existing staff and newly employed Peer Specialists/Carer Consultants completed questionnaires prior to the commencement of the new staff's ward duties and then again at approximately 6-months post. All relevant ethics committees approved the current project there are no disclosures to be made.

### *Measures*

*Consumers and Carers Questionnaire.* This purpose designed 14-item, telephone conducted questionnaire was used to ascertain consumers and carers perceptions regarding their experiences with either Peer Specialists or Carer Consultants while utilising the services of their respective acute unit. Distinct forms were used to gather information from consumers (e.g., *"How good was the Peer Specialist at increasing your sense of hope for recovery"*) and carers (e.g., *"How good was the Carer Consultant at reducing your distress by sharing their coping strategies"*) where 0 = *very poor*, 4 = *very good*. Two open-ended questions invited qualitative data regarding perceived unique contribution of such staff and suggestions for improving such services.

*Pre-existing Staff Questionnaire.* This purpose designed 20-item, self-report measure was used to gauge participant's perceptions regarding the introduction of Peer Specialists and Carer Consultants as employees of acute units within CNAHS. Two forms of this questionnaire were used prior to induction (e.g., *"Peer Specialists will foster hope for recovery in consumers"*) and again at approximately 6-months post-induction (e.g., *"Peer Specialists foster hope for recovery in consumers"*.) where 1 = *totally disagree*, 10 = *totally agree*. Four open-ended questions invited qualitative data regarding perceived benefits, difficulties, potential resolutions, and additional comments.

*Newly Employed Peer Specialists and Carer Consultants Questionnaire* This purpose designed 18-item, self-report measure was used to gauge participant's perceptions regarding the introduction of Peer Specialists and Carer Consultants as employees within acute units. Two forms of this questionnaire were used prior to commencing ward duties (e.g., *"Carer Consultants sharing their strategies will reduce carer distress"*) and again at approximately 6-months post commencement of unit duties (e.g., *"Carer Consultants sharing their strategies reduces carer distress"*) where 1 = *totally disagree*, 10 = *totally agree*. Four open-ended questions invited qualitative data regarding perceived benefits, difficulties, potential resolutions, and additional comments.

## *Procedure*

Depending on the medium of contact (i.e., face-to-face, telephone), potential participants were provided with either a letter of introduction or a verbal report that detailed the aims of the current study and advised of ethics approval from relevant bodies. All potential participants were ensured of confidentiality, advised that participation was voluntary, and that they could discontinue at any time.

### *Consumers and Carers.*

Both the Peer Specialists and the Carer Consultants maintained contact records in regards to the consumers and carers they worked with. From such records, a random sample of potential participants was collated from a two-week block either side of the 6-months post-employment period for each new staff member. Consumers and Carers were contacted via telephone and invited to verbally respond to a questionnaire.

### *Pre-existing Staff.*

Prior to commencement of unit duties for newly employed Peer Specialists and Carer Consultants, CNAHS representatives involved with the implementation of such an initiative toured the targeted acute units and spoke with staff members. Pre-existing staff were provided with information regarding the new roles and had the opportunity to have their questions answered.

At pre- and post-assessment, Clinical Nurse Consultant's on targeted acute units were contacted to arrange appropriate times to approach potential participants and invite them to complete a questionnaire. Such questionnaires were predominantly completed prior to ward rounds and returned to the researcher, however some staff opted to forward the completed questionnaires via internal mail.

### *Newly Employed Peer Specialists and Carer Consultants.*

Peer Specialists and Carer Consultants were invited to complete pre- questionnaires during a CNAHS orientation workshop and the research team collected completed questionnaires. Post-questionnaires were posted to prospective participants and were returned via reply-paid envelopes.

### *Peer Specialist and Carer Consultant Mentors.*

Appointed mentors for the Peer Specialists and Carer Consultants were asked to provide their feedback on the experience of mentoring via a discussion focus group. Topics covered included: emotional support, structural issues, planning, and recommendations.

## Results

### *Consumers in Response to Contact With Peer Specialists*

Of the 30 consumers who participated in the telephone conducted questionnaire, 25 recalled having contact with a Peer Specialist while utilising acute services. Four of the five consumers who did not recall contact with a Peer Specialist reported not knowing of such a staff member and did not recall being offered such services. The fifth participant declined to engage with such services. Additionally, of the 25 participants, 10 reported being aware of a Carer Consultant on the ward.

Descriptive statistics of consumer response scores post-contact with Peer Specialists are summarised in Table 1. Overall, such results were positive. The highest ratings indicated that Peer Specialists were considered good or better at helping the consumer feel supported, helping them identify their coping strategies, and increasing the consumer's sense of hope for recovery. Additional ratings indicated that Peer Specialists were considered better than acceptable at encouraging consumer self-management, increasing consumer understanding of experienced symptoms, sharing their personal coping strategies, and connecting the consumer to community resources.

Table 1
*Descriptive Statistics of Consumer Response Scores Post-contact with Peer Specialist*

| | *Mean* | *SD* | Min | Max |
|---|---|---|---|---|
| *Response Items* | | | | |
| Increasing understanding of symptoms | 2.88 | .83 | 1 | 4 |
| Sharing their personal coping strategies | 2.76 | 1.13 | 0 | 4 |
| Helping to identify consumer coping strategies | 3.04 | 1.10 | 0 | 4 |

| | | | | |
|---|---|---|---|---|
| Increasing sense of hope for recovery | 3.16 | .90 | 1 | 4 |
| Helping consumer feel supported | 3.00 | 1.04 | 0 | 4 |
| Encouraging self-management | 2.96 | .98 | 0 | 4 |
| Connecting with community resources | 2.64 | .70 | 2 | 4 |

*Note.* **Participants (N = 25) were asked to rate their responses on a scale where responses ranged from 0 =** ***very poor*** **to 4 =** ***very good***

Qualitative data was obtained through open-ended questions and many respondents commented on the helpful nature of all staff with one respondent reporting the received acute services to be better than associated services obtained in the private sector.

Participating consumers were also asked if they found anything to be different or special about working with a Peer Specialist in comparison to other staff. Obtained comments reflected quantitative data with the dominant theme being that the Peer Specialist's lived experience normalised situations, promoted a greater sense of feeling understood, of feeling comforted, and exemplifying the potential for recovery. For example, statements provided by interviewed consumers included: the Peer Specialist "Understood what we were going through and helped me understand", "Made that stay the best one. I felt really comfortable", and "Knew what it was like. They lived it and got better enough to work".

Conversely, two respondents reported conflicts in personality. However, when asked how the Peer Specialist service could be improved, most respondents encouraged employing more Peer Specialists and/or increasing their working hours. One respondent suggested that promoting the valuable role of Peer Specialists to the broader community could reduce the stigmatisation surrounding mental health.

## *Carers in Response to Contact With Carer Consultants*

Of the 25 carers who participated in the telephone conducted questionnaire, 21 recalled having contact with a Carer Consultant while utilising acute services. The four carers who did not recall contact with a Carer Consultant reported not knowing of such a staff member and did not recall being offered such services. Additionally, of the 25 participants, four reported being aware of a Peer Specialist on the ward. One such respondent attributed the compliance of her family member to the helpful efforts of the Peer Specialist.

Descriptive statistics of carer response scores post-contact with Carer Consultants are summarised in Table 2. Overall, such results were positive. The highest ratings indicated that Carer Consultants were considered better than good at helping carers feel supported and reducing carer distress by sharing their coping strategies. Additional ratings indicated that Carer Consultants were better than acceptable at increasing carer's sense of hope for the recovery of the consumer being cared for, helping carers identify and build upon their personal coping strengths in their caring role, assisting carers in learning about the hospital system, and explaining the Well Ways Program.

Table 2
*Descriptive Statistics of Carer Response Scores Post-contact with Carer Consultant*

| | *Mean* | *SD* | Min | Max |
|---|---|---|---|---|
| *Response Items* | | | | |
| Assisting with learning about hospital system | 2.86 | 1.24 | 0 | 4 |
| Explaining the Well Ways Program | 2.76 | 1.48 | 0 | 4 |

| | | | | |
|---|---|---|---|---|
| Helping carer feel supported | 3.57 | .68 | 2 | 4 |
| Increasing sense of hope for consumer's recovery | 2.95 | .92 | 1 | 4 |
| Reducing carer distress | 3.24 | .89 | 1 | 4 |
| Helping to identify carer coping strategies | 2.90 | 1.00 | 1 | 4 |

***Note.* Participants (N = 21) were asked to rate their responses on a scale where responses ranged from 0 = *very poor* to 4 = *very good.***

Participating carers were also asked if they found anything to be different or special about working with a Carer Consultant in comparison to other staff. Many respondents acknowledged the good work of all unit staff with comments such as, "all staff were professional and relaxed". However, obtained comments reflected quantitative data with the dominant theme being that the Carer Consultant's personal experience with similar issues provided them with a knowledge and insight that helped carers feel more comfortable and supported.

One carer summed up her experience as follows: the Carer Consultant "Explained their experience very well. It was nice to know that someone knew what I was experiencing" and another who reported, "After 10 years, it was the first time I ever felt a connection". Overall, comments suggested that the Carer Consultants provided a worthwhile service.

Respondents were also asked for suggestions on how the Carer Consultant service could be improved. All reported suggestions involved more available time with the Carer Consultant through ongoing follow-up post-discharge, providing a country service, employing more Carer Consultants, and making their positions full-time.

## *Pre-existing Staff Perceptions Regarding Peer Specialists Roles*

A paired-samples t-test was conducted to evaluate shifts in pre-existing staff perceptions of Peer Specialists and Carer Consultants from pre- to post-commencement of duties. With the exception of reporting a greater understanding of their role, participant's scores declined on nearly all measured items from pre- to post-commencement of Peer Specialist employment duties (see Table 3). There was a statistically significant decrease in scores, indicating less favourable perceptions over time for the following:

**Table 3**
***Descriptive Statistics of Pre-existing Staff Perceptions Regarding Peer Specialists** (PS) Roles*

| | Pre<br>*M* (and *SD*) | Post<br>*M* (and *SD*) | Min | Max |
|---|---|---|---|---|
| *Response Items* | | | | |
| Benefits consumers | 7.89 (1.55) | 7.09 (1.91) | 5 | 10 |
| Understanding of their role | 6.28 (2.58) | 6.39 (2.34) | 1 | 10 |
| Foster hope for recovery | 7.48 (1.29) | 6.67 (1.90) | 5 | 10 |
| Encourage personal responsibility | 7.17 (1.68) | 6.52 (2.30) | 3 | 10 |
| Enhance connection to resources | 7.48 (1.41) | 6.72 (2.14) | 5 | 10 |
| Benefits other unit staff | 7.20 (1.66) | 6.30 (2.56) | 3 | 10 |

| | | | | |
|---|---|---|---|---|
| Feel confident to make referrals to PS | 6.54 (2.40) | 6.46 (3.02) | 1 | 10 |
| Will offer support to PS | 8.93 (1.07) | 7.93 (2.02) | 6 | 10 |

***Note.*** **Participants (N = 46) were asked to rate their responses on a scale where responses ranged from 1 =** ***Totally Disagree*** **to 10 =** ***Totally Agree.***

Firstly, Peer Specialists working within acute mental health units was perceived as less beneficial to consumers from pre- ($M = 7.89$, $SD = 1.55$) to post-evaluation ($M = 7.09$, $SD = 1.91$), $t(45) = 2.26$, $p<.05$. The eta squared statistic (.10) indicated a moderate effect size. Secondly, Peer Specialists working within acute mental health units was perceived as less beneficial to other staff from pre- ($M = 7.20$, $SD = 1.66$) to post-evaluation ($M = 6.30$, $SD = 2.56$), $t(45) = 2.17$, $p<.05$. The eta squared (.10) statistic indicated a moderate effect size, Thirdly, Peer Specialists were considered less able to enhance a consumer's connection to community resources from pre- ($M = 7.48$, $SD = 1.41$) to post- evaluation ($M = 6.72$, $SD = 2.14$), $t(45) = 2.04$, $p<.05$. The eta squared (.09) statistic indicated a moderate effect size. Finally, pre-existing staff reported less willingness to offer support to Peer Specialists from pre- ($M = 8.93$, $SD = 1.07$), to post-evaluation ($M = 7.93$, $SD = 2.02$), $t(45) = 3.07$, $p<.005$. The eta squared (.18) statistic indicated a large effect size.

Although some summary comments obtained through open-ended questions implied non-existent benefits to consumers and somewhat reflected the above data, the majority of comments were positive and optimistic. In collating such comments a recurrent theme of empathy arose whereby the consumer was consistently reported to benefit from liaising with a staff member who had lived experience. For example, one respondent commented, "Peer Specialists can support consumers on a personal level that can not be matched by mental health professionals".

Additionally, pre-existing staff consistently reported consumers to benefit from Peer Specialist interactions through the varied information provided during group processes, one-on-one sessions, and through first-hand knowledge of available community resources. Further comments suggested that pre-existing staff also benefited from Peer Specialists who provided another support outlet and constructively occupied consumer time.

The information provided regarding difficulties arising from the introduction of Peer Specialists was mixed. Encouragingly, the substantial difficulties first projected at pre-assessment were not founded. At post-assessment, some pre-existing staff reported "nil difficulties" while others on the same ward reported numerous difficulties. The majority of difficulty appeared to arise in the areas of role clarity and communication with pre-existing staff. Furthermore, Peer Specialists were reported to have limited understanding of the mental health system and the varied roles of staff members. Pre-existing staff were forthcoming with information and offered valuable resolutions for reported difficulties (e.g., further training).

## *Pre-existing Staff Perceptions Regarding Carer Consultants Roles*

With the exception of a slight increase on scores in understanding of the Carer Consultants role and pre-existing staff's confidence in making referrals to such services, participant's scores declined on most measured items from pre- to post-commencement of Carer Consultant duties (see Table 4). There was a statistically significant decrease in scores, indicating less favourable perceptions over time for the following.

**Table 4**
***Descriptive Statistics of Pre-existing Staff Perceptions Regarding Carer Consultant** (CC) Roles*

| | Pre<br>*M* (and *SD*) | Post<br>*M* (and *SD*) | Min | Max |
|---|---|---|---|---|
| *Response Items* | | | | |
| Benefits carers | 7.87 (1.50) | 7.20 (1.85) | 1 | 10 |
| Understanding of their role | 6.15 (2.62) | 6.59 (2.40) | 1 | 10 |
| Reduce carer distress | 7.30 (1.31) | 7.13 (1.80) | 1 | 10 |
| Assist with acute service pathways | 7.28 (1.54) | 6.72 (2.12) | 1 | 10 |
| Enhance connection to resources | 7.61 (1.47) | 7.02 (2.01) | 1 | 10 |
| Benefits other unit staff | 7.37 (1.54) | 6.80 (2.43) | 1 | 10 |
| Feel confident to make referrals to CC | 6.74 (2.23) | 6.85 (2.78) | 1 | 10 |
| Will offer support to CC | 8.85 (1.15) | 7.96 (1.87) | 4 | 10 |

***Note.* Participants (N = 46) were asked to rate their responses on a scale where responses ranged from 1 = *Totally Disagree* to 10 = *Totally Agree.***

Firstly, Carer Consultants working within acute mental health units were perceived as less beneficial to carers from pre- ($M = 7.87$, $SD = 1.50$) to post-evaluation ($M = 7.20$, $SD = 1.85$), $t(45) = 2.02$, $p<.05$. The eta squared statistic (.08) indicated a moderate effect size.

Secondly, pre-existing staff's willingness to offer support to Carer Consultants declined from pre- ($M = 8.85$, $SD = 1.15$) to post-evaluation ($M = 7.96$, $SD = 1.87$), $t(45) = 1.49$, $p<.005$. The eta squared (.05) statistic indicated a small effect size.

Information gathered through open-ended questions qualified the above data. However, mixed among comments that reported non-existent benefits of employing such staff members, some pre-existing staff from each site also indicated favourable experiences attributed to the role of Carer Consultants. For example, respondents made comments such as, "Carer's appear less frustrated with the system" and their role "does lift some of the load from other staff". Another participant wrote, "Carer Consultants provide enhanced support for families". Finally, one respondent wrote, "I refer a lot of families to Carer Consultants – all of whom have given very positive feedback regarding their contact".

The information provided regarding difficulties arising from the introduction of Carer Consultants was also mixed. For example, some staff reported no apparent difficulties while others on the same ward commented on communication barriers, training requirements, and insufficient role clarity.

## *Newly employed Peer Specialists and Carer Consultants*

A Wilcoxon Signed Rank Test was conducted to evaluate shifts in newly employed Peer Specialists and Carer Consultants perceptions of their respective roles. Overall, participant's scores increased on all measured items from pre- to post-commencement of employment duties (see Table 5). There was a statistically significant increase in scores indicating more favourable perceptions over time for the following two areas.

**Table 5**
***Descriptive Statistics of Newly Employed Staff Perceptions Regarding Carer Consultant (CC) and Peer Specialist (PS) Roles***

| | Pre<br>*M* (and *SD*) | Post<br>*M* (and *SD*) | Min | Max |
|---|---|---|---|---|
| *Response Items* | | | | |
| Feel positive about employment of PS | 9.00 (0.94) | 9.25 (2.00) | 3 | 10 |
| Understanding role of PS | 8.40 (0.52) | 9.42 (0.90) | 8 | 10 |
| PS foster hope for consumer recovery | 8.70 (0.95) | 9.33 (0.89) | 7 | 10 |
| PS encourage consumer responsibility | 8.10 (0.88) | 9.08 (1.00) | 7 | 10 |
| PS enhance connection to resources | 7.80 (0.42) | 8.25 (1.36) | 6 | 10 |
| PS role benefits other unit staff | 7.70 (0.68) | 8.75 (1.82) | 4 | 10 |
| | | | | |
| Feel positive about employment of CC | 8.58 (1.08) | 8.75 (1.66) | 5 | 10 |
| Understanding role of CC | 7.33 (1.23) | 8.58 (1.44) | 5 | 10 |
| CC reduce carer distress | 8.17 (1.27) | 8.33 (1.88) | 5 | 10 |
| CC help carers navigate service paths | 7.67 (1.16) | 8.00 (1.35) | 5 | 10 |
| CC enhance connection to resources | 8.00 (0.95) | 8.08 (1.17) | 6 | 10 |
| CC role benefits other unit staff | 7.83 (0.94) | 8.42 (1.57) | 6 | 10 |
| | | | | |
| Feel confident about receiving referrals | 7.58 (1.08) | 8.17 (2.95) | 1 | 10 |
| Feel confident about being supported | 6.83 (1.19) | 7.33 (2.74) | 1 | 10 |

***Note.* Participants (N = 12) were asked to rate their responses on a scale where responses ranged from 1 = *Totally Disagree* to 10 = *Totally Agree.***

Firstly, obtained scores indicated a greater understanding of the new role Peer Specialists have in promoting consumer recovery from pre- ($M = 8.40$, $SD = .52$) to post-evaluation ($M = 9.30$, $SD = .95$), $z = -2.08$, $p < .05$. Secondly, the perception that Peer Specialists encourage personal responsibility by modelling coping strategies increased from pre- ($M = 8.10$, $SD = .88$) to post-evaluation ($M = 8.90$, $SD = 1.0$), $z = -2.06$, $p < .05$.

Information gathered through open ended questions substantiated the above data and maintained an air of optimism from pre- to post-assessment. The predominant theme of responding indicated substantial gains achieved through consumers identifying with the lived experience of the newly employed staff. Consumers were reported to confide with Peer Specialists and Carer Consultants thus providing additional information that helped inform other staff on treatment and follow-up options.

The majority of difficulties were similar to those addressed by pre-existing staff (e.g., role clarity and communication between staff members working with the same consumer). Additional areas of concern related to fitting in with pre-existing team dynamics and the unexpected pressures of working within an acute environment. Both groups of Peer Specialists and Carer Consultants reported the need for a referral system that better informed them of consumer needs and appropriateness for making initial contact.

### *Mentors for Peer Specialists and Carer Consultants: Discussion Focus Group*

The two assigned mentors participated in an hour-long discussion focus group chaired by a member of the research team. In considering the impact of introducing Peer Specialist positions, it was evident that such positions are highly sought after and help reinforce consumers hope for recovery.

In regards to the impact of introducing Carer Consultant positions, mentors reported that the carer community felt “heartened” and the provision of such positions is acknowledgement of their valuable carer role. Carers SA particularly noted an increase in referrals to carer agencies since the inception of Carer Consultants.

Mentors also reported the educational component of their role to be most valuable and effective in enhancing staff’s competencies. They reported to observe a strong within group support process develop which both Peer Specialists and Carer Consultants valued. Consequently, the mentors collaborated on developing a Mentor Training Program by which peer-to-peer mentoring processes will be formalised and inclusive of relevant training.

## Discussion

Central Northern Adelaide Health Service (CNAHS) employed Peer Specialists and Carer Consultants on five permanent acute units within the region. The current report aimed to summarise and evaluate information obtained from consumer/carer feedback, pre- and post-employment staff questionnaires, and Peer Specialist/Carer Consultant mentor discussion.

Overall, the feedback provided from consumers and carers was consistently positive. Both groups of Peer Specialists and Carer Consultants were reported to be effective supports for increasing hope for recovery. Above all, the lived experience of such staff members was repeatedly commented to be a valuable and appreciated source of acknowledgment and understanding.

Conversely, pre-existing staff on the targeted acute units perceived the introduction of Peer Specialists and Carer Consultants *less favourably* over time. However, such staff also reported a greater understanding of the respective roles. Such results are influenced by numerous factors including the following.

Firstly, pre-existing staff provided surprisingly high pre-assessment scores. To the contrary of reports which cited the negative attitudes of mental health professionals as a major barrier to effective consumer participation (e.g., Gordan 2005; Happell & Roper, 2006. Lammers & Happell, 2004) the high initial scores reported in this paper implied a degree of optimism and acceptance among pre-existing staff.
It is also possible that inflated initial scores were reflective of the information provided during pre-employment introduction sessions. Although there was limited scope for an increase in such scores over time, the average reported scores remained in the positive response domain.

Secondly, it is possible that the systemic and cultural adjustment challenges faced by introducing a novel and inexperienced group of staff was overlooked by everyone involved with such an endeavour. It is believed that the experience of such challenges contributed to less favourable perceptions over time among pre-existing staff that held high initial expectations. Specifically, it is hoped that the reported decline in pre-existing staff’s willingness to offer support to either Peer Specialists or Carer Consultants will improve as all staff and coordinating bodies endeavour to further implement positive change and address restraints.

Finally, both the pre-existing and newly employed staff participants reported difficulties with cross-communication. Both groups desired more opportunity and/or an agreed upon structure to liaise with each other at various stages of consumer and family care (i.e., initial referral, pre-contact, follow-up debriefing). With such communication issues, it is possible that the involvement and value of Peer Specialists and Carer Consultants was not questioned or expressed by various parties. For instance, consumers and carers who utilised the services of Peer Specialists and Carer Consultants predominantly reported positive experiences and valued the inclusion of such staff on the acute units. Possibly, the pre-existing staff who reported nil benefits of employing the newly introduced staff were not provided with opportunity to receive such feedback.

Conversely, Peer Specialists and Carer Consultants perceived their role *more favourably* over time**.** The overall buoyancy of the pre- and post-assessment scores suggests a resilient optimism by the Peer Specialists and Carer Consultants regarding the value of the lived experience roles and this is supported by the reported consumer and carer feedback. Interestingly, the newly employed Peer Specialists and Carer Consultants also had high pre-assessment scores and despite aforementioned challenges, their scores increased over time. It is possible that an increase in scores is also associated with such staff receiving ongoing positive reinforcement from the consumers they worked with, the peers they received support from, their mentors, and the ongoing training/education offered them.

The newly employed Peer Specialists and Carer Consultants who reported greater understanding of their respective roles evidently embrace the premise of the recovery framework adopted by CNAHS. As further experience of the role continues, Peer Specialists and Carer Consultants are also refining their practice skills in promoting consumer recovery and encouraging personal responsibility by modelling coping strategies.

As would be expected with such an endeavour, particular difficulties were addressed and continue to be addressed with the progress of time and experience. In general, pre-existing staff articulated difficulties arising in areas of selection, training, and management of additional staff. At the time of writing, the developing mentor program endeavours to provide sustained role and skill development approaches for any new Peer Specialist and Carer Consultant staff.

Acknowledging that no new staff member without previous experience is fully skilful at service delivery, the Peer Specialist and Carer Consultant will continue to develop a broad base of competencies, skills, and evolving practice standards. In order to overcome the knowledge and skill gaps reported by and affecting existing unit staff. more extensive training and orientation is planned for the new Peer Specialists and Carer Consultants prior to commencement on any unit.

Furthermore, as developing positions, the unique roles of Peer Specialists and Carer Consultants were reported as misunderstood and potentially under-utilised (i.e., lacking referrals). Such issues are consistent with the initial restraints of many newly developing employment positions and the informal qualitative reports of similar interstate roles suggests that the initial 12-18 month timeframe is a period of augmenting role clarity and embedding systemic change. It may be beneficial for pre-existing staff to be informed of similar interstate projects and to be given the opportunity to openly discuss logistics. Finally, both groups of Peer Specialists and Carer Consultants reported an overall personally rewarding employment experience.

In summary and coinciding with existing literature, the current evaluation indicated that the employment of Peer Specialists and Carer Consultants within various CNAHS acute units was positively associated with consumer, organisational, and personal gains. For example, the lived experience of additional staff was reported as beneficial to everyone involved and was viewed as providing a valuable connection point for consumers and carers. The consumer and carer feedback suggested that the inclusion of Peer Specialists and Carer Consultants was a worthwhile and appreciated venture. Additionally, participating consumers and carers provided consistently positive feedback whereby they reported feeling more supported and experienced a greater sense of hope for recovery for respectively themselves or the person they care for.

Although pre-existing staff's perceptions somewhat deteriorated over time, their average ratings were still of a positive and/or agreeable nature. Genuine incorporation of new team roles usually takes considerable time to embed, so a settling process is natural. The ongoing action of pre-existing staff and newly employed staff to effectively problem solve issues arising clearly reflects a solid commitment to genuinely and fully incorporating such lived experience roles into the team. While the complications inherent with the experience of a structural and cultural shift were evident, numerous gains were reported from the organisational perspective. For example, the introduction of Peer Specialists and Carer Consultants was reported to alleviate time and resource constraints.

The information gathered via this evaluation is being used to direct future endeavours and to address identified issues. An impetus to integrate consumers and carers into all aspects of mental health service exists. The aim is to benefit everyone involved, however it can be speculated that the ultimate driving force is to provide the best possible care for current consumers and their families. CNAHS continues to strive toward optimal service delivery and the current initiative contributes to the growing body of national findings that supports the inclusion of Peer Specialists and Carer Consultants as valuable mental health team members. CNAHS is committed to the best possible mental health service provision and anticipates further developments as lived experience and trained staff coalesce to provide cutting edge services.

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# The Impact of Participation in a support Group for Carers of a Person with Schizophrenia: A Qualitative Study.

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## Abstract

Caregivers of people with a mental illness experience considerable ongoing burden and psychological distress as a consequence of their caregiving role. Support groups for such carers aim to address this burden and distress.

While the literature is limited, the qualitative and quantitative research to date suggests that carers benefit from attending support groups. This qualitative study furthers existing research by examining the experiences of participants of an ongoing support group. Specifically: what were participants' experiences, both positive and negative, of the support group? And, what are the factors that influenced their attendance? Results suggest that participants had mostly positive experiences of being in the support group. Results are compared to previous research and unique themes discussed.

**Keywords:** support groups; mental illness; carers; family members

# Introduction

With the advent of deinstitutionalisation in Australia over the last two decades, family members of persons with a mental illness have often assumed a caring role. A substantial body of research suggests that in such a role caregivers experience considerable ongoing burden and psychological distress (Cuijpers, 1999). There are multiple domains in which carers are affected: they are always 'on duty'; have unfavourable experiences in interactions with health professionals; family functioning can be negatively affected; and they can suffer "stigma by association", grief, guilt, powerlessness, anger and other distressing emotions. Despite their central role in the healthcare of their relative with a mental illness, only a minority of carers receive services from mental health agencies (Dixon, Luckstead, Stewart, & Delahanty, 2000; West et al., 2005).

Recognising carer burden a "Family and Friends" group (FFG) was established for the carers of people with severe mental illnesses. Specifically the FFG was designed to address carers' needs for psycho-education, grief resolution (Young, Bailey, & Rycroft, 2004), peer and emotional support (Arblaster et al., 2001). Like other support groups, the FFG was "geared for mutual support, information and growth and is based on the premise that people with a shared condition who come together can help themselves and each other to cope, with the two-way interaction of giving and receiving help" (Reay-Young, 2001, p. 6).

Compared to other types of family interventions for mental illness such as family psychoeducation, carer support groups have received little research attention. Available research however, does suggest that these support groups are effective.

Chou, Liu and Chu (2002) used a randomised control design, with seventy participants, to examine the utility of an eight session carer support group that focused on the provision of information, problem-solving, support and coping. Carers attending these support groups compared to those who did not, had statistically significant improvements on measures of caregiving burden and depression. Winefield, Barlow and Harvey (1998) also found carers made significant psychological gains after participating in a support group and maintained these gains for at least two months. However, this study lacked a control group thus factors other than support-group attendance may be responsible for reported gains.

Quantitative research has also demonstrated that people attending support groups have increased knowledge of mental illness and mental health services, improved morale (Citron, Solomon, & Draine, 1999; Pickett-Schenk, Cook, & Laris, 2000), increased social support and improved confidence to meet their relatives needs (Citron, Solomon & Draine,1999). Citron et al. (1999) also found negative effects of group attendance whereby after attending the group 18% of participants were at least somewhat more overwhelmed by their relative and 20% were at least somewhat less able to meet the needs of a person with a mental illness. Such results require further investigation.

The results from these quantitative studies provide consistent findings that, generally, support group attendees find such groups beneficial. Qualitative research supports these findings. Winefield, Barlow and Harvey (1998) conducted qualitative interviews with carers who had attended a short-term (8 session) support group. Participants reported attending the group helped them develop a more positive attitude towards the ill relative, that contact with other carers decreased their sense of isolation and that they were empowered to advocate for better services. Interestingly, they found carers' needs were related to time caring. Carers who had been in the role for up to five years wanted information and expected professionals to provide answers. After about 10 years, carers were more accepting of their situation and were addressing their own grief. Thereafter carers focused on advocacy and lobbying. Qualitative research has also shown after completing an 11-week, professionally led support group, carers experienced an increased sense of hope, universality (i.e. that others share their problems and experiences), adaptation to and acceptance of their situation, and the gaining of a sense of empowerment through an increased understanding and knowledge of mental illness (Van Hammond & Deans, 1995).

In summary, both quantitative and qualitative studies found that carers who attend support groups benefit in terms of psychological wellbeing, understanding mental illness and coping skills. The current study aims to further this body of research by using a qualitative research design to examine, in an Australian setting, the factors that influence people to attend support groups and the impact of a time-unlimited support group for carers of people with a mental illness.

# Method

We sought to understand, from the perspective of participants attending the FFG: 1. What are their experiences, both positive and negative, of the FFG? And 2. What are the factors that have influenced their attendance?

## Participants

Nineteen carers who had attended at least one session of the FFG were sent a letter inviting them to participate. These carers all cared for a person with schizophrenia treated at a Community Care Unit (CCU) in Melbourne Australia. This CCU provides residential rehabilitation services for those with serious mental illness.

## Design

Data was gathered from an anonymous survey and focus group. Participants were asked to provide demographic details and respond to questions about the following topics: initial reasons for attendance; ongoing reasons for attendance; reasons for the cessation of attendance; the positive and negative impact of attending the FFG; and, what they would need to happen for them to resume or continue to attend the FFG (survey and focus group questions available from KW).

The survey (with return prepaid envelope) was sent with the letter inviting participation. Two group facilitators (KW, PM) conducted the 2-hour focus group with 8 participants. It was recorded and transcribed.

## Analysis

Survey responses and the focus group transcript was subject to thematic analysis using the following process:

(i) Each statement made by the participants was coded according to theme it represented.
(ii) Similarly coded statements were clustered together.
(iii) These clusters of statements were given labels to represent the themes and sub-themes of the

cluster.

Trustworthiness was enhanced in three ways. 1. Two methods (survey and focus groups) were used to collect the data. 2. Two researchers independently assigned the codes and made consensus decisions about final code assignment. 3. A second researcher (MG or LS) considered the theme and sub-theme assigned (by KW) to each cluster of statements. Discrepancies were discussed until consensus agreement.

# Results

**Demographics**

Survey respondent characteristics

Eleven carers (58% response rate) returned their questionnaires. This data indicates a diverse range of respondents in terms of age, region of birth and relationship to CCU resident (see table 1).

**Focus group participant characteristics**

Eight carers (42% response rate) participated in the focus groups. Compared to the survey respondents the focus group participants were less diverse in ethnic background and appeared to have attended more FFG sessions (see table 1).

Table 1: Sample characteristics

| | | Survey | Focus group |
|---|---|---|---|
| Age: | Median | 51-55 | 56-60 |
| | Range | 20-65+ | 46 – 65+ |
| Sex: | Male | 3 | 2 |
| | Female | 7 | 6 |
| | Missing | 1 | 0 |
| Region of birth: | Asia | 1 | 0 |
| | Europe | 4 | 1 |
| | Southeast Asia | 1 | 0 |
| | Oceania | 2 | 7 |
| | Missing | 3 | 0 |
| Employment status: | | | |
| | Employed (PT or FT) | 1 | 2 |
| | Part-time | 2 | 3 |
| | Full-time | 1 | 1 |

| | | | |
|---|---|---|---|
| | Pensioner | 6 | 1 |
| | Home duties | 1 | 1 |
| Relationship to CCU resident: | mother | 4 | 4 |
| | father | 4 | 2 |
| | sister | 1 | 0 |
| | brother | 1 | 0 |
| | grandmother | 1 | 1 |
| | friend | 0 | 1 |
| Age of CCU resident: | mean | 34 | 29 |
| | range | 21-55 | 24-42 |
| Sex of CCU resident: | male | 10 | 8 |
| | female | 1 | 0 |
| Number of other carers also with caring responsibilities for the CCU resident: | none | 4 | 4 |
| | one | 3 | 3 |
| | two | 0 | 1 |
| | three | 3 | 0 |
| | missing | 1 | 0 |
| Number of FFG sessions attended: | mean | 5.5 | 13 |
| | range | 1-12 | 1 – 39 |
| | don't know | 2 | 1 |
| | missing | 3 | 0 |
| Time since diagnosis: | mean | Data not collected | 8.6 |
| | range | | 4 – 20 |
| Number of admissions: | mean | Data not collected | 4 |
| | range | | 1-10 |
| | don't know | | 1 |

## Why participants attended the Family and Friends group

### Initial reasons

**1. Don't know.**

For some participants they did not know what they might get from attending the FFG.
" I really didn't know what to expect" Penelope

**2. Seeking solutions.**

Participants attended the FFG seeking strategies to improve their ill-relatives wellbeing and to gain knowledge about the illness and CCU. They sought to find out how to cope and they also wanted to influence the running of the CCU to improve services for their ill-relative.
"We were interested in finding out all the ways to look after our son carefully and provide [him with] relief from his suffering" survey 1

**3. Seeking relationship.**

Participants wanted to meet people in similar situations who they could share experiences with, and learn and get support from. The relationship with the facilitator, who encouraged and reminded them about the group, also played a part in some individual's decision to attend.
"To exchange experiences with others in similar situations and to gain understanding" survey 7

Ongoing reasons to attend

**1. Relationships.**

The relationships formed with the group members motivated participants to continue their attendance. Notably an ongoing reason for attending was to give support to others, a factor that was not mentioned as a motivator for attendance earlier on.

"Yes, as we not only were supported, but realised we could support others" survey 1

**2. Self care.**

Participants continued going to the FFG for their own self-care, to have a break and receive understanding and support.
"I realised there is an awful lot of people out there that need help; not just the patients but the parents, the carers" Christine

Barriers - Why participants stopped attending

**1. Resources.**

A lack of resources was the dominant reason for ceasing to attend. Participants did not have the time to attend due to other life and caring commitments. Participants lacked transport to get to the group or it was too far to travel. Participants' health problems were also a barrier.

**2. Ill-relative factors.**

When the ill-relative was no longer at the CCU participants tended not to attend the group (although this was allowed). Participants also reported their ill-relative, directly or indirectly (e.g. when caring responsibilities prevented attendance) stopped them attending the group.

"[son] is really unwell and I don't like leaving him for too long, so it makes it a bit tricky" Megan

**3. Focus on talking.**

One participant did not continue as they found the focus was on talking rather than action. Similarly, another cited an instance where a former group member discontinued finding it depressing to hear stories similar to her own.

"it became obvious to me that it was a group meeting which was focused on talk but not action, and I think both are essential" survey 3

Understandably, participants reported the resolution of these barriers would enable their future attendance at meetings.

Participants' negative experiences

The "negative" things that people had to say about the group were mostly the same as the barriers. Two additional themes were disappointment and meeting agenda and scope.

**1. Disappointment.**

Participants reported experiencing disappointment, despair and loss of faith in the mental health system. Such disappointment was prompted by failed attempts to instigate practical activities to improve the CCU (e.g. starting a group for children and starting a cooking class).

"we've tried to start something…and that just kind of fizzled out and that was it. It is the lack of going forward with things that you try to start [and] frustration when you start things you really want to see work. And okay, you know a lot of things are going to fall flat. Seeing it fall flat when you put so much effort into it … kind of leaves you with a little bit of despair and you think oh well is this really as hopeful as you think it is. You lose a little bit of faith" Claire

**2. Meeting agenda and scope**

Finally, whist not constantly agreed upon, there were group activities that some participants did not like and it was thought that the meeting agenda could be improved via the use of a suggestion box. One participant suggested the scope of the group was too narrow for the participation of younger people.

Participants' positive experiences

Positive experiences were by far the biggest area that participants discussed in the focus groups. The survey data was consistent with, albeit less detailed, focus group data. Four themes emerged; relationship, tasks, outcome and transition.

**1. Relationships**

This was the largest theme and consisted of the following sub-themes: friendship; universality; support and altruism; and attitude.

(i) Friendship

Participants articulated a sense of friendship that developed over time. Different types of friendships evolved from friendliness and socialising, to more intimate friendships that provided a sense of companionship and closeness.

"Just the companionship has been really good." Claire

(ii) Universality

Yalom (2005) identified universality, the sense that others experience similar problems, as an essential factor in successful groups. Participants identified universality in a number of ways. Participants saw themselves as similar because of similar experiences. This appeared to be meaningful for the participants and put them in a position to offer advice to each other.

"Knowledge from people who [are] also facing the same problems" Megan

Similarity, however, was not uniformly endorsed. One participant stated that they were all different with no two stories being the same.

The experience of universality was related to a sense of being understood by FFG members in contrast to experiences outside the group where they were not understood outside. This shared understanding meant participants did not need to explain themselves.

"they [group members] instinctively know without me saying anything. They were there and they could see it on my face because they have been there and done that." Claire

"they [people who don't care for a person with a mental illness] don't know what it is like so they could think, oh well, you know, surely they could make him have a bath or do something." Megan

(iii) Support and altruism

Participants valued the support they received from the FFG members. Support was given in a variety of ways including being comforted, reassured, validated, listened to, provided with information and through social contact.

"at least they [group members] were there to stick an arm around you and say 'oh, never mind, this sort of thing, these things happen to all of us'. That was really reassuring." Claire

In addition to receiving support, participants also valued giving support, empathy, information and advice.

"But I think that people can help each other and that's …a big achievement." Anne

(iv) Attitude

Participants talked about the non-judgemental attitudes of FFG members contributing to a positive experience. Like the experience of being understood, this non-judgemental attitude in the group was in contrast with the stigma experienced outside of the group. Humour was also viewed as a helpful aspect, helping with creating relationships and enhancing coping. Participants also valued the positive attitude of the facilitator.

"So you can look back at what they have done and laugh and not be so bogged down in the seriousness of the illness." Megan

**2. Tasks: what the group worked on.**

In addition to the importance of relationships in the FFG, participants also emphasised the tasks that the group engaged in. Three types of tasks, detailed below, were mentioned.

(i) Working with the system

Making changes to both the CCU and the mental health system was a valued aspect of the FFG. Making such changes was seen as a way to improve participants' own situation.

"making their [ill-relatives] lives easier was making our lives easier" Anne

Part of this advocacy included working out what could be changed and trying to get funding for other projects.

"It is not exactly changing the system, it's more like getting funding for projects; as far as changing the system you haven't got a bloody hope." Megan.

(ii) Educational and social activities

The participants talked about the activities that they enjoyed in the FFG, this included having invited speakers, attending a psychoeducational course for carers, attending information sessions and going out for lunch.

(iii) Working with emotions and caring for self

There were a number of ways the group addressed feelings. These included distraction, telling stories about one's experiences, discussion and validation of the need for self-care, exploring self-blame, and talking about or venting feelings.

"You can just you know, forget how serious it is for you know, an hour or so." Megan

**3. Outcomes of participation in the FFG**

(i) Improvements in emotional health

There were a number of positive effects that attending the group had on participants' emotional health. These included a sense of increased positive feelings, self-worth, motivation, acceptance of the situation, encouragement and hope.

"I feel a lot better… [about] myself now" survey 8

(ii) Increase in self-efficacy

Some participants also experienced an increase in their confidence to do something about their situation and assert themselves.

"It [FFG] has given me the strength to say that… it's my decision, so I am getting strength to stand on my convictions on things." Rachael

"It [the FFG] allows you to approach your own circumstances from a totally different perspective. For example, from feeling a victim to being a victor." survey 2

(iii) Increased knowledge

Participants gained knowledge through attending the group, including an understanding of how to cope with their ill-relative's behaviour and the mental health system. Learning occurred through their interactions with each other and also the speakers invited to the group. Participants also found that there was a ceiling to the amount of knowledge that can be usefully acquired.

"[you get] a lot of knowledge because it was the first time that our son had been not at home and [there were] a lot of things he was doing which weren't… that good. Other people had the same experiences so they could give me knowledge on how to cope with it. It wasn't easy but I could, you know, I got a lot from one lady who, you know, she just said look, you know, this is, try this, try that, and I was, you know, it was really good" Megan

"I mean there is only so much knowledge you can actually store up there and use. Claire

### 4. Transition

A number of participants talked about the stages that they went through from a 'beginner' FFG member to an 'experienced' group member. When they began the group they sought information and strategies to cope with their situation, after this they focused on helping themselves and talking about their own experience. Finally, they attended the group in order to help others and pass on information to them.

"I kind of found it was like a transition stage. Started off in stage one when I first got involved for information I'd like to grasp on how I could help my son; two, I learnt that I needed to help myself talking about; and three it was also talking about I had valuable information that I could help others with" Claire

# Discussion

## Transitions

One of the features of this research was the transition participants made throughout their involvement in the group. This transition is evident in two ways. First, the reasons participants first attended the groups differed to the reasons for their ongoing attendance. For instance, regardless of the FFG being set up specifically for carers needs, participants' initial reasons to attend were focused on the improvement of the 'ill-relative'. They were seeking strategies and knowledge that would assist them with this goal. It can be argued that the mental health system is patient-focused (Furlong & Leggatt, 1996), and that carers, and perhaps especially parents, see themselves in a role of looking after the ill-relative. In these contexts it is understandable that the participants would initially attend a group with a motivation to learn better ways of looking after the ill-relative, regardless of the groups stated focus on carers' needs. Over time, in addition to this focus on strategies to improve the "ill-relative's" symptoms and / or functioning, participants also began to focus on themselves and their needs for social connectedness, respite and giving and receiving support. Whilst forming relationships with similar others was an initial reason for attending, after some time in the group, participants also valued providing support to others. Importantly, these latter needs did not seem to replace the need for knowledge and strategies as participants continued to value the gaining of knowledge through attending short-term education courses and listening to speakers. Thus, the focus on caring for self and supporting other group members, was in addition to carers focus on their ill-relatives needs.

A second type of transition was mentioned by participants; the transition from a beginner to an experienced group member. Whereby experienced group members were able to pass on information to others. This transition suggests that over time while attending the support group participants became more confident in their own expertise and capability to develop strategies or solutions.

Taken together, these results are consistent with findings from those of previous research. Reay-Young (2001), reviewed qualitative studies of carer support groups and identified that carers' needs change over time. Initially carers require information on mental illness and treatment and how to cope with their ill-relatives behaviour. Following this carers begin to address their own emotions and share their experiences with similar others. Finally, carers may want to help others in similar situations and focus on advocacy and lobbying. Interestingly, Reay-Young (2001) identifies carers' needs changing depending on the length of time in a caring role. In our findings participants identified their needs changing depending on length of time attending the support group. This might be because previous research has mainly focused on short-term support groups whereas the family and friends group was open ended. How the length of time as a carer, or length of time in a support group corresponds to the changing needs of carers is an interesting area for future research.

## Relationships

It has already been noted that after some time participants were motivated to attend the group due to the relationships with other group members where they were understood, were not judged, could identify with each other and created friendships. In these relationships they could both give and receive support. Similar factors were mentioned when participants were asked about their positive experiences of the group. Specifically, participants identified the relationships in the group created a sense of friendship, universality, support, altruism and acceptance. Such factors can be thought of in terms of group cohesion; that is, the therapeutic relationship created between group members and leaders (Burlingame, Fuhriman, & Johnson, 2002). Given that cohesion is commonly valued among participants in psychotherapy groups (Burlingame et al., 2002), and those attending support groups for carers of people with mental illness (Chou et al., 2002; Citron et al., 1999; Van Hammond & Deans, 1995; Winefield et al., 1998) it is no surprise that it was also a theme discussed amongst the participants in this focus group. Cohesion is an important aspect of groups as it relates to positive therapeutic outcomes and helpful therapeutic processes (Burlingame et al., 2002).

### Barriers

Some carers were prevented from attending the FFG. It may be argued that participants who were most vulnerable had greater barriers to attending the group; that is they were without transport, had poor personal health, their ill-relative limits their access to services, the ill-relative was living in the community (and assumedly requiring more support), and the participant had limited time due to caring commitments. Such barriers to the participation in family psychoeducational interventions (Sherman & Carothers, 2005; Tarrier, 1991) and support groups (Heller, Roccoforte, & Cook, 1997) have been identified elsewhere. These vulnerabilities suggest the participant had high needs for support, yet it was these same vulnerabilities which served as barriers to attending the group thus limiting opportunities for enhancing coping and compounding the burden.

### Negative experiences

Participants valued pursuing tasks to make changes at the CCU. However, participants reported that often their efforts did not pay off and led to a sense of disappointment. Further research is needed to understand the impact of such disappointment. It is possible that thwarted attempts at change decreased participants' sense of power or confidence in their ability to lobby and advocate. Advocacy and lobbying has been identified as one of the functions of support groups (Reay-Young, 2001). In order to enhance this function perhaps support group facilitators need to encourage participants to take on realistic and achievable advocacy goals to increase chances of success, bolstering confidence and motivation for further advocacy.

Participants mentioned other limitations of the FFG. These were that the meeting was unsuitable for younger people and some activities were not personally relevant. Similar to other research (e.g. Reay-Young, 2001) some participants found it difficult to listen to sad stories, which was a disincentive to continued attendance. This suggests that support group facilitators need to be particularly careful in creating a safe and containing environment to enable a helpful discussion of personal stories.

## Limitations and Conclusions

There are several limitations of this study to be taken into account when interpreting these results. The sample was small, limiting the breath of experiences identified. Furthermore, the comments made by participants in the survey and the focus group were most often brief without detailed descriptions of the phenomenon they were describing. Finally, the surveys and focus groups were conducted simultaneously, in retrospect it may have been beneficial to use the focus group results to design a more targeted and detailed survey to explore themes emerging from the focus group data.

In conclusion, these results are consistent with those reported by other researchers in this field (Chou et al., 2002; Citron et al., 1999; Pickett-Schenk et al., 2000; Winefield et al., 1998). Taken together, this and other similar qualitative and quantitative studies provide evidence of the effectiveness of support groups for carers of people with a mental illness.

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# *Wisconsin: Leading the Way to Person-Centered Planning in Community-Based Health*

## *(A Short Report)*

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## Introduction

A person-centered approach is reshaping practice throughout behavioral healthcare with its emphasis on the individual who has strengths, talents, and interests rather than a person as a case or a diagnostic label. Person-Centered Planning (PCP) incorporates the person's right to fully participate in all aspects of their recovery planning; their right to make decisions and choices about their treatment, while ensuring important aspects of their culture also be documented in the service plan itself. This collaborative process empowers and provides an opportunity through a psychosocial rehabilitative model for the person to inherently find their own path to recovery.

It is now widely recognized that people with mental illness can participate actively in their own treatment and can become the most important agents of change for themselves. Person-Centered Planning skills, along with Evidence-based Practice (EBP) interventions, such as Wellness Management and Recovery, ranging from greater knowledge of psychiatric illness and its treatment to coping skills and relapse prevention strategies, play a critical role in people's recovery from mental illness.

It is anticipated that EBP will be a key intervention in PCP recovery outcomes. For example, Wellness Management and Recovery (WMR) aims to empower consumers with severe mental illness to manage their wellness, define their own recovery goals, and make informed treatment decisions by teaching consumers the necessary knowledge and skills. WMR strongly emphasizes that consumers determine and pursue personal goals and implement action strategies (objectives) in their daily living to achieve them. The program employs interventions to help consumers improve their ability to overcome the effects of mental illness on social and role functioning.

PCP encourages people receiving services and their supporters to focus on goals aimed at increased functionality and community integration rather than solely on reduction of symptoms and decreased use of hospitalization. It helps people to focus on increasing the quality of their lives and look to a better future with more meaningful activities and social relations. The barriers to success resulting from the person's disability are identified and the plan is an effort to explain to everyone concerned how those barriers will be overcome while enhancing the person's chances of successfully achieving the agreed upon goal.

In the State of Wisconsin, under the Bureau of Mental Health & Substance Abuse, the State has been awarded a one year grant (the "CMS Real Choice Award") to bring recovery based; Person-Centered Planning (PCP) to Wisconsin's community -based mental health programs beginning in 2008. A precursor to this grant was a previously awarded grant to implement recovery-based Evidence-based Practices (EBP) under a new statue called, Comprehensive Community Services, (CCS), and technical assistance, as requested by Alice Mirk, (Chief, Integrated Services Section, Bureau of Mental Health & Substance Abuse Services, Wisconsin Department of Health & Family Services from NTAC (National Technical Assistance Collaborative) which is part of NASMHPD (National Association of Mental Health Program Directors).

In 2004, Wisconsin created a new statute called Comprehensive Community Services (CCS) to administer a comprehensive service array for persons with severe mental illness. The statute establishes a scope of psychosocial rehabilitation services with standards for certification and criteria for determining need under Medicaid rules. The emphasis is on recovery, measured by decreases in dysfunctional symptoms and increases in level of health, well being, stability, self-determination, and self-efficacy.

Five counties initially applied for CCS and implemented the components of CCS. These same five counties were then selected by the Bureau to be offered two full-day s and three months of on-going technical assistance via follow-up phone calls on person-centered planning (PCP) as part of the NTAC consultation. Each of these counties use the Mental Health Functional Screen in their programs and agreed to use the SAMHSA Recovery Oriented Systems Inventory (ROSI) for surveying consumer satisfaction, prior to and after applying the PCP approach.

The Division of Quality Assurance and the Division of Health Care Financing also participated in these training sessions to ensure that PCP would be integrated into the regulatory and reimbursement environment in Wisconsin. PCP is one of the new criteria in the proposed Center for Medicaid and Medicare Services (CMMS) rule on psychosocial rehabilitation (Notice of Proposed Rule Making: Coverage for Rehabilitative Services 42 CFR Parts 440 and 441). PCP is considered critical to the advancement of system transformation.

A national behavioral health-consulting group, Alipar Inc, facilitated these training sessions and follow-up calls. The owner of AliPar, Inc. co-authored the book "Treatment Planning for Person-Centered Care: The Road to Mental Health and Addiction Recovery." In preparation for the bi-weekly teleconferences, each county team took turns preparing an Assessment, a Narrative Summary and a Person-Centered Plan of a consumer actively engaged in their mental health program. The documents were e-mailed to each of the other counties prior to the scheduled teleconference. The focus of the teleconference was on the use of PCP with its emphasis on the person's assessed strengths, central theme of the person and their stages of change. The focus on the person-centered plan was on the use of the person's own goals, strengths, objectives, and interventions applied by the providers. This process proved to be beneficial in the development of new skill sets. As a whole, the group determined defining objectives (as opposed to goals and interventions) was the most difficult part in the formation of the person-centered plan.

Since the Division of Quality Assurance and the Division of Health Care Financing participation in these training sessions, these entities were able to monitor and then later facilitate the progress made to ensure that PCP was being fully integrated into recovery planning and outcomes for these state regulated programs in Wisconsin. The monthly follow up teleconferences allowed for ongoing collaboration with each county technical training team. Through this process, each county team worked together building new skill sets while gaining a strategic advantage in this era of transformation. This process created an opportunity for each county to collectively apply their own unique circumstances towards a common goal.

Together, these two approaches PCP and EBP are expected to enhance the service array and enhance a person-centered approach currently being offered by these five existing community-based mental health programs. Each of these counties will be at a strategic advantage towards demonstrating a recovery-oriented, evidence-based, person-centered model of delivery.

## As a result of the PCP training these counties have already achieved the following objectives:

-Appreciation for the need for practice change (and just how difficult that is to do) in terms of conducting person-centered treatment planning
-Preparation for state and/or federal audits which focus on meeting medical necessity criteria for services
-Identification of emerging new frameworks that will guide and develop the person-centered plan
-Understanding of the importance of a strengths-based assessment process
-Defining the key elements of a recovery plan
-Understanding how to apply a stages of change framework to engagement and person-centered planning
-Apply when indicated, Evidence-based Practice as a key intervention within the recovery/service plan

This group of providers agreed that the potential effect of PCP initiatives on their consumer’s with mental illness was significant. Although the benefits of learning how to plan to manage one's illness and make progress toward recovery are compelling, all agreed that recovery is hard work. The switch from being a passive recipient of care to an active partner is very challenging for many consumers. Providers note:

- Results of the training and the follow-up technical training phone calls were: Significant increases in PCP skills were documented.
- County learning was given strong support by state staff.
- Consumer concerns are being addressed through the development of training to address their specific issues.

- County clinical and supervisory staff has additional skill development needs but are committed to the PCP process and are eager to refine their ability to engage consumers in PCP.

The State is hopeful that knowledge about PCP will be widely circulated and used in a variety of mental health specialties as providers begin to appreciate the need for practice change in the era of transformation. Those providers will be encouraged to expand these newly developed skill sets as they are tested and proven to be effective with the newly empowered consumers.

As providers focus on the individual who has strengths, talents, interest rather than theperson as a case or a diagnostic label our mental health recovery process will become a journey of healing and transformation for both providers and consumers.

Consumer ownership of their recovery plan allows providers to view the situation from the consumer's perspective who is now perceived as a capable human being who is full of strengths and resources and the treatment approach is geared toward empowering consumer to achieve a desired future and meaningful life. This collaborative process results in a recovery-oriented plan that is directed by consumers and produced in partnership with providers.

By focusing in on the wisdom of consumers, providers will transition into a consumer- driven process that will assist consumers to enhance their resiliency and hope to the ravages of their illnesses.At the end of the day, providers who implement PCP will address consumer's unique recovery needs by mapping their road to Recovery, Resilience and Wellness.

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# Spinal Cord Injury and its Association with Negative Psychological States

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## Abstract

Spinal cord injury (SCI) is believed to place the individual at a high risk of psychological disorder. The objective of this paper was to examine the relationship between SCI and negative psychological states by comparing levels of negative psychological states in SCI and able-bodied controls. Participants included 33 people with SCI who had completed their inpatient rehabilitation (that is, when living in the community) and 33 able-bodied controls matched for age and sex. In order to determine levels of negative psychological states, the Profile of Mood States and the Spielberger Trait Anxiety Inventory were completed by all participants. The SCI group was found to have raised levels of psychopathology, with 20% having elevated negative psychological states typical of people with a psychiatric disorder. People with SCI have an increased risk of suffering debilitating levels of psychopathology. Future research needs to investigate psychosocial rehabilitation strategies for lowering negative psychological states such as depressive mood in people with SCI after they have completed their rehabilitation program.

**Key Words**: spinal cord injury, depression, anxiety, post-traumatic stress disorder

# Introduction

Spinal cord injury (SCI) results from trauma when the cord is lacerated, bruised, severed or damaged as a result of disease. While SCI is a relatively uncommon disorder, its effects can be devastating (Middleton, Tran & Craig, 2007). The level of impairment resulting from the injury depends upon factors such as the level and completeness of the lesion. The consequence of SCI is usually permanent paralysis of voluntary muscles below the lesion, reduced mobility, impairment of social and vocational activities, with a negative impact on body systems such as respiratory, cardiovascular, urinary, gastrointestinal, reproductive and sensory (Sommer, 2001). Due to improved survival rates, the prevalence of SCI is increasing and the risk (world standardized incidence) is low, at around 15 per million persons per year, though risk is higher for males aged 15 to 24 years at around 40 per million (O'Connor, 2006; Wyndaele & Wyndaele, 2006). The majority of people who sustain a SCI commonly do so as a result of motor vehicle accidents, fall related injuries (especially in the elderly), and sports injuries (O'Connor, 2006).

The impact of SCI on mental health and psychological function has been variously debated (Elliott & Kennedy, 2004; Middleton et al., 2007). Stage theorists assumed that risk of psychopathology was minimal, suggesting that any psychological upset or despondency was a necessary component of a stage process of adjustment to their injury (Buckelew, Frank, Elliott, Chaney & Hewett, 1991; Elliott & Kennedy, 2004). Other more recent research has suggested that SCI is associated with raised risks of negative psychological outcomes that should not be considered a "normal" response to the injury (Craig, Hancock & Dickson, 1994a; Craig, Hancock & Dickson, 1999; Elliott & Kennedy, 2004; North, 1999). Rates of depression have been estimated to range from 20% to 43% when the person with SCI is attending rehabilitation as an inpatient (Frank, Kashani, Wonderlich, Lising, & Visot, 1985; Judd, Stone, Webber, Brown, & Burrows, 1989). Risk of depressive symptoms such as depressive mood and anxiety after discharge from rehabilitation has been estimated to be around 15% (Bombardier, Richards, Krause, Tulsky, & Tate, 2004) up to 50-60% (Craig et al., 1994a; MacDonald, Neilson, & Cameron, 1987; Kennedy & Rogers, 2000). Research also suggests that risks of negative psychological states remain high unless SCI individuals receive effective treatment such as cognitive behaviour therapy during rehabilitation (Hancock, Chang, & Dickson, 1998).

The risk of negative psychological states has been found to be associated with factors such as pain, poor sleep and feelings of helplessness (Craig, Hancock & Dickson, 1994b; Norrbrink Budh, Hultling, & Lundeberg, 2005; Rintala, Loubser, Castro, Hart, & Fuhrer, 1998) as well as frequent hospitalization, medical complications, poor self-care, and difficulties with transportation (Tate, Forchheimer, Maynard, & Dijkers, 1994). In preliminary research, some researchers are finding risks of post-traumatic stress disorder (PTSD) in people with SCI (Kennedy & Evans, 2001; Radnitz, Schlein, & Hsu, 2000). This is not surprising given that SCI is generally a traumatic and life-threatening event. Additionally, while the majority of people with SCI have been found to be not at risk of negative psychological states, around 30-40% have been found to have more helpless expectations and externally focussed in their thinking (Craig, Hancock & Chang, 1994). While factors such as level of lesion, age, age at the time of injury, sex, time since injury and completeness of the lesion have not been consistently found to be associated with lower quality of life (QOL), negative psychological states and pain intensity have been found to lower QOL in people with SCI (Middleton et al., 2007). Coupled with the potential raised risks of psychological disturbance, research has also shown that substance abuse and risk of suicide are more prevalent in the SCI population relative to the able-bodied population before and after the injury (Craig et al., 1999; Heinemann, Doll, Armstrong, Schnoll, & Yarkony, 1991; Stanford, Soden, Bartrop, Mikk, & Taylor, 2007). Unfortunately, rarely has research compared the risk of negative psychological states to matched able-bodied controls during rehabilitation or after rehabilitation when the SCI person is living in the community. Therefore, the aim of the present study was to investigate the level of negative psychological states in people with SCI living in the community relative to able-bodied persons matched for age and sex.

# Methodology

## Participants

Subjects included 33 adult persons (26 males; 7 females) who had a SCI (mean age= 41.1, SD=11.6; range 22 to 60 years). Exclusion criteria included a history of psychopathology before the SCI, traumatic brain injury, and non-English speaking. The mean time since their injury was 11.7 years (SD=11) and 42% had complete lesions (that is, American Spinal Injury Association or ASIA impairment grade A). The able-bodied controls consisted of 33 adult persons with a similar sex ratio (7 females) and similar age (mean age= 39.5, SD=12.3; range 22 to 57 years). All SCI and able-bodied subjects were approached to take part in the present study while they were participating in an ongoing larger study into the relationship between brain activity and neurological damage. They were admitted into the study after they gave written consent. Institutional ethics approval was obtained prior to their participation in the study.

### *Measure of negative psychological states*

The Profile of Mood States (POMS; McNair, Lorr, & Droppleman, 2005) was used to estimate the level of negative psychological states in the two groups. The six POMS sub-constructs (Tension, Depression, Anger, Vigor, Fatigue, Confusion) and the Total POMS mood state score were used. The POMS has been shown to be a reliable and valid instrument in measuring psychological states and psychopathology (McNair et al., 2005). Inspection of the items of the POMS suggests it will provide an estimate of psychopathology free of medical conditions prevalent in a disease like SCI that are likely to inflate the depressive mood score (eg. such as problems sleeping, or reduced physical activity). Even though the POMS has been used widely in non SCI fields, it has rarely been used to estimate the extent of psychopathology in SCI people. Therefore, we believed the use of the POMS for this task would make a valuable contribution to the rehabilitation literature. The Spielberger Trait Anxiety Inventory (Spielberger, Gorsuch, Luschene, Vagg, & Jacobs, 1983) was used to assess trait anxiety. This has also been shown to be a reliable and valid questionnaire (Spielberger et al., 1983).

### *Analysis*

Independent t-tests were used to detect significant differences between the two groups. Based upon prior studies, a moderate to large effect size (0.6) was assumed to occur for the difference between the SCI and able-bodied groups (Craig et al., 1994a), with 33 subjects in each group providing sufficient power to detect true differences (power= 70%). The Sign Test (Siegal, 1956) was used to determine the probability that the SCI group would always be higher in negative psychological state scores than the able-bodied group. A value of 0.5 was therefore given to each prediction of difference for all 8 measures between the two groups, since there is theoretically a 1 in 2 probability of the SCI group being greater or lower than the able-bodied group. A value of 1 was given to each incorrect prediction (that is, SCI value was actually lower than relevant score for the able-bodied group). Using this technique, the probability of estimating the direction of difference by chance can be determined.

**Table 1: Descriptive statistics for the POMS sub-contructs and POMS Total Score for SCI Group 1 and Able-bodied Control Group 2**

| | Mean 1 SCI | Mean 2 Control | SD1 | SD2 | ±95CI 1 | ±95CI 2 | t-value (df=64) | prob. |
|---|---|---|---|---|---|---|---|---|
| Tension | 7.5 | 6.9 | 6.6 | 4.8 | 5.2-9.9 | 5.3-8.7 | 0.4 | .69 |
| Depression | 9.0 | 4.4 | 12.0 | 4.1 | 4.8-13.3 | 2.9-5.8 | 2.1 | .03 * |
| Anger | 8.1 | 5.3 | 8.3 | 4.6 | 5.2-11.1 | 3.6-6.9 | 1.7 | .09 |
| Vigor | 15.6 | 17.5 | 6.1 | 4.8 | 13.5-17.7 | 15.8-19.2 | -1.4 | .15 |
| Fatigue | 8.3 | 7.9 | 6.9 | 4.5 | 5.8-10.7 | 6.4-9.6 | 0.2 | .83 |
| Confusion | 6.5 | 5.5 | 4.6 | 3.1 | 4.8-8.1 | 4.4-6.6 | 1.0 | .32 |
| POMS Tot | 23.8 | 12.6 | 38.6 | 18.3 | 10.1-37.6 | 6.1-19.1 | 1.5 | .13 |
| Trait anxiety | 36.8 | 34.9 | 10.5 | 6.7 | 33.1-40.6 | 32.4-37.4 | 0.8 | .39 |

*<.05

**Table 2: 2x2 contingency table with the number of participants with SCI who reported abnormally high levels of psychopathology versus those with low levels relative to the able bodied controls**

| | Low POMS Total (<70) | High POMS Total (≥70) | |
|---|---|---|---|
| SCI | 27 | 6 | 100% |
| Able-bodied controls | 32 | 1 | 100% |

$X^2$=4.0, df=1, p<.05, Odds ratio= 7.1

# Results

Table 1 shows the results for the independent t-tests for the POMS sub-constructs, the POMS Total score and Spielberger trait anxiety measure. Inspection of the data demonstrates that the people with SCI had consistently higher levels of psychopathology in all the 8 measures relative to the able-bodied controls (in some cases only marginally, such as for Fatigue). The Sign Test analysis suggests that the chance probability of all 8 measures being higher in the SCI sample relative to the control is remote (p<.05). The SCI group was found to have significantly higher levels of depressive mood (p<.05, df=64). The failure to find significant differences for Anger and POMS Total was due in part to the large variation in scores in the SCI sample (in all POMS measures the SCI standard deviations were as large or larger than the mean values). It is noteworthy that the POMS Total psychopathology score for the SCI sample was twice the level of the able-bodied controls (23.8 versus 12.7). This large variation in psychopathology scores in the SCI sample is further illustrated in Table 2, which shows 2x2 contingency data in which participants who reported abnormally high levels of psychopathology were compared to those with lower levels in both groups. A score of 70 in the POMS Total score was used as the cut off score given that scores of 70 or over typically occur in psychiatric populations (McNair et al., 2005). Persons with SCI had a significantly higher chance of having a psychopathology score of 70 or above ($X^2$=4.0, df=1, p<.05), with a high odds ratio score of 7.1 (that is, the odds of persons with SCI having high levels of psychopathology is seven times that of able-bodied persons). There were no significant correlations between time since injury and ASIA level with self-reported psychological states.

# Discussion

The data presented in this paper confirmed the findings of the literature that suggest a significant proportion of people with SCI are at risk of developing negative psychological states (Elliott & Kennedy, 2004; Middleton et al., 2007; North, 1999). The SCI group had significantly raised levels of self-reported depressive mood relative to the able-bodied controls. While differences between the SCI group and the controls did not reach significance for the other seven measures, the SCI group had consistently higher levels of negative psychological states for all measures, compared to the able-bodied controls. Furthermore, people with SCI had seven times the risk of having increased levels of negative psychological states typical of people with a psychiatric disorder compared to the able-bodied controls (20% of the SCI people had elevated levels of negative psychological states). It is possible that some questionnaires (such as the Beck Depression Inventory) inflate negative mood scores because they contain items biased towards medical complications associated with SCI (eg. items that focus on sleep, weight and physical performance). However, inspection of the items in the POMS suggests this is not a problem, as items require subjects to respond to 60 adjectives about how they feel. Therefore, the elevated POMS scores associated with SCI more than likely reflect valid increases in self-reported negative psychological states. This finding is somewhat concerning given that the participants had been living in the community on average 11 years after their injury, and were people who were getting on with their lives. They were not psychologically upset people recruited from hospital wards due to complications or mental health problems. Clearly, the findings have implications for current psychosocial strategies being used during and after rehabilitation.

One limitation in this study was the use of only a self-report questionnaire to assess psychological states. Future research therefore needs to utlize a comprehensive range of assessment including diagnostic clinical interviews designed to detect psychopathology. However, as stated above, the findings of this paper have revealed possible challenges for current rehabilitation strategies designed to counter negative psychological states. Further research should assess and gather best evidence regarding treatments that can reduce psychological states in SCI people during rehabilitation, as this may then reduce the prevalence of negative states in the long-term by assisting the person with SCI to maintain a healthy mental health and adjustment (Craig et al., 1998). Potential treatments include pharmacological therapies to counter psychopathology such as depression, as well as non-pharmacotherapies such as cognitive behavioral therapy or other psychosocial therapies known to be beneficial for improving psychological status. It is crucial however, that psychosocial and mental health be seen as important outcomes for rehabilitation following SCI (Middleton et al., 2007).

It is also becoming clear that our knowledge about the association between negative psychological states and SCI needs clarification. Ten years ago rehabilitation researchers and clinicians were calling for comprehensive research that could clarify the nature of the psychological reaction of people to SCI (Elliott & Frank, 1996; Jacobs, Zachariah & Bhattacharji, 1995). Unfortunately, little has changed today. We need to determine the prevalence of people with SCI who develop despondency or mild depressive disorder (eg. elevated negative psychological states) as distinct to a major depressive disorder (MDD), dysthymia or possibly adjustment disorder. We also need to determine how many people with SCI develop depressive symptoms due to a primary anxiety disorder such as PTSD. The influence of pre-morbid psychopathological factors on psychopathology both during and after rehabilitation also needs clarification. Clearly, prospective research needs to be conducted to resolve the gaps in our knowledge about the association between SCI and negative psychological states. Such comprehensive data could well lead to an improvement in rehabilitation strategies that address the psychosocial needs of people with SCI.

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