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# Safe Minds – Perceptions of Safety in a Rehabilitation Clinic for Serious Persistent Mental Illness

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## Abstract

**Objective:** To determine whether women with severe, persistent mental illness feel safe when attending rehabilitation programs. **Method:** After discussion with stakeholders, a written questionnaire was designed and administered to women attending a large, mixed-gender urban outpatient psychosocial rehabilitation clinic. Responses were analyzed using descriptive statistics. **Results:** Sixty-eight women participated in the study. While the majority (N=42) reported feeling safe in their current program, those reporting sexual advances during previous treatment (N=19) were more likely to also report feeling currently unsafe. **Conclusions:** Women who report having been approached by co-patients or staff in a sexual manner during prior treatment continue to experience psychiatric rehabilitation program sites as unsafe places. While not wanting women-only clinics, many women ask for women-only programming.

**Key Words:** Women; Safety; Schizophrenia

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## Introduction

Though much safer than they once were, psychiatric inpatient wards continue to be settings where harmful experiences occur (1). This is perhaps inevitable since the acuity level on inpatient units is high and since severe mental illness is associated with aggression (2,3). The situation is not limited to inpatient settings. Frueh et al. (4) recently reported that, among 142 adults attending a day hospital program, 31% had experienced physical assault, 8% had been sexually assaulted, and 63% had witnessed traumatic events over the course of treatment. This group found an association between patients' exposure to sexual assault prior to the beginning of psychiatric treatment and a subsequent experience of sexual assault by a psychiatric staff member. The Frueh research group classified such experiences as 'sanctuary harm' and conducted qualitative interviews with 27 patients to learn more about such incidents. Of the 27, 18 had the bad experience on an inpatient ward. One prominent theme that emerged from the interviews was the danger inherent in a psychiatric hospital setting: the fear of physical violence and the perceived arbitrary nature of the rules imposed on patients. A second important theme centered around patient-staff interactions, frequently seen as unjust, disrespectful, and impersonal (5).

Patients and staff are known to view safety issues from somewhat different perspectives (6). Staff tends to attribute aggressive events to illness factors whereas patients hold interpersonal and environmental factors to be equally responsible (7,8, 9). Quirk et al. present the patient perspectives from two studies: (a) ethnographic research on three UK acute psychiatric wards, undertaken between 2000 and 2002, and (b) a content analysis of qualitative data from a 1999/2000 survey of psychiatric wards in England. They find that patients, as staff, attribute physical assault risk to the acuity level of co-patients illness but they feel that the risk is enhanced by poor staffing levels and negligence in surveillance (10). Staff is probably better at preventing physical aggression than they are at protecting vulnerable patients from unwanted sexual approaches from other patients (11). That is because of the ambiguity that surrounds interpersonal behavior and the wish on the part of staff to not intrude and not appear seem overly authoritarian. According to Quirk et al., this leaves patients to fend for themselves, something not all are able to do well (10).

One solution is services segregated by sex where women would be protected but, despite the fact that women are usually the targets of violence in psychiatric settings, when asked, most women express a preference for mixed sex wards over single sex wards (12, 13). This may well be because single sex wards do not guarantee safety from assault and exploitation (14). While differences do exist between male and female aggression, both sexes, when acutely ill, are aggressive to similar degrees (15).

Inpatient settings are particularly dangerous because patients tend to be severely ill and not able freely to leave. They stay in such settings overnight when supervision may not be adequate and the perception of danger increases. Outpatient settings are less frightening places. Fearful patients can bring companions to

outpatient appointments and can leave more easily, if frightened. Nevertheless waiting rooms, hallways, elevators, stairwells, smoking areas, bathrooms in outpatient settings can still be perceived as potentially dangerous. Patients often come to the same location for many years so that animosities and fears can grow, both among patients and between patients and staff. Although patients are relatively stable in such settings, acute relapses do occur and smoldering delusional thinking can sometimes erupt. Because several women patients expressed fears when attending their outpatient rehabilitation appointments we decided to systematically question them about their perceived safety and whether or not they would prefer to receive services segregated by sex.

## Methods

### Ethics Review

Informed consent was obtained in writing from each participant individually after one of us (LL) explained the purpose of the study verbally and read out loud a summary of the protocol. The study was reviewed and approved by the institutional review board of the Centre for Addiction and Mental Health, University of Toronto.

### Instrument Design

Published questionnaires were not applicable to outpatient settings so, after lengthy discussion with a variety of stakeholders, we designed a survey instrument. It takes the form of a written questionnaire and includes a mix of closed-ended, open-ended and 5-point Likert scaled questions. There are ten sections in the questionnaire: background information, facilities, services, staff, other patients and clients, access to clinic, experience in other outpatient mental health clinics and inpatient experiences, children at the clinic. A copy of the questionnaire is available upon request.

### Subjects

All female clients with severe and persistent mental illness attending an outpatient psychosocial rehabilitation service (the Archway Clinic) affiliated with the schizophrenia and chronic care division of the Centre for Addiction and Mental Health (CAMH) were eligible to participate. Recruitment was via flyers posted at the clinic site and word of mouth advertisement via case managers. Out of 76 regularly attending women at the Archway Clinic, 68 consented to participate. These women were primarily middle-aged (28% aged 35-44 and 29% aged 45-54) and were long-term clients of CAMH, with 38% reporting that they had been using the service for more than 5 years. Only 10 subjects had begun attending within the preceding year. Participants reported a range of visit frequency ranging from one per month (28%) to one per weekday (4.4%).

### Survey Administration

One survey administrator (LL) was present as all subjects individually completed the survey. She provided clarification of questions and, in cases where women reported difficulty writing, she transcribed their responses verbatim. All participants were paid a \$10 (Canadian) honorarium for their participation.

### Data Analysis

Descriptive statistics were calculated for each questionnaire item to determine frequency of endorsement.

## Results

### Perceptions of Safety

Most participants (61.8%) perceived themselves to be safe while attending the rehabilitation program. Nevertheless, 60% reported having been “hassled” to some degree during appointments (e.g. being asked for cigarettes or money by co-patients, being offered illegal drugs). Nineteen participants reported that another patient or a staff member had approached them in a sexual manner at some time in the total course of their

psychiatric care. This latter group was significantly less likely than the remainder to endorse satisfaction or perception of safety with various aspects of the rehabilitation program. All the questions reflected this pattern as, for example, Table I.

Table 1. Percent Endorsement of Survey Items in Women Who Reported Previous Sexual Harassment (N=19) vs. Women Who Did Not (49)

Item	Sexual Harassed %	Non-Harassed %	Chi-Square	Two-Tailed Significance (p)
The outpatient washrooms are safe	52.9	91.1	11.517	.002
The stairs are adequately lit	42.1	78.3	8.037	.008
The waiting room is a safe place for children	22.2	64.3	8.927	.004

Spontaneously offered comments also reflected this pattern. Examples of positive comments:

“Every time I have entered Archway I have experienced a pleasant environment.” “All staff are friendly and helpful and emotionally well.” “On the whole, the attitude and service at Archway is great.” “A good place.” “There is an effort being made for the needs of the people that come here.” “The two workers I have at Archway are very caring and helpful.”

Examples of negative comments:

“I as a female do not feel comfortable in Archway. Loud, swearing patients make me nervous.”

“Interior of Archway is safe but the area surrounding feels a bit unsafe.” “Nurses should listen to patients. Psychiatrists should show compassion.” “The nurses and doctors could be nicer. Sometimes they do and say the wrong things.” “Staff could be more considerate.” “More staff should interact with clients.” “More staff should be available to sit and talk.” “I would like it to be more comfortable at Archway.”

The women as a group did not endorse the need for a women-only clinic. Twenty women (23.9%) said yes; 25 (26.9%) said no. The rest were neutral. However, the majority of respondents (47, 72.3%) agreed that they would like to have women-only groups offered within the mixed-sex program. Some examples were: cooking and nutrition classes, art groups for women, shopping group (“go shopping as a group of ladies and not only with the case worker”), guidance group on pregnancy and children, therapy for women who deal with past abuse. “I would like more services focused towards disabled women.”

## Discussion

In agreement with previous psychiatric literature (12, 13), the majority of women surveyed felt safe in the mixed-gender rehabilitation program and rejected the idea of a woman-only service. However, women who reported sexually inappropriate advances during their treatment history were less likely to report feeling safe and were less likely to express satisfaction with the service. This parallels the results of Frueh et al. (4).

This study has implications for service provision; it suggests that there are sub-groups of women who attract



unwanted sexual attention from co-patients and sometimes from staff. This is consistent with data indicating that two-thirds of women who experience sexual victimization will be revictimized at some point in their lives (16). The experience of perceived sexual harassment while accessing mental health services is associated with feelings of discomfort and threat when attending treatment programs, and may become a significant barrier to accessing care. The expression of discomfort may be considered “delusional” and be ignored by treatment providers. This is, in our view, a serious clinical error. Whatever the explanation for such perceptions, they need to be addressed to ensure that patients continue to access the service and benefit as much as possible from the treatment provided.

### Limitations

There are several limitations to this study. The survey instrument was, out of necessity, developed specifically for the survey and awaits psychometric testing. Generalizability of these findings is also limited by the fact that highly dissatisfied or highly fearful patients could choose not to attend the program. In other words, the degree of general dissatisfaction with services provided is probably underestimated in this study. Finally, the study was conducted in one psychiatric setting, and replication at other sites is warranted.

### Utility

These findings have already produced an immediate and lasting effect at the participating site. The results were disseminated at local meetings for front line health care providers, as well as for patients. These meetings led to a modification of the clinic space in order to provide a “for women only” waiting area. The findings have also generated discussion at the institutional level and led to a modification in the reporting protocol for patient charges of sexual harassment. Immediate changes such as these empower patients because they demonstrate that client fears, wishes, and needs are taken seriously and that the staff and the institution are responsive to patient preferences.

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# Living with unexplained somatic symptoms

## A combined qualitative and quantitative study of life-stories from rehabilitation clients

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## Abstract

*Objective:* To compare life-stories written by rehabilitation patients with medically unspecific complaints with life-stories written by other patients at the same rehabilitation centre.

*Methods:* 136 stories were divided into four groups: well-defined somatic complaints, unspecific complaints, a combination of well-defined and unspecific complaints and a group of exclusively mental and psychological complaints. Data-driven categories in the texts were identified and used for non-parametrical statistical tests.

*Results:* Overall, the life-stories described a high amount of stress in both childhood and adulthood. But the patients with unspecific complaints differed from all the other groups in that they experienced a significant more stressful work-load. They were the most dissatisfied group and revealed the highest wish for pension.

*Conclusion:* Although our study has many constraints it support the hypothesis that clients with medically unexplained and vague symptoms express a view of their daily lives as filled with more burdens and difficulties than do other clients in the same rehabilitation setting.

**Keywords:** Chronic fatigue syndrome; Illness beliefs; Life-stories; Somatoform disorders.

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## Introduction

The classification, conceptualization and treatment of patients with “medically unexplained (somatic) symptoms” are an ongoing debate. There are different positions in the debate where the patient is often depicted as a marginal, neglected wasteland between the walled citadels of medicine and psychiatry (Editorial 2004). In a broader interdisciplinary context, they present a problem for the integrity of medicine and psychiatry and are therefore often conveniently removed or exported to related, disciplines; from medicine to psychiatry and further to the social sciences. These different positions do not exclude each other, but rather represent fundamental conflicts between the present professional conceptions of illness (Afari & Buchwald 2003). The scientific debates are, however, characterized by a lack of empirical evidence for the patient’s perspective. Although various descriptions of patient experiences exist in the literature on e.g. somatoform disorders and so-called functional illnesses, these are usually presented in questionnaires and semi structured interviews aimed for clinical assessment. Few have focused on the patients biographies (Bury 1982) or life stories (Frank 1993, Williams 1994) and used an observational or qualitative method of inquiry aimed to elicit and describe the beliefs of the patients in their own terms (Clements et al. 1997).

This article contributes with a phenomenological study that gives priority to the patient and his /her subjective position guided by his own formulations. The aim is to compare life-stories written by rehabilitation patients with unspecific and unexplained medical complaints with the life-stories written by other patients at the same institution with well defined medical complaints, in order to examine the content of their “first persons experience”.

The study is a “natural” study, where the population of a rehabilitation center, were required to write down their life-story as part of a training program.

## METHODS

### **Population and life-stories**

In the period 1998- 2002, 628 patients completed a rehabilitation course at a Danish rehabilitation center (YDUN Rehabilitation Center, Department of Social Medicine, Aalborg Hospital. The clients have been referred with a broad spectrum of medical and psychiatric diagnoses. During a three month rehabilitation course, participants were requested to write down their life-stories as one out of various course activities, and in the first five weeks of the course, time was set aside each day for writing these stories. The participants were free to develop the form and content of the stories as they wished.

In 2003 The Social-Medical Unit, Aalborg Hospital, contacted 610 participants and asked if they were willing to participate in our research project by anonymously making their life-stories accessible. 230 participants approved and contributed their life-story.

10 stories were disregarded due to missing pages and lack of basic information, such as gender and age. To make the data comparable and suitable for a quantitative analysis 84 stories were disregarded because of stories of less than 2000 words, and stories containing less than 250 words under general items of childhood or adulthood.

136 life-stories fulfilled the criteria, and were considered suitable for the analysis. Of these 136 stories, 58 were written by men, and 78 by women, the average age was 40, and the age-range was from 21 to 61 years old. The average story was of 5022 words, the shortest was 2550 words and the longest was 23750 words.

### **Quantitative and Qualitative analysis**

A traditional qualitative analysis has not been applied, rather a systematic reading and recording of units of meaning derived and grounded from the stories. In 30 randomly chosen life-stories, units of meaning in the text have been identified and categorized guided by our interest in 1. general level of stress in childhood and adulthood, 2. specific work-related stresses, 3. self perception and causal understanding of symptoms, 4. user satisfaction and requirement of retirement for pension. A scoring manual was developed on the basis of these data-driven categories. A further 30 life-stories were scored with the manual, following which the manual was corrected and completed. All 136 life-

stories were then coded of the authors RM and MHT according to the final scoring manual containing 105 individual categories. Disagreement between the scoring was solved on weekly meetings and discussed with the research group.

The number of life-stories mentioning the categories has been estimated both as 1) a “dichotomized presentation,” (does a life-story mention a category or not), and 2) as a “quantitative presentation,” (how many times a life-story mentions one category). The dichotomized presentation, could, for instance, be the number of life-stories mentioning “fatigue” one or several times. The quantitative presentation would be the number of life-stories that mention “fatigue” once, twice, three times, four times etc. If the same result for these two ways of presenting the data is seen, it was concluded that the length of the life-stories does not have a significant influence on the result.

The results will be presented as single categories in actual numbers and percentages and where similarities was found as general categories in median and interquartile range. Non-parametric statistical analysis has been applied with the use of Kruskal Wallis test to estimate the statistical significance.

## RESULTS

### COMPLAINTS

In the life-stories ten categories of complaints emerged. In the following these ten complaints are dichotomized presented as a percentage of the total amount of life-stories containing the category of complaint, no matter how many times the individual patient has mentioned the category.

- 62 % General pain
- 56 % Back-pain
- 40 % Fatigue
- 38 % Anxiety
- 25 % Depression
- 23 % Drug Abuse
- 16 % Psychiatric diagnostic symptoms
- 16 % “Worn down”
- 8 % Suicide attempts
- 56 % Other mental problems

### Types of complaints

It was feasible to put the individual categories together in the following four groups:

1. Well-defined compliants: Complaints are mentioned in relation to clear somatic etiology, such as back pain after a car accident or due to medical illness. 19% (18 female, 8 male)
2. A combination of well-defined and unspecific complaints: The complaints refer to a medical diagnosis combined with additional complaints of unexplained medical symptoms. 22% (21 female, 9 male)
3. Unspecific complaints: The compliants are vague and medically unspecific, and mentioned in relation to fatigue, stress and burn-out. The complaints can be confined such as back-pain or headache, however they are mentioned without relation to a specific etiology.
4. 43% (52 female, 6 male) Mental/ psychological complaints: Exclusively mental and psychological complaints such as anxiety and depression. 16% (15 female, 7 male).

The total population has a predominance of females over males, for the group with exclusively vague and unspecific complaints the gender difference is significantly different from the other groups ( $p < 0.045$ ).

### GENERAL LIFE STRESSES

### **Stress categories**

In the life-stories there are 45 categories for experiences of stress. In the following dichotomized presentation the 15 most frequently mentioned categories illustrates the total number of life-stories containing this category.

#### **Childhood:**

- 59 % other problems with parents
- 46 % other undefined burdens
- 37 % high level of responsibility and workload
- 31 % experiences of being bullying
- 29 % learning difficulties
- 27 % loneliness
- 26 % parent abuse
- 21 % physically ill parent
- 21 % economic problems
- 18 % parent divorce
- 16 % parent with drug abuse
- 14 % loss of one or both parents
- 13 % mentally ill parent
- 12 % sexual abuse
- 11 % placement outside home

#### **Adulthood:**

- 59 % high level of workload and stress
- 51 % unemployment, 18% more than three years
- 50 % divorce, one or more times
- 44 % being fired from job
- 43 % economic problems
- 40 % loss of parent or sibling
- 31 % drug abusing spouse
- 27 % loneliness
- 26 % abusive spouse
- 14 % loss of spouse
- 9 % mentally ill spouse
- 9 % children placed outside home
- 8 % physically ill spouse
- 6 % bullied at work
- 5 % sexual abuse outside marriage

### **General categories of stress**

The individual categories have been combined in three general categories as follows:

- 1: Stressful experiences in childhood: consisting of 11 categories concerning family relations, 4 categories concerning social problems and 6 categories concerning other problems.
- 2: Stressful experiences in adulthood: consisting of 15 categories concerning family relations, 4 categories concerning social relations, and 4 categories concerning other problems.
- 3: Stressful experiences in both childhood and adulthood: consisting of all of the 45 categories concerning stressful experiences.

The life-stories are characterized by many descriptions of stressful experiences. In total, 89% describe stressful experiences in childhood, 39% mention at least four categories and in most cases stressful experiences such as incest, suicide attempts, drug abuse, and abuse. 94% describe stressful experiences in adulthood. 29% mention at least four of these categories.

Tabel 1.

**Stress and type of complaint**

The number of times a patient mentions one or more of the categories in the three general stress categories in the median and interquartile range.

	1. Well-defined complaints (N = 26)	2. Combination of well-defined and vague complaints (N= 30)	3. Unspecific complaints (N=58)	4. Mental / Psychological complaints (N=22)
<b>1: Stressful experiences in childhood</b>	3 (0.75 - 11.25)	7 (4.00 - 10.25)	8 (4.00 - 13.25)	8.5 (5.75 - 14.00)
<b>2: Stressful experiences in adulthood</b>	7 (3.00 - 16.25)	6.5 (4.75 - 15.00)	10 (7.00 - 17.00)	9 (4.75 - 15.25)
<b>3: Sum of Stressful experiences</b>	12 (4.00 - 29.50)	17 (7.00 - 22.50)	19 (11.75 - 28.25)	19.5 (13.00 - 28.50)

Many stressful experiences are mentioned by all four groups of patients. Although the groups with unspecific complaints and with mental /psychological complaints, do not differ significantly from each other, compared to the two other groups, their mention of stressful experiences is significantly higher, particularly in childhood.

Overall comparisons were made between the four groups using the Kruskal Wallis test. Where the overall effect was found to be significant all pairwise comparisons between the four groups were examined, also using the Kruskal Wallis test

*Dichotomized estimates:* General category 1: groups 1,2,3 and 4 ( $p < 0.01$ ), 1 and 3 ( $p < 0.01$ ), 1 and 4 ( $p < 0.001$ ). General category 3: groups 1 and 3 ( $p < 0.02$ ).

*Quantity estimates:* General category 1: groups 1,2,3 and 4 ( $p < 0.02$ ), 1 and 3 ( $p < 0.01$ ), 1 and 2 ( $p < 0.05$ ) 1 and 4 ( $p < 0.01$ ). General category 2: groups 2 and 3 ( $p < 0.05$ ). General category 3: groups 1 and 3 ( $p < 0.03$ ), 1 and 4 ( $p < 0.05$ )

**WORK-LOAD**

70% of the patients mention that they have been stressed by having had a lot of responsibility and a heavy workload. The three categories; high level of responsibility in childhood, heavy work-burden in adulthood, and an experience of being burnt out, is combined in a general category called “heavy work-load”

Tabel 2.

**Work-load and type of complaint**

The number of times one or more of the categories are mentioned, is illustrated in median and interquartile range:

	1. Well-defined complaints (N = 26)	2. Combination of well-defined and vague complaints (N= 30)	3. Unspecific complaints (N=58)	4. Mental / Psychological complaints (N=22)
<b>Heavy work load</b>	1.5 (0.00 - 4.00)	1.5 (0.00 – 4.25)	2.0 (1.00 - 4.00)	1.0 (0.00 - 3.00)

In the above general category for heavy workload, the patient groups have been examined for all combinations. 68% of those patients who describe themselves as being “burnt-out” belong in the group of unspecific complaints. The patients with unspecific complaints differ from the other groups by scoring higher on the heavy workload general category, examined both by dichotomized numbers, and by quantitative numbers. The group with mental / psychological complaints, differs from the other groups by mentioning a significant lower number of categories than the patients with unspecific complaints.

*Dichotomized estimate:* General category 4: groups 1,2,3 and 4 ( $p < 0.03$ ), 2 and 3 ( $p < 0.02$ ), 3 and 4 ( $p < 0.02$ ).

*Quantity estimate:* Groups 3 and 4 ( $p < 0.03$ ).

### CAUSAL UNDERSTANDING AND COHERENT LIFE-STORY

Causal understanding was defined as those points in the life-stories where two different categories are connected to one another. In all four groups:

40% correlate two psychological categories

19% correlate experience of stress with actual mental condition

16% correlate physical complaints with actual mental condition

These three categories for correlation have been combined in a general category, labelled “causal understanding.”

Tabel 3.

#### Causal understanding and type of complaint

The number of times the patients mention one or more of the categories for causal understanding is given by the median and interquartile ranges for the general category and by the amount and percentages for the individual categories.

	1. Well-defined complaints (N = 26)	2. Combination of well-defined and vague complaints (N= 30)	3. Unspecific complaints (N=58)	4. Mental / Psychological complaints (N=22)
<b>Causal understanding</b>	1 (0 – 3)	2 (0 – 3)	1 (0 – 3)	1 (0 – 3)

<b>Correlation between stressful experience and actual physical condition</b>	4 15%	4 13%	11 19%	8 36%
<b>Correlation between physical complaint and actual mental condition</b>	4 15%	4 13%	11 19%	3 13%



<b>Other types of psychological insight</b>	13 50%	8 26%	22 37%	14 64%
<b>Wish for psychological help</b>	9 35%	8 27%	14 24%	10 46%

The patient group with mental/psychological complaints (4), reveal the highest incidence of causal understanding while the groups 2 and 3, with unspecific complaints, reveal the lowest

*Dichotomized estimate:* Groups 1, 2, 3 and 4 ( $p < 0.05$ ), 3 and 4 ( $p < 0.04$ ), 2 and 4 ( $p < 0.008$ )

The form of the life-stories was examined. If coherence between the individual categories was found in more than half of the life-story, the story has been categorized as coherent.

Tabel 4.

**Coherence of life-story and type of complaint**

Amount and percentage of patients that reveal a coherent life-story:

	1. Well-defined complaints (N = 26)	2. Combination of well-defined and vague complaints (N= 30)	3. Unspecific complaints (N=58)	4. Mental / Psychological complaints (N=22)
Coherent life-story	9 34%	7 23%	9 15%	12 55%

The group with unspecific complaints, reveal the least coherent, and most fragmented life-stories, whereas the group with mental problems have the most coherent life-stories.

*Dichotomized estimate:* groups 1,2,3 and 4 ( $p < 0.005$ ), 3 and 4 ( $p < 0.001$ ), 2 and 4 ( $p < 0.04$ )

**SELF PERCEPTION**

Tabel 5.

**Negative self perception and type of complaint**

Amount shown as a percentage that reveals a negative self-perception

	1. Well-defined complaints (N = 26)	2. Combination of well-defined and vague complaints (N= 30)	3. Unspecific complaints (N=58)	4. Mental / Psychological complaints (N=22)
Negative Self- perception	7 27%	16 53%	32 55%	17 77%

53 % of all life-stories contain a category with a negative self-perception. The group with specific complaints presents the least negative self- perception, whereas the group with mental / psychological problems presents the most negative self-perception. The group with unspecific complaints has a more negative self- perception than the group with well-defined complaints.

*Dichotomized estimate:* groups 1,2,3 and 4 ( $p < 0.006$ ), 1 and 3 ( $p < 0.02$ ), 1 and 2 ( $p < 0.05$ ), 1 and 4 ( $p < 0.001$ )

### USER SATISFACTION AND REQUIREMENT FOR RETIREMENT AND PENSION

59 % of the patients have described their dissatisfaction with sentences like: "not very helpful", "did not work at all" in relation to the following categories:

General Practitioner 14%  
Health System 36%  
Psychologist 5%  
Social services 33%  
Work 3%  
Friends and Family 6%  
Rehabilitation centre 16%, fellow participants 1%

Tabel 6.

Dissatisfaction and type of complaint

These nine categories have been brought together in a general category, labelled "patient dissatisfaction". The number of times the patients mention one or more of the categories is in the median and interquartile range.

	1. Well-defined complaints. (N = 26)	2. Combination of well-defined and vague complaints (N= 30)	3. Unspecific complaints: The new disease (N=58)	4. Mental / Psychological complaints (N=22)
<b>Patient Dissatisfaction</b>	0.0 (0.00 – 1.00)	1.5 (0.00 - 2.00)	1.0 (1.00 - 2.00)	1.5 (0.00 - 2.00)

Patient groups 2 and 3, are significantly more dissatisfied than the other two groups.

*Dichotomized estimate:* groups 1, 2 and 3 ( $p < 0.03$ ), 1 and 2 ( $p < 0.01$ )

Tabel 7.

### Requirement of retirement for pension and type of complaint

Numbers as a percentage that express a wish for early retirement.

	1. Well-defined complaints. (N = 26)	2. Combination of well-defined and vague complaints (N= 30)	3. Unspecific complaints (N=58)	4. Mental / Psychological complaints (N=22)
Wish for pension	7 27%	13 43%	34 59%	4 18%

56% would like retirement for pension. Among the group with mental complaints, the wish for pension/early retirement is the lowest, and among the group with unspecific complaints the wish is the highest.

*Dichotomized estimate:* Groups 3 and 4 ( $p < 0.01$ ), 1 and 4 ( $p < 0.04$ )

## DISCUSSION

### Resume

Overall, the life-stories from the participants at the Rehabilitation Centre were characterized by experiences of stress in both childhood and adulthood. The groups with unspecific complaints and with mental/psychological complaints

did not differ significantly from each other as regard to amount of perceived stress. Compared to the two other groups, however, they mentioned significantly more stressful experiences, particularly in childhood. Concerning stressful work related experiences, the patients with unspecific complaints differed from the other groups in that they experienced a significant higher level of work-load. The group with unspecific complaints wrote the most incoherent life-stories, whereas the group with mental / psychological problems, wrote the most coherent stories. The group with unspecific complaints revealed a more negative self-perception compared with the group with well-defined complaints, however, not as negative as the group with mental / psychological problems. The latter was the least likely to ask for retirement and pension. The group with unspecific complaints revealed the highest wish for pension and was the most dissatisfied group.

These results should be taken with a grain of salt. The material is not necessarily representative for the big and varied group of patients with “unexplained medical complaints”. We have named our study a “natural study” because it reflects the situation on a rehabilitation centre with patients of many illnesses. Our intention was to give a more detailed picture of the patients own perception of their life and to examine if they themselves perceive the etiology of their illness.

The quantitative and qualitative analysis of these self-presentations is not compared with the patients’ “objective” medical and social situation, due to phenomenological position to convey and recognize the patient experience as valid in itself.

Although the life stories are “first persons” self-presentations they do reflect the context in which they are written. A story always has a sender and a receiver even it is hidden in an internal dialogue of the writer. And although the life stories were written for the patients itself and not intended to be read by others, they did have the potential of being discussed with the professionals at the rehabilitation centre and therefore did have a message.

A traditional qualitative analysis has not been applied as e.g. described in the method of grounded theories, but has consisted of a systematic reading and recording of units of meaning with the intention to examine hypothesis already given. The large number of life stories gave us an opportunity to combine the method of “inductive narrative analyses” with a quantitative method. Even it is not consistent with evidence based medicine the combination of qualitative and quantitative methods are recommended suited to test medical hypothesis (Pope & Mays 1995).

With these reservations our study do give an empirical supplement to the battleground between professionals and laypersons viewpoints on the understanding of the clientele of unexplained medical complaints.

To be a patient at a rehabilitation centre is to be situated in a context where the recognition of the validity of the symptoms is a more or less hidden agenda for them. Attributions about the causes of an illness or its symptoms are important in determining a patient’s response to the illness (Sensky et al. 1996). Patients with functional illnesses as chronic fatigue syndrome often attribute their illness to physical causes and minimize psychological or personal contributions (Powell et al. 1990, Schweitzer et al. 1993, Butler et al. 2001). Our study supports that patients situated at a rehabilitation centre do give stress and workload high priority in their perception of apprehension of their illness rather than physical and medical causes.

We hope that this might be recognized in the debate where patients with unexplained medical symptoms do have the not very respectable concept of “new age disease” and where the focus sometimes are more on minor characteristics of somatoforme patients as e.g. their dissatisfaction, low self esteem and wish for pension and retirement rather on their burdensome general life experiences.

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# The theories, mechanisms, benefits, and practical delivery of psychosocial educational interventions for people with mental health disorders

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## Abstract:

Many different interventions for people with mental health disorders fit under the banner of psychosocial educational interventions. These interventions seek to bestow therapeutic, cognitive and sociability benefits through education, goal setting, skill teaching, challenging thinking patterns, and social interaction. This review investigates the theories behind psychosocial educational interventions and finds them to be mostly based on psychoeducation theory. The results of a variety of psychosocial educational interventions are described and it was found that such interventions can bring significant benefits to those suffering from mental health disorders. Details are provided on the important components in the practical delivery of psychosocial educational interventions to enable beneficial results. The findings of this review provide support for the use and further expansion of psychosocial educational interventions for those with mental health disorders. It is essential that psychosocial educational provision has long term funding to enable it to be embedded, and to make it sustainable.

**Keywords:** psychosocial interventions, psychoeducation, education, mental health disorders

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## Introduction

The increasing emphasis on education for those with mental health problems is partially due to the consumer movement with its advocacy for an individual's rights and empowerment (Landsverk & Kane 1998). Psychoeducation covers a fundamental right of individuals to be informed about his or her illness (Colom & Lam 2005). Authier (1977) described psychoeducation as a therapeutic approach that does not focus on abnormality diagnosis, prescription, therapy, or cure, but on goal setting, skill teaching, satisfaction, and goal achievement. Furthermore, Colom & Lam stated that psychoeducation focuses on compliance enhancement, early identification of prodromal signs, the importance of life-style regularity, exploring individuals' health beliefs and illness-awareness, and enabling the individual to understand the complex relationship between symptoms, personality, interpersonal environment, and medication side-effects. Psychoeducation is employed in many countries throughout the world, for example, the UK, Denmark, USA, France, Poland, Australia, South Africa, and Norway.

There are various psychosocial educational interventions many of which incorporate psychoeducational theories and principles. Particular psychosocial educational interventions have included topics such as research skills, legal issues and stress management (Greenberg, Fine, Cohen & Larsen 1988, cited in Hayes & Gantt 1992). To date there have been no comprehensive literature reviews of psychosocial educational interventions and the present literature review seeks to fill this gap. Specifically this literature review will consider the theories behind psychoeducation, the benefits that psychosocial educational interventions can provide people with mental health disorders, the mechanisms involved, and the specific practical aspects of psychosocial educational intervention programmes that provide any beneficial effects.

## Discussion

### **The theory behind psychoeducation**

Morse (2004) explained that the theory behind psychoeducation is based upon individual psychology; a holistic approach to understanding what it means to be human. There are three strands embodied in individual psychology. Firstly, dynamic psychology, which is the study of emotional aspects, for example: motivation, purpose, fears, hopes, goals, and perceptions of self. Secondly, how we learn and acquire new knowledge and skills. Thirdly, developmental psychology, which incorporates biological substrata, organic factors, and individually unique maturational processes. In addition to these three strands, Morse stated that participant social interactions are considered to be crucial in the delivery of psychoeducation. Furthermore, Wood, Brendtro, Fecser & Nichols (1999) stated the importance of cognitive psychology in psychoeducation, as it involve challenging maladaptive thinking processes and suggesting alternative adaptive patterns of thinking. Wood et al. described the theoretical perspective of psychoeducation as integrated, holistic, multicultural, multimodal, functional, systemic, comprehensive, and functional. This inclusive, adaptive and flexible theoretical perspective underpins many different psychosocial educational interventions and has been applied in a variety of forms and situations, and to a variety of different mental disorders.

### **Benefits of psychosocial educational interventions**

Mowbray & Megivern (1999) conducted research on the Michigan Supported Education Intervention Project (MSEIP) for individuals with mental health problems. Through qualitative data analysis they found that the delivery of education in a group setting, that utilised problem solving and role modelling, resulted in increased feelings of empowerment. The study employed two intervention models and a control group. One intervention was a classroom model based on a programme by Unger, Danley, Kohn, & Hutchinson (1987, cited in Mowbray & Megivern 1999) which utilised an academic support curriculum with small group exercises and experiential learning; the topics covered included managing the academic environment, stress management, and developing career choices. The other intervention was a group support model that offered the same topics but it employed consumer driven structured group activities. Mowbray & Megivern found that both group and classroom models significantly increased quality of life, self-esteem, social adjustment, and further college vocational training participation. They also found that participation in the group and classroom interventions provided an increase in the use of specific problem-solving strategies and improvements in a measure of optimal goal setting. These results are very positive but their possible generalisability is limited due to the fact the study was based solely in and around Detroit, USA.

A Canadian study by Michalak, Yatham, Wan & Lam's (2005) focused on providing psychoeducation for individuals suffering from bipolar disorder (BD). There were five aims of the programme; to help patients identify the signs and symptoms of BD and to enhance knowledge about illness course and relapse risk factors; to raise awareness of the impact of BD on psychological, cognitive, physical, emotional, and social functioning; to improve knowledge of pharmacologic treatment modalities for BD and common side effects; to provide guidelines for increased medication effectiveness and safety; and to provide cognitive strategies for coping with BD. Through utilising a psychoeducation intervention to achieve these aims they found that the participants had significantly improved quality of life in terms of physical functioning and general life satisfaction. Despite this study not utilising a control group or controlling for changes in medication it adds to previous research supporting the use of psychoeducation for BD sufferers. Additional support also comes from a Spanish based control group study by Colom et al. (2005). In this study participants took part in an educational programme that taught recurrence identification and improved life-style regularity in a group setting. Colom et al. found that the programme was successful in improving illness awareness and treatment adherence at the 6, 18 and 24 month follow up points.

There has also been research into psychosocial educational interventions involving participants with major depressive disorder. Dowrick et al.'s (2000) study assigned individuals living in the community who were suffering from major depressive disorder to either a problem solving course, a course on the prevention of depression, or to a control group. They found that both the intervention courses resulted in a reduction in the number of participants meeting a diagnosis of depression, a reduction in depressive symptoms, and improved subjective functioning. At the

study's 12 month follow up, Dowrick et al. found a slight advantage for the problem solving programme over the course on prevention of depression in reducing depressive symptoms. It possibly the case that the problem solving skills acquired allowed participants to cope with the continuing and changing demands in their lives in the longer term. To counter a lack of significant effects for both intervention strategies at the 12 month follow up Dowrick, et al. recommended booster sessions. This study's results have good generalisability to major depressive disorder sufferers in various European countries as the study employed participants from urban and rural communities in Finland, Republic of Ireland, Norway, Spain, and the United Kingdom.

Klausner et al. (1998) also studied depressed individuals, in this case non-hospitalised participants suffering from late-life depression in New York, US. The study utilized a psychoeducation intervention largely based on Snyder's (1994, cited in Klausner et al. 1998) goal-focused model of hope. This intervention model employed individualized goal formulation, psychoeducation, and skills training in the areas of anxiety management, cognitive restructuring, individualized behavioural assignments, and the utilization of past success to guide achievement. They found that this intervention resulted in a significant reduction in depressive symptoms. They also found positive improvements in measures of hope, hopelessness, anxiety, and social functioning. The authors stated the limitations of their study as being a relatively small participant group and the need for further research to determine if these positive results can be repeated in other age and mental disorder groups.

As well as studies involving participants with affective disorders there has been a great deal of research conducted into psychosocial educational interventions for those suffering from symptoms of schizophrenia. In their literature review Ascher-Svanum & Whitesel (1999, p. 297) found that individuals suffering from schizophrenia who had taken part in an educational intervention gained benefits that included: "improved compliance with the medication regimen, lower relapse rate, longer participation in aftercare programs, improved social functioning and quality of life, decreased negative symptoms, improved insight into illness, improved skills acquisition, improved attitudes toward medication intake, and a better understanding of mental illness." In their US based randomised control study Ascher-Svanum & Whitesel (1999) delivered an educational programme for people diagnosed with schizophrenia based on Ascher-Svanum & Krause's (1991, cited in Ascher-Svanum & Whitesel 1999) manual. The educational intervention included topics on diagnosis, prevalence, course, causes, prognosis, medication management, non-medical treatments, stress factors, community resources, substance abuse, and legal issues. They found that there were significant improvements in knowledge about schizophrenia and illness insight, and a significant decrease in negative cognitions about medication intake. More recently, Hogarty et al. (2004) conducted a US based two year randomised control trial into cognition and behaviour. Symptomatically stable outpatients who met a diagnosis of schizophrenia or schizoaffective disorder were given enriched supportive therapy (EST). EST fosters illness management through applied cognitive coping strategies, stress management, social cognition strategies, skills training, and education. They found that EST can have positive effects on neurocognition, cognitive style, social cognition, and social adjustment. However, the researchers stated that Cognitive Enhancement Therapy (CET) had a greater effect in reducing cognitive deficits in their participants than EST.

In addition to affective and psychotic disorder sufferers, psychosocial educational interventions have also been employed with a group of PTSD sufferers in the US (Gray, Ellahai & Frueh 2004) and a group with cognitive deficiencies in the Netherlands (Commissaris, Verhey & Jolles 1996). In both these studies the interventions proved to be beneficial for the participants in areas such as compliance and well being, however, both studies had only a small number of participants and more research needs to be conducted to support and increase the potential generalisability their findings. These results and the results from studies with BD and psychotic participants clearly demonstrate that psychosocial educational interventions can be beneficial for people with mental disorders, and this supports the further use and expanding the implementation of this type of intervention.

### **Mechanisms**

Various researchers have considered the mechanisms behind the success of psychosocial educational interventions. Hayes & Gantt (1992) found that the interventions appear to enhance participants' sense of dignity and self esteem



due to the increased tools for self-care and levels of trust placed in his or her hands. Landsverk & Kane (1998) suggested that the reason as to why psychosocial interventions that employ psychoeducation are effective is because they increase an individual's resilience to stresses, coping skills, manageability, ability to comprehend life, and the level of their individual life meaning. In addition, Hayes & Gantt reasoned that the benefits that result from a psychoeducational intervention maybe derived through mastery experiences and from increased levels of empowerment.

It seems widely accepted that one of the mechanisms by which psychosocial educational interventions are effective is in the creation of a positive cycle involving treatment and rehabilitation. Adhering to a prescription drug regime allows an individual to take part in psychosocial interventions, which may in turn increase the knowledge of his or her mental illness and its treatment, thereby further facilitating the drug regime adherence. Colom et al. (2005) argued that the psychoeducation is based on a tripod model composed of lifestyle regularity and healthy habits, early detection of prodromal signs, and treatment compliance. The rest of this review will consider what specific practical aspects of psychosocial educational interventions are involved in providing the recorded beneficial effects.

### **The practical delivery of psychosocial educational interventions**

One aspect of psychosocial educational interventions that appears to be very important is participant's interactions with their peers. Ascher-Svanum & Whitesel (1999) stated that individuals can gain information about their illness by interacting with and listening to their peers. They argued that the benefits of educating individuals with mental illness may be due non-specific treatment effects rather than any specific applied learning theories. The beneficial non-specific treatment effects they identified included participant expectations, motivation to participate, the level of interpersonal support from study peers, participant opportunities to express and validate their concerns and questions, the presence of positive peer role models, being part of a cohesive group, and being able to realise that they were not alone in their experience of mental illness. In Rummel et al.'s study (2005) they trained individuals with schizophrenia or schizoaffective disorder to deliver psychoeducation to their peers. They found the outcomes comparable to professionally lead psychoeducation. Rummel et al. attributed the effectiveness of their delivery of psychoeducation to the same advantages of that of peer to peer interactions mentioned above; they particularly emphasised the peer instructor's creditability with their peers and their function as a role model.

The attributes of the leader, whether they are a professional or a group peer, of a psychosocial educational intervention are of great importance to the intervention's effectiveness. Hayes & Gantt (1992) stated that a leader needs to hold the belief that those with mental illness can learn, absorb information, and that they have the potential to live more productive lives; this is so that they can communicate hope and the belief in the potential to grow and change. They also stated that the leader needs to be able to tolerate constant repetition and a slow pace of learning. In addition, the leader also needs to be aware of the motivation level, the pace of learning, and the mood of the group and its members. In their study Hayes & Gantt (p. 59) found that "the group needed to experience that the leader not only had the "map" to understand their illness, but the ability to help guide them through vulnerable states."

Two other important aspects of a psychosocial educational intervention are its form and content. Kopolewicz & Liberman (2003, p. 1495) stated that effective psychosocial educational interventions need to contain "elements of practicality, concrete problem solving for everyday challenges, incremental shaping of social and independent living skills, and specific and attainable goals." Furthermore, they stated that "a continuing positive and collaborative relationship infused with hope, optimism, and mutual respect is central for treating clients with major mental disorders." Hayes & Gantt emphasised the use of group discussions and stressed the value of videotaped content and reading out handouts in eliciting participant thoughts and in promoting topics for discussion. In addition, Hayes & Gantt stressed the importance of involving participants in planning and choosing the content of interventions so that they meet participant needs and increase participant commitment to the programme. Kopolewicz & Liberman noted that motivating an individual to pursue and complete a psychosocial educational intervention can only be achieved by connecting the intervention with an individual's personal goals.

There are specific aspects of an educational programme that will have differing importance depending on the specific mental disorders of the participants. For those suffering from depression, Dowrick et al. emphasised the value of interventions facilitating the acquisition of problem solving skills. In addition, Klausner et al. (1998) emphasized the value to depressed individuals of being able to reframe negative memories and utilize wisdom, flexibility, and resourcefulness to face challenges and attain goals. For those suffering from schizophrenia and schizoaffective disorder Hogarty et al. (2004) emphasised the importance of a cognitive enhancement element to rehabilitation. Many of those with mental disorders, including those with schizophrenia, can have problems with attention, concentration, and memory. Emer et al. (2002) considered the education of individuals who are experiencing these problems. In their review of the literature they found that individuals with memory, attention, and concentration difficulties benefited significantly from instructional methods that included constant repetition of content to reinforce learning. In addition, Bisbee (1979, cited in Emer et al. 2002, p. 226) highlighted the need to use practice, constant feedback, diverse presentation of material, and discussion groups to enhance the learning of participants with these types of problems.

For all of those participants with mental disorders taking part in psychosocial educational interventions the teaching style of those who deliver the intervention is an important aspect of its effectiveness. Emer et al. investigated which group teaching style best promotes information gain for adults with mental disorders and they found that group formats that enabled member interaction promoted more learning and retention than lecture formats. In addition, Dowrick et al. stressed the importance of bearing in mind the fact that potential participants maybe discouraged from attending a programme that is didactic in nature due to previous negative experiences of education.

Emer et al. (2002) considered the structure of interactive educational group formats. They found that higher functioning participants learned significantly more when the information was presented in an unstructured format. They argued this could be due to structured formats interfering with the higher functioning participants' own learning approaches, and that they became bored with a structured style thus reducing their attention, motivation, and learning. Examining the level of learning results of lower functioning participants, Emer et al. found that they showed no preference for either a structured or unstructured format. They stated that this group of participants needed additional help specifically tailored to their processing needs and deficits to gain benefits beyond that of a group approach to education. In addition, Greenberg, Fine, Cohen & Larsen (1988, cited in Emer et al. 2002) argued that lower functioning participants may find that the group format is over stimulating or lacks sufficient organisation for them to benefit from it. These findings suggest that to maximise learning for both high and low functioning participants they may need to be educated separately. Emer et al. noted that if this is not possible, due to time, staff, or financial constraints, then unstructured formats should be used because they meet the needs of a greater proportion of participants. A criticism of the Emer et al. study is that it did not examine whether information gained by the participants translated into actual life choices, i.e., whether the participants were applying what they learned. Although change in behaviour can to some extent result from knowledge gain this is not always the case. Emer et al. suggests that to facilitate behavioural changes, motivational and cognitive behavioural methods should be employed alongside educational interventions.

## Summary and future directions

The American Psychological Association (APA) (1997, cited in Kopolewicz & Liberman 2003, p. 1495) stated that "long-term recovery (from mental illness) requires comprehensive, coordinated, consistent, competent, compassionate, and consumer-oriented treatments for improving the delivery and outcomes of pharmacotherapy and psychosocial treatments." Landsverk & Kane's (1998, p. 420) review found that there is an "increasing body of evidence of research showing education to be an effective component in a comprehensive treatment approach to serious mental illness." This current review revealed that psychosocial educational interventions can be beneficial on a wide variety of measures for sufferers of a many different mental health disorders. It also found that it can empower participants and that this allows them to collaborate more with their healthcare providers in their treatment and

rehabilitation. In addition, this review revealed the importance in the provision of psychosocial educational interventions of peer to peer interactions, the skill and attitudes of the group leader, programme form and content, goal setting, and a positive group ethos. Furthermore, the review found that programmes for specific mental disorders require specifically targeted educational content, and that low functioning participants may need additional individualised help beyond that of the group educational format.

In 1998 Landsverk & Kane stated that future research needs to be conducted to determine the structure, setting, and teaching tools to optimise the effectiveness of psychosocial educational interventions. Much has been learnt in the intervening time but there is still a need for further research to improve the effectiveness and practical delivery of psychosocial educational interventions for all individuals who suffer from mental health disorders. The most important point of this review is that it provides support for the implementation and further expansion of psychoeducational interventions for those with mental health disorders. James (2005) stated that to raise the expectations of a vulnerable learner group, and then take away learning provision and support after only a short period of time could be damaging to potential learners and to the credibility of the provider. It is therefore important that psychosocial educational provision has long term funding to enable it to be embedded, and to make it sustainable.

### Footnote

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# Psychosocial Issues in Childhood Autism Rehabilitation: A Review

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## Abstract

This article outlines the research that is available on families coping with a child diagnosed with autism or related disorders. The scant research that is available is highlighted along with the strong call in the literature for further work in this area. Autism has been described as a condition with a greater number of stressors than any other disability. Research that has been completed is explored and used as a basis to examine new directions required to meet the needs of families coping with the demands. Strong recommendations for further research have been developed from the available literature. It is the hope and expectation that such a review and these recommendations, will go some way to assist other researchers interested in furthering the welfare of families coping with autism and related disorders.

**Keywords:** autism, psycho-social, review, support

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## Background

The literature on childhood autism clearly indicates that there is limited research available on many aspects of the topic. In particular, there are calls in the literature for research into components of effective educational programs (Schroeder, Le Blanc & Mayo, 1996). Also, there is relatively little research that focuses explicitly on parenting stress and coping in families of children with autism (Hastings, Kovshoff, Brown, Ward, Espinosa & Remington, 2005; Pakenham, Samios & Sofronoff, 2005). Or on the social impact upon families of having a child with an autism spectrum disorder (Higgins, Bailey & Pearce, 2005). Although a few specific treatment methods have been established as efficacious for some children with autism in controlled settings, research examining the translation of these treatments into early intervention programs has been minimal (Stahmer, Collins & Palinkas, 2005). Key writers indicate that there is a need to understand the difficulties faced by those with autistic disorders in educational settings in order to manage and help autistic children handle their learning (Jordan, 2005). In addition, there is a call for researchers to explore the experiences of families engaged in such educational interventions for autism (Hastings & Johnson, 2001).

In short, the literature indicates there is a significant need for research to assist with planning for health policy and service delivery to address the profound problems faced by families with a child with autism.

## What We Do Know

### *Family impact of autism*

The one issue that the research is conclusive about is that families of children with autism report a greater number of stressors (e.g., parental depression and anxiety, difficulties in daily management of the child, financial worries, and concerns over adequate educational and professional resources) than those with children with other disabilities (Hastings & Johnson, 2001; Sivberg, 2002; Tarakeshwar & Pargament, 2001).

A child diagnosed with autism represents a constant source of stress on the family unit, as not only are the caregivers affected, but also siblings and relationships among family members (Higgins et al., 2005). The child with autism typically requires vast amounts of parental time and energy (Tarakeshwar & Pargament, 2001). Mothers of children with autism have been found to experience greater stress and difficulties in adjustment compared with mothers of children with other physical and intellectual difficulties (Pakenham et al., 2005). Research indicates that the brunt of caring falls upon the mother, with fathers helping mainly with supervision rather than physical care or domestic tasks. Siblings also appear not to be involved (Holmes & Carr, 1991). Fathers of children with autism report more financial impact and disruption of family activities (Rodrigue, Morgan & Geffken, 1992).

The child's state is the primary factor behind anxiety and stress among parents with autism (Fleischmann, 2005). Among the most difficult problems that parents mention are, poor language skills; inappropriate and embarrassing public behaviour; disruption and destruction in the home; violence and aggression; inappropriate sexual expression and obsessions with eating and toileting (Gray, 2002). Higher levels of autism symptomatology are associated with higher reported parental stress (Hastings & Johnson, 2001). The more severe the child's symptom, the greater is the degree of parental stress (Dunn, Burbine, Bowers & Tantleff-Dunn, 2001). The extremely antisocial, disruptive behaviours associated with autism, such as self-injurious, tantrum and obsessive/compulsive behaviours, may preclude a normal family life (Higgins et al., 2005). Less favourable outcomes are documented in cases of families with aggressive or violent children (Gray, 2002). The parents in these families have higher levels of stress and have few resources in terms of treatment or residential placement to deal with their situation (Gray, 2002). Mothers appear to be the most severely affected member of the family (Dunn et al., 2001; Moes, Koegel, Schreibman & Loos, 1992).

Surveys among members of families with a family member with autism have found a rise in depression, stress and anxiety (Fleischmann, 2005). Caregivers of a child with autism often experience helplessness; feelings of inadequacy and failure; anger; shock; guilt; frustration; and resentment (Higgins et al., 2005). Longitudinal data suggests that families do not experience a single stressor; rather they experience a pile-up of demands (Pakenham et al., 2005). These studies show that social support is very important in combating depression and stress (Fleischmann, 2005).

### *Lack of available services*

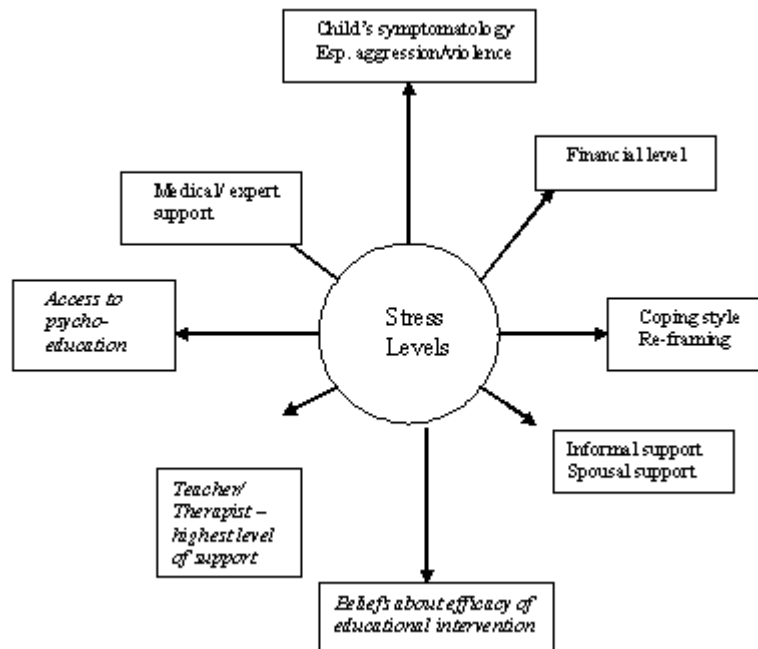
The literature is also conclusive that there is a severe lack of available services for families coping with a member with autism. Services and the provision of short-term breaks (respite) are infrequent and insufficient to meet caregivers' needs (Higgins et al., 2005). The disruptive nature of autistic behaviour, and the lack of public understanding of the disorder, results in limited availability of child-minding services and respite care, which furthers stresses and demands on caregivers (Higgins et al., 2005).

### *Coping strategies*

Research suggests the effectiveness of coping depends on the positive coping strategies used by the parents, the resources available within the family, and the availability of social support from the spouse, family and informal networks (Tarakeshwar & Pargament, 2001). Fathers of children with autism report more frequent use of wish-fulfilling fantasy, and information seeking as coping strategies (Rodrigue et al., 1992). Acquiring social support and

reframing the experience to see some positives are most frequently used coping strategies (Luther, Canham & Cureton, 2005). Hardiness and social support are predictors of successful adaptation (Weiss, 2002). There is no direct relationship between social support and isolation suggesting that some of the parents feel isolated despite receiving social support (Dunn et al., 2001). The Internet allows stressed parents of children with autism to forge ties among themselves and extricate themselves from their isolation (Fleischmann, 2005). Poorer adaptation was predicted by other family stresses, unwarranted maternal self-blame for the handicap, and maternal definition of the handicap as a family catastrophe (Bristol, 1987). Research indicates that it is important to discourage parents from using escape and avoidance as a coping style. Encouragement of more appropriate coping methods and receipt of social support is seen as beneficial in buffering the stress and reducing negative outcomes (Dunn et al., 2001).

Research involving parents of autistic children indicates that a positive evaluation of direct services to their child, (e.g., "...believing that my child's program has my family's best interest in mind.") was the most helpful resource in coping with the challenges of autism (Tarakeshwar & Pargament, 2001). Figure 1 provides a summary on stress factors that effect families with an autistic child.



### *Life stages*

As outlined by Figure 2, work by Schroeder et al. (1996) indicates that there are definable stages and critical points of transition for families coping with a child with an autistic disorder. They demonstrate the need to plan transitions in advance. Gray (2002) outlines the likely transition points. The pre-diagnosis early years are intensely stressful. Diagnosis and placement in treatment and educational programs reduces stress, the child becomes more orderly and the life of the family more settled. Adolescence becomes another period of disruption, with increasing physical and sexual maturity. Increased seizures and parental emotional exhaustion as common problems. Early adulthood also brings increased stresses associated with establishing living and work arrangements.

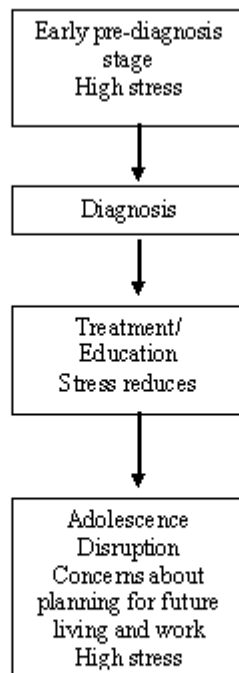


Figure 2: Stages and critical points of transition for families coping with a child with an autistic disorder.

### *Importance of therapeutic and educational support.*

The work that has been completed on educational strategies for autistic children indicates that interventions can have a positive outcome in terms of teaching autistic children new skills and coping strategies (Schroeder et al., 1996). Existing data suggests that stress and depression associated with autism are amenable to psycho-educational intervention (Hastings & Johnson, 2001). Anger management programs based on helping autistic children to recognise triggers, exert control over their physical arousal, and develop strategies through such avenues as role play have been shown through impressionistic reports to be effective (Kellner & Tutin, 1995). Improved verbal and physical sharing has been demonstrated (Sawyer, Luiselli, Riciardi & Gower, 2005). There is some evidence of improvements in the child's sociability, emotional control and attention span during treatment (Gray, 2002). Training courses have been shown to have a beneficial effect on both parent's and children's communication skills (McConachie, Randle, Hammal & Le Couteur, 2005). It is recorded that the best teaching arises from an empathetic understanding and a willingness to be flexible, the worst, from rigidity and an expectation that it is the child who must change (Jordan, 2005).

Parents are an important part of treatment for a child with autism and have been frequently trained and referred to as *co-therapists* (Pakenham et al., 2005). Importantly, the research indicates that special education teachers received the highest support rating in terms of parental perception of support for coping (Newsome, 2000). Several studies have reported decreased parental stress as a result of early intervention with children (Hastings & Johnson, 2001). Indeed, research indicates that beliefs about the efficacy of the educational/therapeutic interventions were associated with lower reported stress (Hastings & Johnson, 2001). As intervention in autism are often intensive, time-consuming, and financially draining, it has been argued there is an ethical imperative to ensure that such programs are assessed



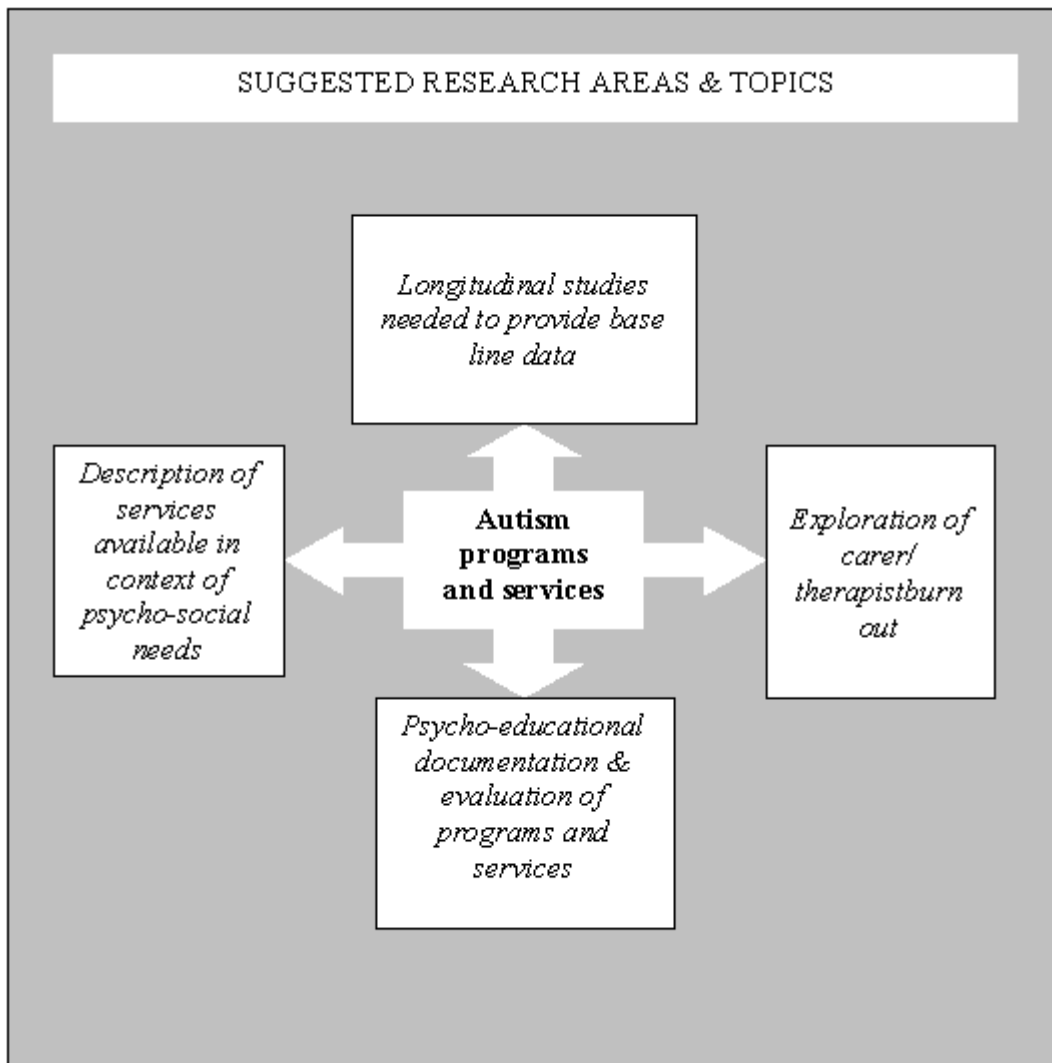
through independent research (Hastings & Johnson, 2001). However, the available evidence indicates that few providers have a clear understanding of evidence-based practice, and all providers report concerns about adequate training (Stahmer et al., 2005). Effective evaluation and documentation of efficacy for educational and therapeutic interventions for autistic children through research is seen as essential to ensure a high standard practice (Simpson, 2005).

Significantly, stress and burnout contribute to a high turnover of rehabilitation staff (Layne, Hohenshil & Singh, 2004). Research indicates that it is the occupational stress inherent in the job function, rather than individual coping resources or demographics that account for the turnover (Layne et al., 2004). It is believed that turnover can negatively affect an organisations effectiveness, or the degree to which an organisation is able to achieve its goals (Layne et al., 2004).

## Moving On - Priority Areas for Research

The available international research points to a number of priority areas of research, if families with a child diagnosed with autism and related disorders are to receive optimum care. In particular, there is presently a call for descriptive and evaluative research on psycho-educational programs and services. It is considered important for the development of this, to date, neglected area to evaluate interventions designed to educate and assist families to cope with autism and related disorders. Such research will first and foremost assist service providers in evaluating their interventions, and thus have quality assurance in the form of reliable and independent information to guide programmatic growth and development. The descriptive research needs to provide insight on the experience from the child and family perspective to ensure developments are mindful of consumer needs. Ultimately the research can make an important contribution to the international community of family, carers, therapists and educators by providing well researched insights and evaluations of a diversity of service and program initiatives for the care of autistic children.

Based on the prior introductory discussion of available research, Figure 3 provides a suggested outline of key parameters required for researchers interested in extending the present work available. It is essential to have longitudinal base-line data that documents both individual and group changes over the period of the child's involvement in the program or service. Such information will provide a basis to build an understanding of the efficacy or otherwise of interventions on the child's development. The base line data needs to be complemented by thorough and independent documentation and evaluation of the particular psycho-educational program under consideration. Particular attention needs to be paid to the issue of therapist/carer burn out. As each program or service will only be one point of connection and support for families with an autistic child, it is also essential to document such service provision in the context of other resources and services available. By taking the four parameters- as outlined in Figure 3 - into consideration a full account of the role, efficacy and benefits of individual services or programs can be gleaned.



## Conclusion

This article outlines the research that is available on families coping with a child diagnosed with autism or related disorders. The scant research that is available is highlighted along with the strong call in the literature for further work in this area. Autism has been described as a condition with a greater number of stressors than any other disability. Research that has been completed is explored and used as a basis to examine the new directions required to meet the needs of families coping with the demands. Strong recommendations for further research have been developed from the available literature. It is the hope and expectation of the author that such a review and these recommendations, will go some way to assist other researchers interested in furthering the welfare of families coping with a child diagnosed with autism and related disorders.

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[The International Journal of Psychosocial Rehabilitation](#)

# Evaluation of a Mentored Self-Help Intervention for the Management of Psychotic Symptoms

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## Abstract

This pilot study employs a quasi-experimental pre-post design ( $n = 27$ ) to evaluate the impact of a mentored self-help workbook (Coleman & Smith, 1997) intervention. Participants are diagnosed with severe and persistent mental disorders and experience medication-resistant psychotic symptoms. The cognitive-behaviorally based workbook is used to target improved self-management of affective and psychotic symptoms. The intervention can be implemented in community mental health settings by staff with less training than specialized or licensed clinicians. Results show statistically significant improvement on the Brief Psychiatric Rating Scale factor for Anxious Depression. This is particularly relevant given the high levels of depression found among individuals diagnosed with schizophrenia.

**Keywords:** cognitive-behavioral, hallucinations, schizophrenia, self-help

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## Introduction

This pilot study explores a low-cost, mentored self-help intervention for auditory hallucinations in a community mental health setting. The intervention involves a mentor's supportive assistance with written assignments exploring individual voice-hearers' experiences of auditory hallucinations (Coleman & Smith, 1997; Hustig & Hafner, 1990). It focuses on assignments operationalized in a published workbook, co-authored by a former psychiatric patient and a psychiatric nurse (Coleman & Smith, 1997). Study participants completed the workbook, rather than attending a specific number and duration of treatment sessions. Participants were adults diagnosed with a severe and persistent mood or psychotic disorder experiencing medication-resistant psychotic symptoms. Results show statistically significant improvement in the Brief Psychiatric Rating Scale (BPRS) factor Anxious Depression for Intervention group participants, over those in the Comparison group.

The "hearing voices movement" that began in Europe following a 1987 conference in Utrecht (Romme & Escher, 1996) inspired Coleman and Smith (1997) to challenge the view of "voices" as symptoms of an illness unrelated to a person's history. In their workbook, Coleman and Smith also challenged the corollary that "voice hearers" are powerless with regards to the voices. These authors noted that hearing voices is "not the exclusive prerogative of saints and psychotics" (Coleman & Smith, p. 8), but rather part of the human condition. Coleman and Smith provided no specific goals for their workbook, but rather suggested that any action plan a voice hearer develops should "be focused around your experiences and how you understand them, and should work to your goals and nobody else's [sic]" (emphases in the original, p. 9).

Despite departures from mainstream mental health/psychiatric thinking, seventeen of the twenty workbook exercises share similarities with various techniques found in the cognitive behavioral treatment (CBT) of psychosis. An established adjunctive treatment approach in Europe and particularly the United Kingdom, CBT of psychosis is increasingly recognized in North America (Dickerson, 2000; Kinderman & Cooke, 2000). Overall, both Coleman and Smith's (1997) workbook and CBT of psychosis: (1) attempt to normalize the voice-hearing experience, and (2) view hallucinations as on a continuum with normalcy. Following Romme and Escher's (1989, 1996) normalizing rationale, workbook exercises begin with an exploration of the onset of voice hearing, and responses to the voice hearing experience, then continue with the voice hearer's written "Life History" (Coleman & Smith, 1997, pp. 15-18).

Four of the 20 workbook exercises closely resemble "focusing" (Bentall, Haddock, & Slade 1994; Haddock, Bentall, & Slade, 1996). Focusing is a CBT of psychosis strategy that examines the features, contents, related thoughts, and attributed meaning(s) of "voices." The workbook, for example, includes an "I've just heard voices" checklist (Coleman & Smith, 1997, pp. 19-20) to photocopy and use daily to describe the voices,

voice content and surroundings, and the voice hearer's associated feelings and thoughts. This checklist also asks for the voice hearer's explanation of the voices. Subsequent workbook exercises have the voice hearer address attributed meaning(s) of the voices through identification of personal frames of reference, beliefs about the voices, and an exploration of alternative belief systems. A difference between the workbook's orientation and CBT of psychosis is that the latter views telepathy as a delusional or maladaptive explanation of voices that should be challenged (e.g., Chadwick, Lowe, Horne, & Higson, 1994; Nelson, 1997). Workbook exercises, in contrast, neutrally explore alternative belief systems (i.e., the illness model, the psychological model, and telepathy).

Workbook exercises move on to emphasize coping with voices, by using focusing and coping strategy enhancement (CSE) techniques, strategies developed in CBT of psychosis (Tarrier et al., 1993; Yusupoff & Tarrier, 1996). Coping strategy exercises begin with an explanation of what "coping strategy" means and examples of different types of coping strategies. Exercises are meant to examine current strategies, changes desired (if any), supports, and attributed meanings. Further exercises are meant to explore alternative strategies and trials of new strategies. A total of thirteen of twenty workbook exercises have similarities to CSE. The workbook frames hearing voices as a potential adaptation to, or even survival strategy for, life events. Guidance is provided to voice hearers for working with professionals in this context. The net result for voice hearers interested in working with their voices is an unusual combination of client driven, non-judgmental exercises roughly similar in many respects to CBT intervention strategies with psychosis.

At the time of this study's inception, empirical results from case study, single subject design, and small group comparison study methodologies cautiously favored using CBT of psychosis with clients experiencing various psychotic symptoms. Subsequent randomized clinical trials (RCTs) have provided further support for individual CBT of psychosis (Durham et al., 2003; Kuipers et al., 1998; NHS Centre for Reviews and Dissemination, 2000; Rector & Beck, 2001; Sensky et al., 2000; Tarrier, et al. 1999; Turkington, Kingdon & Turner, 2002). RCTs have utilized multiple outcome measures, including measures of overall psychotic symptoms, negative psychotic symptoms, depression, anxiety, self-esteem, self-concept and other constructs. Generally, CBT of psychosis in the United Kingdom is largely based on the work of Beck and colleagues, with overall agreement that the principal aim "for medication-resistant psychosis is to reduce the distress and interference with functioning caused by the psychotic symptoms" (Garety, Fowler & Kuipers, 2000, p. 73). It is noteworthy that the outcome measures used in CBT of psychosis intervention research do not directly measure this intent, but rather measure symptom reduction, in addition to a plethora of other variables.

Summarizing outcome results with psychotic symptoms and adjunctive CBT of psychosis, Boyle (2002) stated that "although some therapeutic results may be modest, most statistical comparisons with other treatments, across a range of outcome measures, favour CBT" (p. 296). Gaudiano (2005) tabulated 19 publications on 16 RCTs of CBT for psychosis that included individual and group modalities, inpatient and outpatient samples, first episode psychosis, recurrent psychosis, and older patients with schizophrenia. Gaudiano cautiously concluded that "whether commonly used therapies such as CBT are specifically efficacious in treating psychotic symptoms" needs to be further researched, although evidence is clear that psychosocial interventions generally can contribute "significantly to the well-being of individuals suffering from psychosis beyond the effects of routine care" (p. 46). Mueser and Noordsy (2005), following Gaudiano's review, nevertheless concluded that although "the mechanisms and specificity of CBT for psychosis remain unknown, the evidence amassed supports its effectiveness" (p. 68).

Coleman and Smith's (1997) workbook is intended for use with the support of a trusted other (e.g., friend, significant other, family member, and/or mental health professional), referred to in this study as a "mentor." With the workbook, power and authority are to reside solely with the voice hearer, who sets the pace and may disengage with the supportive other and/or discontinue the process without negative consequences at any point. In addition, the voice hearer "owns" the workbook in a tangible, concrete way seldom applicable to

traditional therapy. This locus of control reflects the self-help philosophy of the workbook.

It occurred to the present authors that Coleman and Smith's (1997) written guidelines might constitute an additional repertoire of teachable coping strategies for psychotic symptoms in typical mental health settings. Despite workbook similarities to strategies found in formal individual CBT of psychosis, mentoring the workbook requires less training and experience than is needed for CBT. Could an intervention built around the workbook produce measurable positive changes in self-esteem, social functioning, depressive and psychotic symptomatology, the very areas that formal CBT of psychosis has explored? The present study addressed this question.

## Methods

This study utilized a non-equivalent comparison group design with non-random assignment to evaluate pre-post intervention change in scores on standardized measures (see below). The study was conducted in a south Florida community mental health agency that serves adults diagnosed with severe and persistent mental disorders. At the start of the study, the host agency served 480 "members." Approximately 61% of agency members were male and 39% female, 51% Anglo and 49% Minority, with an age range from 18 to over 65. Agency members had to report experiencing and/or display psychotic symptoms to meet inclusion criteria (see below).

The sample was one of convenience, based on staff referrals from the host agency. The Comparison group ( $n = 13$ ) consisted of participants not scheduled to intervention protocol ( $n = 17$ ) after signing informed consent paperwork and completing pre-test packets. Randomization was not possible, as participants were assigned to intervention protocol based on their ability to meet initial scheduling windows available. Over the course of the study, one participant suffered a stroke and left the Intervention group and two Comparison group participants discontinued services at the agency. Pre-test data from these three non-completers are not included in the data set, since no corresponding post-test data was obtained. Thus, data from the total of 27 participants who completed the study are included in the analysis (Comparison group  $n = 11$ , Intervention group  $n = 16$ ).

The sponsoring university's Internal Review Board and the host agency's administration approved the study. The primary researcher met individually with each person referred to the study in order to explain the project and answer any questions about informed consent documentation. Once informed consent was given, participants could withdraw from the study at any time without penalty or reduction of agency services.

### Measures

The current study elected to measure change in overall symptomatology, symptoms of depression and anxiety, and self-esteem, using standardized instruments. These instruments have been used in CBT of psychosis outcome studies in the United Kingdom (e.g., Haddock, Bentall, & Slade, 1996; Kuipers et al., 1998; Tarrier et al., 1999), or in community mental health research in the United States of America (Newman, DeLiberty, McGrew, & Tejeda, 2005). Measures are discussed below.

The Rosenberg Self-Esteem Scale (RSE, Fischer & Corcoran, 1994; Rosenberg, 1989) is a self-report instrument used to measure self-esteem. The RSE specifies a four-point scale used to self-rate ten statements and was scored as a Likert scale. Possible scores range from a low of 0 to a high of 30 (highest self-esteem). The instrument's short length and ease of administration made it suitable for inclusion in a pre and post-intervention packet of multiple measures.

The Hoosier Assurance Plan Inventory – Adult (HAPI-A) is a standardized, clinician-rated psychosocial assessment instrument utilized by the state of Indiana with adults diagnosed with severe and persistent mental disorders. The HAPI-A includes the factor Symptoms of Distress and Mood (Factor 1, based upon three



items, A – Consumer’s Rating of Symptom Distress, B – Anxiety-Worrying, and C – Depression-Sad, Blue, or Suicidal Thoughts/Actions), and the item Thought Disorder, Item H. Item H reads: “Have you had any unusual experiences (e.g., are there times you hear, see, or smell things other would claim are not there)?” Two other HAPI-A factors can be used to measure disruption in life (Factor 3 – Community Functioning, and Factor 4 – Social Support-Skills & Housing). In the state of Indiana, the HAPI-A demonstrated sensitivity to change for clients with psychiatric diagnoses, or psychiatric diagnoses and chronic addiction, over a 90-day period HAPI-A (Newman, DeLiberty, McGrew, & Tejeda, 2005).

For the HAPI-A, a lower score indicates a more severe problem or symptom. Score range per item on the HAPI-A is from seven to one. Since Factor 1 – Symptoms of Distress and Mood is made up of three items, its score ranges from 21 to three. Factor 3 – Community Functioning, and Factor 4 – Social Support-Skills & Housing, are each comprised of four items, hence these scores range from 28 to four. Item H (Thought Disorder) ranges from seven to one and is reported separately.

The BPRS is a clinician-rated global instrument for measuring symptoms of psychopathology that includes items related to depression and anxiety (Faustman & Overall, 1999; Overall & Gorham, 1962). Overall and Klett (1972) identified four general factors within the BPRS, including the factor Anxious Depression. This factor is based upon three subscales, i.e., Anxiety, Guilt Feelings, and Depressed Mood. The BPRS measures clinical symptoms across a range of mental diagnoses, such as those present in the clinical sample studied. Possible BPRS global scores for overall symptomatology range from 18 to 126, where 18 indicates no symptoms and 126 indicates all symptoms rate as extremely severe. The higher the BPRS global or factor score, the more severe is the symptom rating.

#### Inclusion Criteria

Study data collection began in the fall of 2001 and extended into the winter of 2004. Given a sample of convenience, non-random assignment to group, and non-equivalent groups, results should not be generalized to the larger population of Americans diagnosed with major mental disorders and experiencing psychotic symptoms who reside in the community. Study inclusion criteria included agency membership; this excluded developmentally delayed or mentally retarded individuals, as well as individuals using alcohol or illicit substances.

Additional inclusion criteria were as follows: (1) 21 to 65 years of age; (2) no legal guardian; (3) English literacy/fluency; (4) agency record of a DSM-IV (American Psychiatric Association, 1994) diagnosis of Schizophrenia, Schizoaffective Disorder, or Mood Disorder with psychotic features; if the disorder on record was none of these and criterion six (below) was met, intervention protocol was deemed potentially appropriate and the agency member was permitted to enroll in the study ( $n = 1$ ); (5) agency record of a DSM-IV Global Assessment of Functioning (Axis V) score in the range of 35 to 60; (6) reports by agency staff of observable symptoms such as delusional verbalization or aberrant behavior, and/or verbalization of a problem related to auditory hallucinations, “voices,” intrusive thoughts, or excessive doubts or worries, despite reported adherence to prescribed psychotropic medication; (7) community residence (defined to include residential treatment facilities, assisted living facilities, and group homes); and (8) either no alcohol or illegal substance use diagnoses, or no current alcohol or illegal substance use per staff and self-report, if such diagnoses were on record at the agency.

The first author extracted data on participant demographic and clinical characteristics from agency case files. MSW-level social workers not affiliated with the host agency and blind to intervention/comparison group status administered pre and post-test instruments. Weekly intervention sessions with each participant began after completion of the pre-test packet, with the host agency requirement that the first author act as mentor. Broad variation in both number of sessions and duration of the intervention was expected and, indeed, occurred (range from 12 to 42 weeks, with one outlier at 57 weeks; details below).

A mentored session with an Intervention group participant began with the Topography of Voices Rating Scale

(TVRS). The TVRS is a one-page, unstandardized self-report instrument (Chadwick, Birchwood & Trower, 1996; Hustig & Hafner, 1990) used as an “ice-breaker” to support open discussion of symptoms. Sessions were one-on-one and followed a semi-structured format of 15 to 45 minute duration. (The mentor documented details of each session on the Mentor Report Form.) After completing the TVRS and responding to initial inquiries on medication and current status, the participant was handed the workbook. Each workbook exercise was read aloud and any confusion clarified prior to the participant completing it. Verbal responses were redirected with a gentle “write it down.” Once the workbook was completed, the mentor facilitated contact between participant and assessor to schedule the post-test. As a participant completed intervention protocol, the mentor referred both that participant and a Comparison group participant to an assessor for post-testing (this was not possible for five Intervention group participants, because of differing group sizes).

#### Research Questions and Data Analysis

This study aims to determine if a low cost mentored intervention that uses Coleman and Smith’s (1997) workbook provides benefits to clients experiencing psychotic symptoms beyond what treatment as usual provides. This aim is reflected in the following four research questions: (1) does self-esteem increase post-intervention, relative to self-esteem of a comparison group not receiving the intervention?; (2) does depression-anxiety decrease post-intervention, relative to a comparison group?; (3) does overall psychotic symptomatology decrease post-intervention, relative to a comparison group?; and (4) does disruption in life lessen post-intervention, relative to a comparison group?.

Repeated measures analysis of variance (Repeated measures ANOVA, or RMANOVA) assessed whether positive change occurred over: (1) self-esteem, (2) depression-anxiety, (3) overall psychotic symptomatology, and (4) disruption in life. Two measures were used for the latter three of the four constructs, and Bonferroni corrections set Type I (p) error at .025 (i.e., .05/2) for these analyses. The general linear model (GLM) approach within the Statistical Package for Social Sciences (SPSS) Version 11.0 was used to conduct the analysis.

ANOVA is relatively robust regarding failures to meet assumptions of homogeneity and normality (Garson, 2005). The F-test (or F-ratio) is the key statistic for ANOVA and its formula reflects whether the variance among the group means (for given sample size and within group variances) is significantly larger than the error variance within the groups. With smaller variances and smaller samples, F is conservative, i.e., it is more difficult to detect statistical significance (Garson, 2005). When using the GLM model within SPSS, the F-test is unaffected by unequal group sizes. In studies evaluating cognitive-behavioral or other individual psychotherapy approaches, large samples of individuals diagnosed with serious mental disorders are seldom available (Gottdiener & Haslam, 2002). Researchers have used any one of several effect size statistics to describe the magnitude of any significant differences observed between intervention conditions. In this study, effect size was estimated using the “partial eta square” statistic, which reflects the proportion of variance associated with a given variable.

## Results

Specific demographic and clinical characteristics of Intervention and Comparison group participants are shown in Table 1. Overall, Intervention group participants tended to be: (1) an average of seven years older, (2) more likely to have more debilitating psychiatric disorder diagnoses, and (3) more likely to be of non-Hispanic White ethnicity/race, than Comparison group members.

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Table 1 *Intervention and Comparison Group Demographics (n = 27)*

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Intervention Group	Comparison Group
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	(n = 16)	(n = 11)
Characteristic	<i>n (%)</i>	<i>n (%)</i>
Gender		
Female	4 (25)	3 (27)
Male	12 (75)	8 (73)
Race/Ethnicity		
White	13 (81)	7 (64)
Minority	3 (19)	4 (36)
Marital Status		
Single/Divorced	15 (94)	10 (91)
Married	1 (6)	1 (9)
Education		
High School or below	7 (44)	6 (55)
Post High School/GED	9 (56)	5 (45)
Residence		
Independent	11 (69)	7 (64)
Group home	5 (31)	4 (36)
Diagnostic Category		
Psychotic Disorder	15(94)	7(64)
Mood Disorder	1(6)	3(27)
Other Disorder	0(0)	1(9)

Table 2 shows that at pre-test, the Intervention group had significantly higher BPRS global scores. However, the difference on the BPRS Anxious Depression factor was not statistically significant and other differences appeared trivial and were not statistically significant.

This pilot study employs a quasi-experimental pre-post design (n = 27) to evaluate the impact of a mentored self-help workbook (Coleman & Smith, 1997) intervention.

*Table 2 Between Group Differences at Pre-test*

Measure	Group	Mean $\pm$ SD	Range	F	<i>p</i>	Partial
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		(I = 16, C = 11)		(dF: 1, 25)		Eta Squared
RSE	Inter.	19.31 ± 6.26	8-30	0.613	.441	.024
	Comp.	21.09 ± 5.03	14-30			
BPRS Anx.Dep.	Inter.	8.06 ± 3.13	3-13	3.428	.076	.125
	Comp.	5.80 ± 2.86	2-13	(1,24)		
			(10)			
HAPI-A Mood	Inter.	15.94 ± 4.19	9-21	.146	.706	.006
	Comp.	16.55 ± 3.82	6-21			
BPRS Global	Inter.	37.56 ± 7.79	25-50	5.729	.025	.193
	Comp.	29.60 ± 8.97	19-43	(1,24)		
			(10)			
HAPI-A Tht.Dis.	Inter.	4.88 ± 2.03	1-7	1.552	.224	.058
	Comp.	5.82 ± 1.78	1-7			
HAPI-A Comm.	Inter.	20.56 ± 5.14	11-28	.439	.514	.017
	Comp.	21.82 ± 4.35	14-28			
HAPI-A Soc.Supp.	Inter.	23.69 ± 4.01	11-28	.001	.982	<.001
	Comp.	23.73 ± 5.02	14-28			

The number of mentored self-help sessions for 15 Intervention group participants ranged from eight to 18 (mean = 12.6) with a duration range of 12 to 42 weeks (mean = 28.3), excluding the one participant with 25 sessions over 57 weeks. In sum, there was a pronounced central tendency of 13 sessions over a 29-week period, despite differing levels of education/literacy and scheduling idiosyncracies. As noted above, the intervention aimed only for workbook completion (a behavioral criteria) rather than for a specific “dosage” of

intervention, thus neither the duration of the intervention nor the number of sessions should be taken as an indicator of quantity or intensity: Longer duration indicated slower progress in completing workbook exercises.

Pre-post differences analyzed using RMANOVA are shown in Table 3. Using RMANOVA and appropriate Bonferroni corrections, no significant differences were found for self-esteem, overall psychotic symptoms, or disruption in life. For depression and anxiety, the two measures used were the BPRS Anxious Depression and HAPI-A Distress-Mood factors. Because the statistical test required two separate analyses, a Bonferroni correction set Type I error ( $p$ ) at .025 (i.e., .05/2). No significant difference was found between groups for the HAPI-A factor, however, a significant difference was found between groups for the BPRS factor, with a strong effect size,  $\eta^2 = .218$ . Further, the correlation between the change in scores for the BPRS factor Anxious Depression and the change in scores for the HAPI-A Factor Symptoms of Distress and Mood was significant at the .05 level ( $r = -.341$ ). In sum, one of two measures of depression-anxiety symptoms suggested that these symptoms showed significantly greater reduction for the Intervention group and the two measures were significantly correlated with each other.

Table 3 *Pre-post Test Differences: ANOVA Results*

Measure	Group (I = 16, C = 11)	Mean $\pm$ SD	Range	F (dF: 1, 25)	$p$	Partial Eta Squared
RSE	Inter.	18.81 $\pm$ 4.17	10-26	0.006	.940	<.001
	Comp.	20.73 $\pm$ 4.27	16-30			
BPRS Anx.Dep.	Inter.	6.69 $\pm$ 3.24	3-13	6.985 (1, 24)	.014	.218
	Comp. (10)	7.70 $\pm$ 3.89	1-15			
HAPI-A Mood	Inter.	15.31 $\pm$ 4.50	8-21	.193	.664	.008
	Comp.	16.73 $\pm$ 3.04	11-21			
BPRS Global	Inter.	37.94 $\pm$ 12.0	18-65	.577 (1, 24)	.455	.023
	Comp. (10)	34.70 $\pm$ 10.8	23-51			
HAPI-A Tht.Dis.	Inter.	5.25 $\pm$ 1.77	2-7	.016	.902	.001
	Comp.	6.09 $\pm$ 1.14	3-7			
HAPI-A Comm.	Inter.	22.19 $\pm$ 3.60	14-27	.067	.797	.003
	Comp.	23.82 $\pm$ 3.09	16-28			

HAPI-A Soc.Supp.	Inter.	23.13 ± 4.84	14-28	.707	.408	.028
	Comp.	24.64 ± 3.07	17-28			

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## Discussion

The study used three standardized instruments with an Intervention and a treatment-as-usual Comparison group, to examine pre-post differences over four constructs. Research questions related to self-esteem, depression-anxiety, overall psychotic symptomatology, and disruption-in-life, respectively. Interestingly, five of seven outcomes showed non-significant change scores that favored the Comparison group over the Intervention group. These outcomes do not reach statistical significance, and whether they would sustain with a more powerful study is a question for future research.

The study is an exploratory pilot and findings are limited. Results cannot be generalized, given the small sample size, non-random assignment to group, non-equivalent groups, and other study limitations (see recommendations below). Overall, a conservative interpretation of results is that the one significant difference in pre-post instrument scores occurred due to chance. An alternative interpretation is that the mentored self-help intervention made an actual improvement in the level of depression-anxiety experienced by Intervention group participants. This is particularly relevant, if so, given the high levels of depression and depression-associated suicide among individuals diagnosed with schizophrenia. The alternative interpretation supports further research on the intervention.

Recommendations for a future study address limitations of the current one and include: (1) random assignment to group; (2) use of different mentors simultaneously, each mentor working one-on-one with individual participants, to avoid the confound of a single individual administering the intervention; (3) advance stipulation of the number of sessions to standardize “dosage;” (4) use of specific standardized instruments to assess symptoms of depression and anxiety; (5) use of a standardized measure of self-efficacy rather than self-esteem; and possibly (6) use of qualitative measures, rather than the HAPI-A, to assess disruption in life.

The statistically significant result obtained was over the construct depression-anxiety and one might cautiously conclude that the single pre-post difference was an artifact of multiple measures over multiple questions, i.e., that one of seven measures (14%) showed improvement purely due to chance, despite a priori formulation of research questions and an appropriate use of Bonferroni corrections in the analysis. The change in the more disturbed Intervention group might also indicate regression towards a mean; if so, however, one might have expected the global score of the same scale to show a similar shift and this did not occur. The BPRS Anxious Depression factor pre-post difference showed a strong effect size, and although the difference was only seen with one of two measures, the difference scores on both the BPRS and the HAPI-A factors correlated significantly at the .05 level. A more positive interpretation of observed results is that the intervention served to assist individuals with severe and persistent psychotic symptoms in reducing distress associated with at least some of those symptoms.

Few CBT studies have measured secondary aspects of psychosis such as depressive symptoms or anxiety, although Sensky et al. (2000) and Turkington, Kingdon and Turner (2002) reported improvements in depressive symptoms. Rector and Beck (2001) noted “upwards of two-thirds of patients receiving a diagnosis of schizophrenia will also experience a major depressive episode” (p. 285). Kaplan and Sadock (1998) reported up to ten percent of people diagnosed with schizophrenia die from suicide and that an estimated 4,000 people diagnosed with schizophrenia in the United States die annually by suicide (see also World

Health Report, 2001). Further, only a small percentage of these people commit suicide because of psychotic symptoms: depressive symptoms are associated with over two-thirds of these suicides. Beck (in Kingdon & Turkington, 1994) correctly highlighted depressive symptoms as natural sequelae of a schizophrenic diagnosis. If the mentored self-help workbook intervention is shown in future studies to decrease levels of depression in this population, the intervention format lends itself to implementation in community mental health agency settings through supportive staff.

An excursion into speculative thought is in order, given (1) the observed reduction in BPRS Anxious Depression scores for the Intervention group, (2) the positive impact of all major forms of individual therapy for those diagnosed with schizophrenia (Gottdiener & Haslam, 2002), and (3) the prevalence of depressive symptoms and suicide in this population. Given the demonstrated positive impact of all forms of individual therapy, depressive symptoms and associated suicides might be reduced by use of interpersonal, relational interventions. The implication for practice with this population is that developing interpersonal practitioner-client relationships based on mutual respect, trust, and client choice is a critical foundation of treatment. Use of a self-help workbook co-authored by a mental health consumer might assist the development of such practitioner-client relationships, whether the workbook was used one-on-one or within a group format. Study results indicate that the workbook – despite its departures from mainstream mental health thinking – when used one-on-one with a supportive mentor, appeared to do no harm and that it may in fact be a positive process for clients experiencing medication resistant psychotic symptoms.

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# The Effect of Socio-Cultural Context on Conceptualizing Autistic Disorder In the People's Republic of China

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## Abstract

This essay reviews how culturally based variations in thinking, expectations, and even norms of social behavior influence Chinese psychiatrists' conceptions, diagnosis, and treatment of mental illness, with a specific focus on Autistic Disorder (AD). Knowing the effects of the Chinese social-cultural context on the causal explanation, diagnosis, and treatment of AD as well as conducting a line-to-line investigation of the diagnostic criteria are prerequisites for the understanding of how AD is manifested in the People's Republic of China (PRC). Whether an individual is less likely to be diagnosed as having AD in the PRC because more criteria are

required in the PRC, is unclear, and should be the subject of future research. An understanding of that diagnostic practice, as well as of the rationale and practice of treatment for individuals with AD, would support the understanding of AD in a cross-nation study. Key words: Autistic Disorder; China; Chinese Classification of Mental Disorders; Mental health; Socio-cultural context.

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## Introduction

The conceptualization of Autistic Disorder in modern psychiatry is an ongoing and dynamic process influenced by a range of discourses and research. From a socio-cultural perspective, an individual's thinking is rooted in his or her culture and society (Bruner, 1986; Feldman, 1987; Stetsenko & Arievidt, 2004; Vygotsky, 1978), and as this applies to professional psychiatrists, their conceptualization of Autistic Disorder (AD) is necessarily entrenched in the society in which they reside. Psychiatric professionals apply a combination of scientifically based expertise and everyday thinking to link physical, psychological, and environmental factors to the cause, diagnosis, and treatment of AD. Furthermore, culturally produced sign systems, such as language and written texts, constantly reinforce the collective meanings that underlie the thinking of psychiatrists. Psychiatrists internalize collective meanings as cultural beliefs, daily practices, role expectations, and social justifications. Conversely, their thoughts about AD are transformed into public meanings, which are shared by their particular psychiatric community, and which fit specific social, cultural, and political milieus.

Knowing the effects of a particular social-cultural context on the causal explanation, diagnosis and treatment of AD as well as having performed a line-to-line investigation of the diagnostic criteria are prerequisites to understanding how AD is manifested in the People's Republic of China (PRC). To this end, we explore how culturally based variations in thinking, expectations, and even norms of social behavior influence Chinese psychiatrists' conceptions, diagnosis and treatment of mental illness, with a specific focus on AD. Our investigation of the socio-cultural and historic contexts for the construction of AD in China uses an ecological approach. We begin by briefly examining the history of mental illness in China, and tracing the development of thinking regarding its cause, diagnosis, and treatment among psychiatric professionals and society in general. These background details provide a context for understanding the very recent classification of AD as a psychiatric diagnosis. We then analyze the conceptualization of AD through its formal classification and diagnostic systems and conduct a qualitative analysis of the diagnostic criteria for AD in China. The investigation provides an opportunity to generate better conceptual framework and a more fruitful research outcome for a cross-cultural interpretation of diagnostic practice and treatment of AD.

## Conceptualizing Mental Disorders in China

Conceptions of mental illness in China have evolved over centuries under the constant influences of the social, cultural and political environments. Thinking about the nature of autism, not the diagnostic term itself can be traced back to the beginning of Chinese history, and it is clear that this thinking has been based on Chinese society's everyday understanding of mental disorders. Below, we describe how Chinese psychiatric societies have conceptualized mental disorder over time. An understanding of Chinese conceptualization of mental illness can further facilitate a cross-cultural understanding of mental disorders.

An absence of appropriate identification and treatment for individuals with AD (a term interchangeable with Childhood Autism) is the result of the religious practice and Traditional Chinese Medicine (TCM) of the 18<sup>th</sup> century. First, the general perspective was that mental disturbances were the consequence of bad deeds perpetrated either by oneself or by members of one's family. The religious nature of this conceptualization meant that blessings for individuals with a mental disorder were sought from the gods in local temples (Yip, 2005a). Second, based on the ancient doctrines of TCM, many Chinese attributed mental illness to an imbalance in vital forces -- a cause rooted, at least in part, in the physical world.

According to Fàbrega (2001), TCM attributes the causes of illness to a complex relationship between impairments of the circulative function of “qi” and “blood” in an organ or in a stream across the body and, based on a philosophical understanding of phenomena among Heaven, the Earth, and Humanity, an imbalance of the forces of “Yin” and “Yang,” thus implying that both external/environmental and internal/personal factors influence the physical and mental functioning of individuals. A complicated metaphysics referring to the elements of Metal, Wood, Water, Fire, and Earth was also used to explain sicknesses and their treatments (Chan, Ying, & Chow, 2001).

The understanding of mental disorders remained unchanged throughout the 19<sup>th</sup> century. Individuals’ mental health problems were either unrecognized or identified as physical ailments by herbalist doctors. These herbalist doctors treated patients using single or compound ingredients of Chinese medicine, which they prescribed after a holistic assessment of the patient and the illness (Xu, 1982). Then, in 1898, an American missionary established the first psychiatric institution in Guangzhou (Liu, 1981; Yip, 2005b). Thereafter small asylums were founded in Beijing, Shengyang, and Suzhou (Yip, 2005a). Over time, a more westernized understanding of mental illness emerged in Chinese society. Even so, only a small number of individuals with mental illness were treated in hospitals. Others were confined in prisons, and the majority remained at home and cared for by their families.

Changes in the conceptualization of mental disorders in the PRC were slowed by the unstable social, cultural and political milieus of the early 20<sup>th</sup> century. China was preoccupied with multiple distressing large-scale events: the dramatic end of the empirical Qing dynasty, devastating losses in the Sino-Japanese war, the revolution and the establishment of the PRC. Of particular significance was the decade-long Cultural Revolution, during which collective political education<sup>2</sup> replaced a more westernized treatment of mental disorder. As Yip (2005a) states, “Medical professionals identified clients with mental illness as ‘class brother’ to fight against ‘mental illness’ which originated from ‘evil Capitalistic think’” (p.28). Mental illness was thus not thought of as a social problem. As Allodi and Duksza (1978) explain, “the official line is that mental illness is rare in China since the Revolution because of the accomplishments of the preventive public health programs in controlling parasitic, infectious and venereal diseases, and alcoholism, and because of the lack of social stress, (unemployment), and the ‘fine moral and social tradition’ of the country” (p. 365). It was thought that political education and healthy life practices were the basis for preventing mental illness. As a result, discussions about, and investigations of, mental illness were limited.

It was not until the nation regained its strength in the late 1970s, that scientific thinking and research into mental disorders emerged and were integrated into an international perspective. More specifically, with the Reform and Opening policy<sup>3</sup> of 1978, the articulation of westernized thinking and psychiatric knowledge once again reappeared, and with it, the establishment of an international discourse, a gradual shift in the understanding of mental disorder, and a diagnostic system and treatment modalities that had elements common to psychiatric communities around the world began to be established in China. Most individuals with mental disorders, however, were treated at a primary care level or at home due to the lack of psychiatric professionals (Chen, 2002).

## **The Construction of Autistic Disorder in the PRC**

The changes in the social and political climates and the opening up to international discourse enabled the Chinese psychiatric community and the public to construct an objective picture of AD in the 20<sup>th</sup> century, although multiple political issues have continued to impede the recognition of AD. In 1982, Tao reported four cases of IA (Infantile Autism) in the PRC that supported the definition developed by the US National Society for Autistic Children (and subsequently approved by the American Psychiatric Association) that “autism has been found throughout the world in families of all racial, ethnic, and social backgrounds” (Tao, 1987, p. 289). Moreover, Tao (1987) compared the clinical features of IA found in fifteen Chinese individuals to the individuals in Kanner’s 1943 cases, suggesting that his findings “replicated those of Kanner and of Cantwell, Rutter, and Baker (1976) on the subject of socioeconomic status of parents” (p. 289). He further suggested

that the findings heralded the opening of a discourse between the United States and the PRC. Both Chinese physicians and, at this stage, the urban public began to hear the term “Infantile Autism.” It remains common, however, for the public to form a direct sense of IA from its translation in Chinese, which is “gu du zheng” (孤独症) or “zi bi zheng” (自闭症). For many, the referential and representational meanings of “gu du” and “zi bi” are “aloneness” or “self-shut-off,” thereby suggesting a personality type rather than a set of behavioral descriptions as suggested by Kanner (1943).

In China, the philosophy of TCM and notions of Western psychiatry suggest two distinct causal interpretations of AD. As already explained, TCM implies a causality of mental illness related to vital and spiritual forces, as well as to healthy life practices in the social, cultural, and political milieus. The causality of that claim is related to the function of the total well being of the individual, rather than of the brain (Chan et al., 2001). However, the causal interpretation of AD based on the Western psychiatric system is quite different. Certain Chinese psychiatric professionals have adopted the research framework of Western studies to conduct their research and to generate empirical findings that articulate the possible causal explanations of AD in the PRC. Samples include: Lu and Yang (2004), who argue that children with AD have a neurological mal-development in the embryonic stage; Guo and Liu (2003), who suggest the possible genetic abnormality of twin brothers; and Ke and her colleagues, who conclude that sensory integration dysfunction is related closely to Pervasive Developmental Disorders (Ke, Wang, Chen, Zhou, Jiao, Wang, Jin, & Lin, 2004).

The contemporary classification and categorization of mental disorders has been constructed to meet current socio-cultural needs in China. Throughout the profound social reforms and the rapid development of the economy of the last two decades, China has moved towards becoming a modern nation. A set of operational criteria for diagnosing IA was established in the Chinese Classification of Mental Disorders and Diagnostic Criteria, Second Edition (CCMD-2; Chinese Association of Neurology and Psychiatry, 1989). Although qualified by the questionable inclusion of IA within the category of Childhood Schizophrenia, it was a significant milestone inasmuch as it indicated the achievement of a momentous understanding, an acceptance, and an acknowledgment of the applicability of diagnostic practice in Chinese psychiatry (Zhang, Yang, Jin, Wu, & He, 1994). A national field trial of the CCMD-2, however, found that having IA in the diagnostic manual did not have a positive impact on diagnostic practice in the early 1990s. According to Zhang and his colleagues, “childhood disorders were a somewhat weaker classification because a great proportion of its content was introduced directly from foreign systems of diagnosis, and in addition, most of the participants in the field trial were not engaged in child psychiatry and they were not familiar with it” (Zhang et al., 1994, p. 127). In 1995, the Chinese Classification of Mental Disorders and Diagnostic Criteria, Second Edition, Text Revision (CCMD-2-R; Chinese Medical Association, 1995) was published to reflect a classification of mental disorders similar to those in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV; American Psychiatric Association [APA], 1994) and the International Classification of Diseases, Tenth Revision (ICD-10; World Health Organization [WHO], 1990). In the CCMD-2-R, Childhood Autism was classified as a mental disorder under the category of Pervasive Developmental Delay.

The CCMD-3 is the current diagnostic guideline that includes psychiatric perspectives on AD in China. It is utilized to: “(1) improve the service for the patients, and to meet the needs of (our) society, (2) fit in with Chinese cultural background and tradition, (3) maintain the superiority of CCMD previous versions, (4) match ICD and DSM systems, and (5) be concise and manipulative” (CCMD-3, 2001, p. 173). The diagnostic criteria of AD were satisfied in a national field trial (Li, Su, & Luo, 2002), and the term AD gradually gained publicity in Chinese clinical practice and research. Accordingly, the number of referrals for suspected AD increased dramatically. In 1999, AD became the most common consultation and diagnosis of clinical cases in the Institute of Mental Health at Peking University (Guo, Zhang, & Liu, 2002).

Given that Chinese health professionals did not recognize AD until the late 20<sup>th</sup> century and the continuing lack of resources, funding, and trained professionals, the development of diagnostic tools and treatments programs for AD remains limited in the PRC. A decade after Tao’s report of four cases with IA,

Western diagnostic tools such as the Autism Behavior Checklist, the Psycho-Educational Profile, and the Childhood Autism Rating Scale, were adapted for AD assessment in the PRC (Lu, Yang, Shu, & Su, 2004; Sun, Wei, Yu, Yuan, Yang, Jia, & Yan, 2000; Wong, Hui, Lee, Leung, Ho, Fung, & Chung, 2004; Yang, Huang, Jia, & Chen, 1993). Not until the 21<sup>st</sup> century, Chinese psychiatric professionals developed their own screening and assessment tools that are reliable and valid for the conditions of Chinese individuals with AD (Liu, Wang, Guo, Yang, & Jia, 2004). However, advancement in the diagnosing of individuals with AD was not accompanied by development of effective treatments. Many individuals with AD do not have the benefit of appropriate intervention programs at the public school (Clark & Zhou, 2005). According to McCabe (2003), “educational opportunity and experiences for children with autism vary as a function of parent advocacy and a school’s willingness and ability to serve these students” (p. 20). Parents and professionals who are aware of Western psychiatric practice implement various types of intervention program for individuals with AD without any funding support. Treatment programs that include applied behavior analysis (ABA), discrete trail training (DTT), and sensory integration training, as well as acupuncture and herbal medicine (Clark & Zhou, 2005), are selected based on the parents’ beliefs and the philosophy of the organizations or commercial sectors. For instance, the Beijing Xingxing Yu Education Institute for Children with Autism was established under such initiative. The organization and parents of individual with AD work together to provide ABA and DTT to individuals with AD (McCabe & Tian, 2001). There remains a pressing need for legislative support and effective treatment programs for individuals with AD.

## The Diagnostic Criteria of Autistic Disorder in the CCMD-3

The effect of socio-cultural context on the conceptualization of AD can be demonstrated by examining the construction of diagnostic criteria. The Chinese psychiatric community has created reliable and culturally valid diagnostic guidelines for AD. We present a Chinese-English translation of the Chinese version of the diagnostic criteria for AD in the CCMD-3 to reveal how professionals assess behavioral functions or characteristics associated with AD in the PRC and to better portray how Chinese psychiatric professionals conduct their diagnoses, since the English-language and the Chinese-language versions of the diagnostic criteria for AD in CCMD-3 are not identical (See Table 1).

Table 1

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Diagnostic Criteria of Autistic Disorder/ Childhood Autism in the CCMD-3

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A. At least seven items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3).

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(1) Qualitative impairments in social interaction:

1. Lack of interest in group play, aloneness, inability to share group enjoyments.
  2. Lack of skills to interact with others, inability to apply age appropriate skills to develop peer relationships. For example, interacting with peers mainly by pulling, pushing, or hugging them as means of interaction.
  3. Engaging in self-entertainment, inadequate interaction with surrounding environment, lack of related observation and presupposed emotional response (e.g. oblivious to the presence of parents).
  4. Marked impairment in the use of appropriate eye-to-eye gaze, facial expression, gestures, and body postures while interacting.
  5. Marked impairment in make-believe play and social imitative play (e.g. inability to play “each family” game).
  6. Inability to seek sympathy and relief of physical discomfort or distress, unable to express care and sympathy for others’ physical discomfort or distress.
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(2) Qualitative impairments in communication:

1. Delay in the development of, or total lack of, spoken language, and inability to communicate through gesture or
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imitation.

2. Marked impairment in language comprehension, frequent inability to understand directions, inability to express one's own needs and distress, reduced tendency to ask questions, and lack of response to others' speech.
  3. Difficulty with language acquisition, use of meaningless mimic language or echolalia, pronoun confusions.
  4. Repetitive use of words and phrases inappropriate to context or making unintelligible sounds.
  5. In individuals with adequate speech, marked inability to initiate or sustain a conversation or engage in simple verbal exchanges.
  6. Abnormalities in the pitch, intonation, rate, and rhythm of speech. For example, tone of voice may be monotonous, stereotyped use of language.
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(3) Restricted interest, stereotyped and repetitive activities, resistance to change in environment and life style:

1. Preoccupation with one or more patterns of restricted interest. For example, the spinning of an electric fan, a single musical rhythm, commercials, weather forecasts, etc.
  2. Hyperactivity, excessive walking back-and-forth, running, self-spinning, etc.
  3. Resistance to changes in stereotyped, repetitive motor mannerisms or body postures, and shows irritation and anxiety over changes.
  4. Persistent preoccupation with odors, objects, or parts of toys, such as special odors, a piece of paper, smooth cloth, wheels of toy cars, and obtains gratification from experiencing them.
  5. Inflexible adherence to specific, nonfunctional routines, or ritualistic movements or activities.
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B. Severity criteria: The impairment of social function.

C. Course criteria: The onset is usually prior to 3 years of age.

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The diagnostic criteria listed in the CCMD-3 are not only a direct translation from the DSM-IV and the ICD-10, but also include material obtained from Western diagnostic resources, tools and/or scales, as well as information on Chinese social needs that present comprehensive features for diagnostic purposes. The topography of core symptoms in the CCMD-3 include: (1) qualitative impairments in social interaction; (2) qualitative impairments in communication; and (3) restricted interests, stereotyped and repetitive activities, requiring an unchanging environment and life style. The CCMD-3 requires seven behavior criteria within three core symptoms to conclude that an individual has AD. A total of seventeen associated diagnostic criteria are listed. Among them, six under the impairment of social interaction, six under the impairment of communication, and five under the restricted repertoire of activity and interests. Examples are used to describe a diagnostic criterion in order to help Chinese professionals reach an understanding.

Descriptive statements of behavior criteria within the diagnostic guidelines reflect an identification of AD in terms of its impairments and behavior patterns within three core symptoms. Some interesting descriptions are noted. In the diagnostic criteria for qualitative impairment in social interaction, inability to apply skills for interaction was specified with three criteria. Profound aloneness was highlighted in two criteria with such descriptions as: lack of interest in group-play, aloneness, and engaging in self-entertainment. The individual's behavior pattern related to its surrounding environment is mentioned in one criterion. In the diagnostic criteria for qualitative impairment in communication, impairment in language comprehension, expression and exchange is included. Language features, such as semantic, syntactic, and pragmatic elements were explicitly described with four criteria. Abnormalities of speech, such as the pitch, intonation, rate, and rhythm, were noted as a criterion. In criteria for restricted, repetitive, and stereotyped patterns of behavior, an



anxious tenseness is suggested in one criterion. Sensory dysfunction, hyperactivity and self-stimulation are described in four criteria.

In addition, some descriptions within the diagnostic systems reflect particular attention to and views of behaviors that indicate impairment of social and communicative functions. The CCMD-3 categorizes “lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level” as an indication of qualitative impairment in social interaction. It is not considered one of the diagnostic criteria for qualitative impairments in communication. The CCMD-3 did not emphasize that the delays or abnormal function must be socially oriented and, hence, in the context of symbolic or imaginary play. It indicates that the impairment of social function is an indicator for severe cases.

The diagnostic criteria for AD in the CCMD-3 are based on both observable behaviors and inner characteristics, such as aloneness, that was proposed by Kanner in 1943. We can only guess at the rationales for the descriptions, and many questions remain unanswered. For example, (1) in keeping with the literal meaning of the Chinese name for AD (孤独症 or 自闭症), the CCMD-3 explicitly highlights the aloneness feature in its diagnostic criteria. This inclusion raises several questions, such as: why do Chinese professionals share Kanner’s (1943) observation of this behavior? Do more Chinese individuals diagnosed with AD prefer self-isolation than do Americans with the same diagnosis? If individuals like to socialize, but lack the skills for appropriate social behaviors and language, are they less likely to be diagnosed with AD in the PRC than in the United States? When “aloneness” is considered a legitimate diagnostic criterion, the diagnostic outcomes for AD might be different. (2) Another unanswered question stems from the fact that “a lack of spontaneous seeking to share interests or achievements with other people<sup>49</sup>” is less explicitly described in the CCMD-3.

Further investigation is required to understand what prevents Chinese professionals from considering that to be an indicator for quality of social interaction, and thus list it as a diagnostic criterion. Is it related to certain social-cultural phenomena and norms that regulate daily practices and social interaction? Do most Chinese parents encourage their children to share their interests and talk about whatever they want? Or are children more likely to internalize adults’ interests while listening to their conversation? Do most Chinese parents encourage their children to share their achievements? Or are their children taught to be self-effacing and not become a person who talks more while doing less? This raises fundamental questions about how Chinese parents view and treat their children. (3) Another interesting description is the specification of the abnormality of speech. “Tone of voice may be monotonous” is highlighted in the CCMD-3. But why do Chinese professionals choose the word “monotonous” to describe a possible speech abnormality? Is a “sing-song” quality characteristic of normal Chinese speech? We note that tones, along with the other two pronunciation elements, initials and finals, are considered sufficient and necessary for accurate speech in Chinese language. There are various tones in Chinese, and every Chinese syllable has an assigned tone. The same syllable with different tones can have different meanings (Yao, Liu, Ge, Chen, Bi, & Wang, 2005). Abnormalities in use of speech elements such as tone all have consequences for the accuracy of spoken language when the language being spoken is Chinese. The CCMD-3 considers it important to list pronunciation of speech as a main criterion in the diagnostic menu. To date, these questions remain unanswered. We know that Chinese professionals have particular views about certain behavior features, and that these criteria are reflected in their subjective judgments and decisions regarding establishing a unified and culturally embedded diagnostic tool. But we do not know how these criteria are arrived at. This remains the subject of future research.

## Conclusion

Thinking about a psychiatric phenomenon is greatly related to social, cultural, and political practices that influence everyday and scientifically based thinking. Culture is seen as a mediator that constantly provides resources for psychiatrists to construct their thinking. By sharing cultural resources, psychiatrists

construct acceptable behaviors, perform joint activities, and build an understanding of a mental disorder. Psychiatrists develop their thoughts in their specific socio-cultural contexts by actively participating in social interactions. They both influence and are influenced by their external environments. The development of their thoughts about mental disorders and AD is both manifested within the self and changed by the socio-cultural context over their lifetimes.

As a product of everyday thinking and psychiatric thought, autism is a dynamic social phenomenon that is constructed in specific socio-cultural contexts. It is not solely for Western society, but is a global construct. Chinese psychiatric communities share the construct of AD in their own social cultural milieu. Both behavioral descriptions and terms that represent inner status are embedded in the diagnostic criteria of AD in the CCMD-3. Whether an individual is less likely to be diagnosed as having AD in the PRC because more criteria are required in the PRC, is unclear, and should be the subject of future research. An understanding of that diagnostic practice, as well as of the rationale and practice of treatment for individuals with AD, would support the understanding of AD in a cross-nation study.

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Footnotes

1 *Qi* is a life energy that flows through the human body. From a Traditional Chinese Medicine perspective, the human body is nourished by, and depends on, its flow.

2 Suggesting that “self criticism” and “mutual criticism” are the most effective ways to regain mental health through eliminating Capitalistic thinking and class evil.

3 A policy adopted by the Communist Party of China that involves a more positive attitude towards all other countries than previously.

4 It is one of the diagnostic criteria for qualitative impairment in social interaction in DSM-IV.

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# The Social and Academic Implications Of Drug Abuse Among Undergraduates: A Case Study Of The Obafemi Awolowo University, Ile-Ife. Nigeria.

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## Abstract

The researcher investigated the incidence of drug misuse among university undergraduates, with particular reference to Obafemi Awolowo University, Nigeria. The study revealed that the academic pursuit of those undergraduates who engage in drug misuse is not unduly jeopardized, and that the abusers do not socialize extraordinarily, contrary to seemingly popular expectation.

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## Introduction

The term 'drug' in the main, would relate to "any substance that, when taken into a living organism, may modify one or more of its functions", while abuse' implies "a particular application of a drug more destructive than constructive for society, or the individual".

One may be hooked emotionally and psychologically, and may have a physical dependence, where one has a drug addiction problem, whether to a legal or illegal drug, there is a craving for it. The individual wants to use the drug again and again, and if it is stopped, there are usually unpleasant physical reactions.

While it is not everyone who uses drug that becomes addicted, many people do, (may, 2006). Drug addiction involves compulsively seeking to use a substance, regardless of the potentially negative social, psychological and physical consequences. Certain drugs, such as narcotics and cocaine, are more likely to cause physical dependence, than are other drugs, (mayo, 2006).

Drug abuse among adolescents and young adults, which embrace university undergraduates, increased significantly in the united states of america in the late 60s and early 70s (eason, 1976). Little was known about hard drug and their usage in nigeria of the 60s. However, as far back as 1973, an expatriate staff at the university of nigeria, nsukka, reported a substance purported to be cocaine, which was used by some students, but the authenticity of the substance was not precisely established.

Soc. And acad. Implic. Of drug abuse in the late 70s, usage of cocaine and heroine became significant in nigeria. Although, the law- enforcement agencies and the government, were not aware of the development, because of the rampant use of, and emphasis on indian hemp. It was not until may 1983, when the guardian newspaper of nigeria, first related the story of the arrival of the drug known variously in the united states as 'snow' or 'angel – dust' that awareness began to rise. And this reached a crescendo between 1984 and 1985, when the federal government of nigeria promulgated a decree (d.n.20 of 1984), which prescribes death penalty for possession of hard drugs.

Drug abuse or drug dependence (as preferred by the world health organization), is defined as “ a state of psychic or physical dependence, or both on a drug, following administration of the drug on a periodic or continuous basis.” Man has long sought ways to enhance his pleasure, and to ease his discomforts. Curiosity, as one of man's outstanding characteristics, appears early in life, and leads to extensive exploratory behaviour. It is not surprising then that, many young persons will wish to try certain drugs in order to determine their effects for themselves. Studies by okoh (1978), oduaran (1979), and johnson (1979), exhibit a plethora of purposes for which students use drugs. The list includes curiosity, boldness, friends-do-it, enjoyment of social gathering, academic pressure. Sound-sleep, sexual- prowess, and performance in sports.

Much of the research in the field of student drug abuse appears to focus on correlates of drug abuse (stanton, 1979; steffen hagen, 1980), psychological characteristics of student drug abusers (paton and kandel, 1978; wright, 1977), Soc. And acad. Implic. Of drug abuse prediction of adolescent drug abuse (robin, 1980) and treatment of adolescent drug abusers (clayton, 1980).

An area in which research is still limited is the impact of drug abuse on the social and educational perspectives of students. This study will thus address itself of this realm. Two hypotheses, which are in the null form, have been posited to guide the study, viz: there is no significant relationship between drug abuse and academic performance. There is no significant relationship between achieving social acceptance within a social setting and the act of misuse of drug. The study was limited to the use of such drugs as tranquilizers, mandrax, amphetamines, marijuana, alcohol, and caffeine-related items like kolanut and coffee.

## Methodology

The study was carried out in the Obafemi Awolowo University. The sample comprised 180 undergraduates of the university. Of the sample, 140 were males, and 40 females. The subjects were randomly selected. The instrument was a validated – teacher-made test, comprising a 35-item supply–response test. The questionnaire was designed to provide information on the area of concern to the study – academic and social pursuits.

The technique employed in distributing the questionnaire was stratified random sampling. The stratification was based on sex – variable male/female. For more randomness within each stratum, a random selection of rooms in each undergraduates' hall of residence was undertaken and questionnaire forms were distributed randomly to any member of the selected rooms. The questionnaire

Soc. And acad. Implic. Of drug abuse contained items meant to elicit information on the respondents rate of drug usage, or non-drug usage. It also contained items that could bring to light how well or otherwise the respondent was performing academically and for the purpose of the equivalent of second class lower, were regarded as high performers, while those below were regarded as low performers.

## Results

Hypothesis one posits that there is no significant relationship between drug abuse and academic performance.

The responses of the respondent are as contained in table 1.

**Table 1**

**Table showing drug abuse and academic performance**

	High performance	Low performance	Total
Drug abuser	35 (19%)	52 (23%)	87
Non-drug abuser	30 (17%)	63 (41%)	93
Total	65	115	180

N= 180

The data were subjected to further analysis, using the chi-square statistic, as presented in table 2.

**Table 2**

**Chi-square comparison of drug abuse and academic performance**

Observed	Expected	O-e	(o-e) <sup>2</sup>	
35	31.42	3.58	12.82	0.41
30	33.58	-3.58	12.82	0.38
52	55.58	-3.58	12.82	0.23
63	59.42	-3.58	12.82	0.22
$\chi^2_c = 1.24$				

P> 0.05 (\*not significant)

Since the calculated value is less than the tabled, it follows that there is no significant relationship between the academic performance of users and the non-abusers. Thus, the hypothesis postulated for the study is upheld.

Hypothesis two postulates that there is no significant relationship between drug abuse and social association. Table 2 shows the responses of the subjects in relation to social association.

**Table 3**

**Drug abuse and social association**

	Strong association	Weak association	Total
Drug abuser	65 (36%)	41 (23%)	106
Non-drug abuser	45 (25%)	29 (16%)	74
<b>Total</b>	<b>110</b>	<b>70</b>	<b>180</b>

The data were further subjected to chi-square statistic for further analysis, at 0.05 level of significance.

**Table 4**

**Chi-square comparison of drug abuse and social association**



Observed	Expected	O-e	(o-e) <sup>2</sup>	
65	64.78	0.22	0.05	$7.72 \times 10^{-4}$
45	45.22	-0.22	0.05	$1.12 \times 10^{-3}$
42	41.228.782	-0.22	0.05	$1.21 \times 10^{-3}$
29		0.22	0.05	$1.74 \times 10^{-3}$
2				
$\chi^2_c = 1.24$				

P > 0.05 (\*not significant)

Since the chi – square calculated is less than chi-square tabled, it follows that there is no significant relationship between drug abuse and undue social association.

## Discussion

The result of the analysis in respect of hypothesis one appears a little surprising. One would have expected that the academic performance of drug abusers would be substantially hampered, for holister (1971) found that marijuana, like most other hard drugs, altered time sense, decreased auditory discrimination, results in difficulty in concentration, and brings about impairment of ability in some psychometric tests, especially those that are related to the manipulation of numbers. West (1972) discovered that a significant percentage of regular users are adversely affected in terms of mental health; while miller, (1974) and makeinde, (1974) found that amphetamines increase the availability of no adrenaline at the nerve cell connections. Also cohen (1978) discovered that flashbacks of lsd state are dangerous; while juman (1981) found that morphine and tranquilizers, analgesics and sedatives, may precipitate hepatic encephalopathy, possibly as a result of increased brain sensitivity to centrally acting drugs. Lastly, lesters (1977) also found that alcohol increased errors with marginal slowing of reaction time.

The result of hypothesis two is equally a little surprising. The ‘popular’ impression one has is that those who are on hard drugs tend to have strong social association, relative to their non-drug user counterparts. But the study revealed that the relationship is not statically significant. This thus, in a way, belies the logical reasoning that the degree of intoxication, due to drug, is highly related to sociability.

Soc and acad. Implic. Of drug abuse

Harmatz’s (1973) discovery that such drugs like marijuana tend to make the user moody, anxious and impulsive corroborates this finding. Also, other findings indicate poor social adjustment on the part of the user; typified by elevated situational hostility, (mirin, 1973), and a preference for passive life styles and low “purpose – in life” scores, (sheen, 1972).

Nature has tried very hard to protect the brain, and messing around with drugs can change the way the brain works naturally. When one takes drugs, parts of the brain start to disagree on what to do, and that creates a big problem. The brain can solve problems, be creative, be logical, make plans, make wise decisions, and do almost anything else one can think of. All parts of the brain work together, to keep us healthy, intelligent and happy (drug enforcement administration, 2006).

## Conclusions and recommendations

The following conclusion emanate from the results of this study, that there is no significant relationship between drug abuse and academic performance; that there is no significant relationship between drug abuse and social association; that though drug might be a necessary condition for sociability, it is not a sufficient condition. The result of this study notwithstanding, the harmful effects of drug abuse cannot be overemphasized. The abuser might justify the practice by positing that it helps in lifting mood, induces confidence and suppresses worries and anxiety. But these feelings are ephemeral, and totally out of tune with reality, and can lead to lethal consequences, in the sense that heart functioning and breathing can be severely depressed, thereby causing death.

In order to really help the situation, the government should have a well- defined comprehensive and realistic policy on control of drugs. This policy should include establishing a federal drug control centre, under the auspices of the ministries of health and internal affairs, which will collate information on drug use, and liaise with similar smaller units, to be based in each state. Public education should be targeted at the vulnerable segment of society, such as the older children, adolescent and young adults. Such educational measures should be carefully presented through methods that avoid threats and dramatization. Also, parents and school authorities should carefully warn their children against the destructive effects of these drugs. Any realistic attempt aimed at dealing with the issue of drug abuse must enjoy adequate multidisciplinary deliberation. Any law, which is designed to control drug abuse behaviour, must embrace suggestions from the country's relevant professional bodies such as psychologists, psychiatrists, sociologists, youth and welfare officers, counselors, educationists, ministry of health officials and law enforcement agents.

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# Disclosure of a Psychiatric Disability in Supported Employment: An Exploratory Study

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## Abstract

People with psychiatric disabilities entering the workplace and their supported employment providers frequently contemplate whether to disclose the supported employee's disability and their support needs to employers and workplace personnel. This study examined the role of disclosing a psychiatric disability and the employment experiences of 162 people participating in ten supported employment programs in the United States. Results indicate that 82% of the supported employees had their disability disclosed in the workplace; however disclosure was typically made by the employment agency. The relation between who disclosed the disability, what was disclosed and the effect on employment outcomes (including typical employment experiences, job adjustment and workplace accommodations) are examined. Practical suggestions are identified for supporting individuals regarding disclosure.

**Keywords:**

Psychiatric disabilities, supported employment, disclosure, employment outcomes

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## Introduction

Individuals with psychiatric disabilities entering the workforce often contemplate whether to disclose their disability to employers or coworkers. Because mental illness is commonly described as a "hidden" disability, the general public is not likely to notice the disability unless perceptible psychiatric symptoms or difficulties resulting from the disability occur. For people with mental illness entering the workforce and their employment providers, determining the scope and nature of supports provided by employment specialists at the workplace may depend on a variety of factors, including the supported employee's choices and comfort level with disclosing their disability at work.

The Americans with Disabilities Act (ADA) (PL 101-336) prohibits discrimination based on disability, yet individuals with may feel reservations about the ramifications of disclosing their disability to workplace personnel due to a fear of vocational stigma, not being accepted by workplace personnel or being viewed as "different", inadequate or incompetent. In a qualitative study, Allen and Carlson (2003) indicated that individuals chose to conceal their disability to preserve self-concept and avoid negative stereotypes. Because of public perceptions about mental illness, many individuals with psychiatric disabilities express fears of disclosing the disability to prospective or current employers.

In addition to the dilemma of possible stigma, in order to be eligible for legal protection under the ADA, an individual must disclose his or her disability to the employer and state the need for accommodations. Drake, Becker, and Bond (2003) note that accommodations for people with psychiatric disabilities rarely require direct expenditures on the part of the employer, rather, the accommodations involve extra supervision, or reallocation of time (such as scheduling adjustments or additional breaks). In another study of relationships between employers and people with psychiatric disabilities, Cook, Razzano, Straiton & Ross (1994) indicated that when individuals disclosed their mental illness, employers were able to provide additional support in the areas of job training, job performance, and supervision. However, Granger, Baron and Robinson (1997), found that less than half of the respondents with mental illness referred to the ADA when disclosing their disability to employers. In a study of disclosure and support provided by psychiatric rehabilitation practitioners in helping supported employees understand how to assert their rights under the ADA, 86% of the participants were unfamiliar with their rights under the ADA and job accommodations, and that they relied on their job coach or job developer to arrange job accommodations (Granger,

2000). Another qualitative study by Giola and Brekke (2003) involving 20 individuals diagnosed with schizophrenia revealed that only four of the participants had knowledge of ADA accommodations and referred to these when disclosing their disability. For these individuals, disclosure enabled them to better perform essential functions of their job and access support at the workplace when symptoms arose. Ellison, M. L., Russinova, Z., MacDonald, K. L., & Lyass, A. (2003) found that over 87% of study participants working in business, technical and educational settings disclosed their psychiatric disability to employers. The issue of disclosure is not often discussed in the context of multicultural issues (Weston, 2002). It is possible that patterns of disclosure could be related to diversity issues in relation to social and personal contexts.

Often, employment specialists also struggle with the matter of disclosure. Without careful consideration, employment specialists may reveal unnecessary information about the individual and his/her mental illness, increasing the supported employee's issues with stigma. In contrast, the employment specialist may be too vague in describing the supported employee and the reasons the individual is involved in supported employment services, which may subsequently lead to unanswered questions and potential suspicions on the part of workplace personnel. Employment specialists need more information about the ramifications of when, how, who and why disclosure is necessary. This study takes a first step toward addressing these issues.

This study explored the role disclosure of mental illness plays in the employment experiences of people with psychiatric disabilities. Several research questions guided the investigation:

1. Are there demographic and disability characteristics that make it more likely that a supported employee's psychiatric disability will be disclosed to workplace personnel?
2. Under what conditions (when, why, and how) is a psychiatric disability disclosed in the supported employment workplace?
3. Does a disclosure of disability, or the source of that disclosure, relate to how typical a supported employee's employment experiences will be in terms of job acquisition and hiring, job features, human resources management processes, and social aspects?
4. Is disclosure of disability associated with the provision of workplace accommodations and coworker supports at the supported job site?
5. Is disclosure status related to the overall job adjustment of supported employees with psychiatric disabilities?

A number of hypotheses about the relationship between disclosure and employment features and outcomes were set forth. It was predicted that disclosure of a mental illness would be associated with lower levels of functioning, a less typical employment situation, and a greater likelihood of workplace accommodation and coworker support. A non-directional hypothesis was postulated regarding the relationship between overall job adjustment and disclosure status.

## Method

This multi-site study utilized a survey design to assess the relation between mental illness disclosure for supported employees and associated employment features and outcomes. Data for the study included demographic, disability, disclosure, employment and support information for 162 supported employees served by 10 mental health vocational programs across 8 states (CA, IN, KS, NY, OR, PA, RI, VA). This disclosure study was a supplement to quantitative research on workplace supports and integration outcomes for people with psychiatric disabilities (Banks, Charleston, Grossi & Mank, 2001) which analyzed job performance, psychiatric symptoms, workplace supports and integration outcomes of 243 individuals with psychiatric disabilities. The workplace supports study indicated that higher levels of social integration correspond with higher wages of supported employees.

## Procedures

Administrators of 10 vocational programs for people with mental illness were initially contacted by telephone and invited to participate in the research project. Programs were selected based on nominations from national experts in the field of psychiatric rehabilitation. All programs were described as having successful employment outcomes and were considered to be using “natural supports” approaches to employment service delivery. Natural supports are defined as “any assistance, relationships, or interactions that allow a person to secure or maintain a community job . . . in ways that correspond to the typical work routines and social interactions of other employees” (Rogan, Hagner, and Murphy, 1993).

Information was provided to agencies about the study purpose, survey content, and data collection procedures. Agencies were asked to complete survey forms for all supported employees working in community-based jobs. The program staff person with the most knowledge of each supported employee and his or her job situation was asked to fill out the survey form. Financial remuneration of \$15.00 was offered for each completed survey.

Confidentiality requirements for submitting data were explained prior to data collection. Reference numbers were assigned to each survey to protect the anonymity of individuals included in the study. Administrators of the participating agencies were re-contacted approximately one year later and asked to complete a follow-up data form for each of the 243 supported employees included in the original study. This one-page supplemental data form consisted of questions about the disclosure of the supported employee’s disability to workplace personnel. All of the 10 agencies agreed to complete the disclosure supplements. Supplemental data forms were returned for 162 of the 243 supported employees. The 33 percent attrition rate is due, in part, to the fact that some staff who had completed the original surveys reported that the supported employees were no longer working or receiving services from the participating agencies.

## Participants

The majority of the sample was male (61.7%) and Caucasian (85.8%), and nearly half of the participants (43.2%) were between the ages of 31 and 40. Greater than half of the sample (58.7%) lived independently while 27 percent resided with parents or other family members and 14 percent lived in a supervised or supported residential setting such as a group home, supervised apartment or supported living setting.

The most prevalent primary disability diagnoses were schizophrenia and other psychotic disorders (47.2%) and affective disorders (36.5%). The mean Global Assessment of Functioning (GAF) score for participants was 59.42 (SD = 9.3). GAF is a rating of overall psychological functioning on a scale of 0-100. According to the DSM-IV, a GAF score between 51 and 60 indicates moderate symptoms or moderate difficulty in social or occupational settings (American Psychiatric Association, 1994). GAF scores were obtained from the participants’ most recent clinical record. Nearly 20 percent of the sample (n = 32) had GAF scores indicating serious symptoms or impairment in functioning while 40 percent (n = 65) had GAF scores indicating minimal to mild symptoms. Demographic and disability characteristics of the subset of 162 persons for whom disclosure supplements were returned were similar to those of the original sample of 243.

## Instruments

**Natural Supports Survey.** The natural supports survey for employees with mental illness was adapted from an earlier 62-item survey designed for participants with developmental disabilities. A detailed description of the design and development of this previous survey instrument is provided in Mank, Cioffi, and Yovanoff (1997). A panel of experts was consulted to help tailor the survey instrument for use with employees with psychiatric disabilities. Modifications to the original survey included changes to items about disability diagnosis and the addition of items about level of functioning, workplace accommodations, level of indirect employment support, service delivery model type, and community connections and supports. The natural supports survey for employees with mental illness was pilot tested with four community mental health agencies to assess item content, scope, and clarity. The final version of the survey included 85 items covering five general areas: demographics, disability information, employment features and outcomes, company personnel, and community connections and supports. Further description of survey



content is provided in Banks et. al., (2001).

**Disclosure Supplement.** The Disclosure Supplement was developed as a follow-up questionnaire to the Natural Supports Survey. The primary purpose of the supplement was to determine which supported employment participants from the original sample disclosed their disability to workplace personnel. The 5-item supplement also requested information about the circumstances surrounding disclosure. Response categories for each question were developed based on a review of the relevant literature and suggestions from the expert panel.

## Measures

Of particular interest in the present study were variables related to (a) disability disclosure, (b) level of functioning, (c) typicalness of employment features, (d) workplace accommodations and coworker support, and (e) overall job adjustment.

**Disability disclosure.** Disability disclosure status was measured as a dichotomous variable (disclosure/no disclosure). For supported employees whose disability was disclosed to workplace personnel, respondents were asked to indicate when, why, and how the disclosure was made. In addition to the predetermined response categories for each question, an “other” category was included to allow for additional responses.

**Level of functioning.** Level of functioning was assessed in two ways: Global Assessment of Functioning (GAF) scores and a measure of severity of psychiatric symptoms at the worksite. GAF scores were gleaned from the supported employee’s most recent clinical record. Severity of psychiatric symptoms at the worksite was rated on a 4-point scale (none, mild, moderate, severe).

**Typicalness of Employment Features.** Respondents were asked how “typical” the employment experiences of the person with a disability were compared to those of employees without disabilities in the same work setting. A 7-point scale (1 = not typical, 7 = quite typical) was used to rate the typicalness of 24 features of employment. For example, respondents were asked to rate “how typical” the individual’s job application process was compared to that of other job applicants. If the individual with a disability was required to submit the same formal job application that other prospective employees are required to submit, then this would be quite typical. If, however, other prospective employees are required to fill out a formal job application while the person with a disability was not required to do so, then the application process would be considered atypical. The 24 typicalness items were organized into four item clusters: job acquisition and hiring (e.g., recruitment, job application, interviewing), job features (e.g., work schedule, hourly pay, break times and location), human resources management processes (e.g., initial job training, supervision, opportunities for promotion), and social aspects (e.g., participation in non-work and at-work social activities). The scale was not designed as a value judgment but, rather, a comparison between the typical experiences of employees with and without disabilities.

Factor analysis was used to analyze the correlational structure of the typicalness items. This was done in order to reduce the total number of variables required to describe the underlying dimensions of typicalness (Tabachnick & Fidell, 1996). A maximum likelihood solution with varimax rotation indicated the presence of four distinct factors with eigenvalues greater than 1.0, capturing 71 percent of the total variance in scores. The factor solution was somewhat satisfactory, although a simple structure was not attained as some variables loaded onto more than one factor. Criterion for loading was .45. One item (i.e., transportation) was dropped due failure to load on a factor. The factor structure closely mirrored the section breaks in the survey itself. A principal components analysis yielded similar results.

Following factor analysis, Cronbach’s alpha coefficients were calculated for each of the four resultant subscales. Coefficient alphas for the subscales ranged from .86 to .95 and suggested a high degree of internal consistency. One

item (i.e., amount of task-related interaction with coworkers) was dropped from the Social Aspect subscale because it did not add to internal consistency alpha. Table 1 presents item loadings of the rotated 4-factor solution and internal consistency coefficients for each subscale.

**Table 1 Factorial Structure of Typicalness of Employment Items**

Items	Factor			
	Job Acquisition	Job Features	Management Processes	Social Aspects
Interviewing	<b>.89</b>	.12	.22	.15
Job application	<b>.76</b>	.24	.12	.04
Recruiting	<b>.73</b>	.16	.34	.24
Role in choosing job	<b>.64</b>	.19	.44	.30
Company benefits	.10	<b>.83</b>	.08	.20
Break location and schedule	.20	<b>.72</b>	.19	.22
Hourly pay	.14	<b>.58</b>	.41	.11
Others do similar work	.21	<b>.55</b>	.35	.14
Opportunity for job variety	.29	<b>.49</b>	.41	.41
Work schedule	.16	<b>.45</b>	.41	.27
Disciplinary process	.24	.27	<b>.81</b>	.26
Layoff conditions	.23	.34	<b>.74</b>	.25
Support in time of crisis	.23	.10	<b>.71</b>	.36
Supervision	.27	.20	<b>.70</b>	.25
Work rules and expectations	.24	.30	<b>.66</b>	.39
Performance evaluation	.26	.45	<b>.66</b>	.14
Orientation or induction	.39	.26	<b>.57</b>	.33
Opportunity for promotions	.26	.44	<b>.57</b>	.31
Initial job training	.45	.16	<b>.48</b>	.37
Participation in at-work social activities	.17	.23	.16	<b>.94</b>

Participation in non-work social activities	.11	.26	.32	<b>.79</b>
Behaves within accepted social norms	.19	.07	.42	<b>.58</b>
<hr/>				
Cronbach's coefficient alpha	.90	.86	.95	.89

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Factor scores were computed using items identified with factor analysis and Cronbach's alpha coefficients. Participant responses to items comprising each typicalness factor were averaged to compute four separate factor scores for each participant. Calculating an average rather than a sum of item responses maintained the 1 (not typical) to 7 (quite typical) scale, simplifies interpretation of factor scores.

Workplace accommodations and coworker support. Respondents were asked if workplace accommodations were in place for supported employees. They were also asked to identify the specific accommodations by using a checklist. Examples of accommodations include job restructuring, flex time, self-management tools, physical changes to the immediate work environment, and additional supervisor feedback. Coworker support was operationalized by two questions: (a) was training and support provided to company personnel? (yes/no), and (b) did company personnel provide support to the employee with a disability? (yes/no). Examples of support provided to company personnel include general disability awareness training or training specific to the support needs of the employee with a disability. Examples of support provided by company personnel include helping the supported employee learn new tasks, meet productivity standards, maintain socially appropriate behavior, participate in social activities at work, or manage job-related stressors.

Overall job adjustment. Job adjustment was defined as the extent to which the supported employee has adjusted to the job following initial training. Six items measuring job adjustment (e.g., work rate is comparable, relationships with coworkers are positive, employee seems satisfied with job) were scored on a scale of 1 (a little) to 7 (a great deal). Responses to items were averaged to compute a composite score on overall job adjustment for each participant (Cronbach's alpha = .91).

## Data Analysis

Two sets of analyses were performed to investigate the disclosure of psychiatric disability and associated employment features and outcomes. In the first set of analyses, univariate tests of group differences were used to examine differences between the characteristics of supported employees whose disabilities were disclosed and characteristics of supported employees whose disabilities were not disclosed. Following a significant  $\chi^2$ , standardized residuals were examined to determine which cells contributed most to the significant  $\chi^2$  value. Descriptive statistics regarding how, when, and why a disability were disclosed were also calculated.

The second set of analyses examined whether disability disclosure variables were associated with differential employment features and outcomes. This set of analyses was performed in three steps. First, t-tests were conducted to study the relation between disclosure variables (disclosure status and disclosure source) and typicalness of employment variables (job acquisition, job features, management processes, and social aspects). Second, multiple response crosstabs were examined to determine whether company personnel variables differed by disclosure status. Third, a univariate analysis of variance was conducted to determine if overall job adjustment was related to disclosure status. With regard to ethnic diversity, there was a small number of non-caucasian participants (N=17), which is less than 15% of the sample of participants.

## Results

Initial findings of the Natural Supports Study focusing on the relationships between mental health diagnosis, workplace supports, and supported employment outcomes have been reported previously by Banks, Charleston, Grossi, and Mank (2001). The results reported here examine disability disclosure in the supported employment workplace and its relation to employment features and outcomes.

## Disability Disclosure

Which supported employees disclosed? A disclosure of disability was made for 82 percent of the supported employees in the present study. Employees who disclosed differed from those who did not disclose on a number of demographic and disability characteristics (see Table 2). Employees were significantly less likely to have disclosed their disability if they were women, had a mood disorder, or displayed no psychiatric symptoms at work. Employees who disclosed did not differ significantly from those who did not disclose in terms of ethnicity, age, living arrangements, or Global Assessment of Functioning (GAF) score.

**Table 2 Sample Characteristics**

Variable	DISCLOSURE <sup>a</sup>		NO DISCLOSURE		Statistic (df)	p-value
	(N=133)		(N=29)			
	<u>n</u>	%	<u>n</u>	%		
Gender					$\chi^2(1) = 6.19$	.013
Female	45	33.8%	17	58.6%		
Male	88	66.2%	12	41.4%		
Ethnicity					Fisher's exact <u>p</u> = .255	ns
Caucasian	116	87.2%	23	79.3%		
Other	17	12.8%	6	20.7%		
Age					$\chi^2(2) = 2.58$	ns
18-30	27	20.3%	3	10.3%		
31-40	54	40.6%	16	55.2%		
>40	52	39.1%	10	34.5%		

Living Arrangement					$\chi^2 (2) = 2.79$	ns
Parents/family	37	29.4%	5	17.2%		
Independent	70	55.6%	21	72.4%		
Supervised/supported	19	15.1%	3	10.3%		
Primary Diagnosis					$\chi^2 (2) = 9.02$	.011
Schizophrenia	64	49.2%	11	37.9%		
Mood Disorder	41	31.5%	17	58.6%		
Other	25	19.2%	1	3.4%		
Severity of Symptoms at Work					$\chi^2 (2) = 6.11$	.047
None	15	11.3%	8	27.6%		
Mild	86	64.7%	13	44.8%		
Moderate/Severe	32	24.1%	8	27.6%		
Global Assessment of Functioning (0-100)					$t (160) = .04$	ns
$\underline{M(SD)} = 59.41(9.6)$					$\underline{M(SD)} = 59.48(8.0)$	

<sup>a</sup>Due to missing data, sample size ranged from 126 to 133 for the Disclosure group.

What was the context of disability disclosure? Table 3 displays the how, when, and why of disability disclosure. An individual's disability was most often disclosed to workplace personnel by supported employee staff. In nearly half the cases of disclosure, the employer was already familiar with the nature of the services provided by the supported employment agency. For nearly three quarters of those whose disability was disclosed, the disclosure was first made during the job development phase. The top three reasons cited for disclosure of disability were to (a) enlist or facilitate the support of workplace personnel, (b) negotiate accommodations, or (c) address symptoms or crisis issues.

**Table 3**

**Circumstances Surrounding Disclosure of Mental Illness to Workplace Personnel (N = 133)**

Contextual Variable	n	%
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How was the disclosure made?<sup>a</sup>

Supported employment staff disclosed to workplace personnel	72	54.1
Employer already familiar with nature of services provided by supported employment agency	60	45.1
Supported employee disclosed to employer	39	29.3

When was disclosure first made? (n = 127)

During job development	91	71.7
During job acquisition and hiring	16	12.6
During employee orientation and training	2	1.6
During ongoing support to the employee	10	7.9
Other	8	6.3

What was the purpose of disclosure?<sup>b</sup>

Enlist or facilitate support of workplace personnel	106	79.7
Negotiate accommodations	91	68.4
Address symptoms or crisis issues		

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Take advantage of tax credits	82	61.7
Respond to request for information from Social Security	19	14.3
Invoke ADA protections	15	11.3
Other	8	6
	10	7.5

<sup>a</sup>30% of respondents endorsed more than one statement. <sup>b</sup>74% of respondents endorsed more than one statement.

#### Employment Features and Outcomes

Typicalness of employment features. The hypothesis that disclosure of a mental illness would be associated with a less typical employment situation was only partially supported. Univariate tests were conducted to compare the group that did not disclose to the group that disclosed on the four typicalness subscales. Cell size for the group that disclosed (n= 133) was substantially greater than the cell size for the group that did not disclose (n = 29). However, Levene's test for equality of variances was not significant for any of the four typicalness subscales. The mean typicalness score for the group that did not disclose was significantly higher than the mean typicalness score for the group that disclosed on the job acquisition and management processes subscales. In other words, those who did not disclose acquired their jobs in a more typical fashion and were managed in a more typical manner. There were no mean differences between groups on the Job Features and Social Aspects subscales. Similar results were obtained when severity of symptoms was entered into the model as the covariate. The covariate analyses enabled us to determine whether any significant relations were found after the effects of severity of symptoms were taken into account.

**Table 4**

**Means, Standard Deviations, and t-test Results for Effects of Disclosure on Four Typicalness of Employment Features**

Typicalness Subscale	Disclosure		No Disclosure		t-test		
	M	SD	M	SD	df	t	partial h <sup>2</sup>
Job Acquisition	5.49	1.37	6.21	1.42	155	2.48*	.04
Job Features	6.02	1.02	6.24	1.00	159	1.08	.01
Management Processes	5.97	1.04	6.46	.93	159	2.31*	.03

Social Aspects	5.20	1.46	5.21	1.82	133	.024	.00
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Note. Partial  $h^2$  = effect size. \* $p < .05$ .

A second set of analyses was performed to determine if the source of disability disclosure (individual v. agency staff) related to the typicalness of the employment situation. Individuals who self-disclosed had more typical job acquisition experiences ( $M = 6.2$ ,  $SD = 1.30$ ) than individuals whose disabilities were disclosed by agency staff ( $M = 5.24$ ,  $SD = 1.32$ ),  $t(109) = 3.42$ ,  $p = .001$ . No significant differences were found for job features, management processes, or social aspects subscales.

Workplace accommodations and coworker support. Multiple response crosstabs revealed that supported employees who disclosed their disability were significantly more likely to have an accommodation in place at the workplace than supported employees who did not disclose their disability,  $\chi^2(1) = 4.14$ ,  $p = .042$ . Fifty-two percent ( $n=133$ ) of those who disclosed had workplace accommodations while only 31 percent ( $n= 29$ ) of those who did not disclose had workplace accommodations. Company personnel were more likely to have received training if the supported employee's disability was disclosed (63%) than if it was not disclosed (31%). Company personnel were more likely to provide support to employees who disclosed their disability (78%) than to employees who did not disclose their disability (45%). Overall job adjustment. The t-test results indicate that, although the mean score for the nondisclosure group ( $M = 5.9$ ,  $SD = 1.51$ ) was higher than the mean score for the disclosure group ( $M = 5.62$ ,  $SD = 1.17$ ), overall job adjustment was not significantly related to disability disclosure status,  $t = 1.092(159)$ ,  $p = .277$ . This finding held even after severity of symptoms was entered as a covariate.

## Discussion

This study provides an analysis of disclosure of the psychiatric disability in the workplace and associated outcomes of 162 individuals with psychiatric disabilities in supported employment jobs. The finding that 82 percent of study participants had their disabilities disclosed to workplace personnel is in line with other studies of disclosure among individuals with psychiatric disabilities who use vocational rehabilitation services or job coaches (e.g., Granger, 2000). This high rate of disclosure is not surprising given the fact that often times the employment service provider will contact an employer about a job prior to the individual with a disability ever submitting an application for employment. For almost half the participants in this study de facto disclosure was made because the employer was familiar with the nature of the services provided by the supported employment agency from which the participant received services. In these instances, the applicants or employees themselves had little role in disclosing their disability once they chose to receive supported employment services. Clearly individuals with psychiatric disabilities who choose to receive supported employment services have unique considerations with respect to disclosure.

In this study we found differences in whether an individual had their psychiatric disability disclosed based on gender, type of psychiatric disability and the presence of symptoms at work. We found that in most situations, the disability was disclosed to workplace personnel, and disclosure of the disability primarily occurred to facilitate accommodations and to provide training and information to the workplace personnel to in turn support the individual.

We hypothesized that disclosure of the mental illness would be associated with lower global assessment of functioning, less typical employment conditions, presence of accommodations at the workplace and increased support by workplace personnel. These data indicated that Global Assessment of Functioning had no relationship to disclosure of the mental illness. Therefore, individuals with high or low GAF scores had their disability disclosed. Regarding typical employment features, those individuals whose disability was not disclosed to the employer had more typical experiences in acquiring the job, however, results indicate individuals have more typical experiences in



job acquisition and hiring if they disclosed the disability themselves rather than disclosure by their employment consultant. From the results of this study, it appears that whether or not an individual disclosed had no bearing on how well the individual adjusted to the job. Individuals who did have their disability disclosed had accommodations arranged at the workplace. Additionally, company personnel received training (such as disability awareness training or other instructions specific to the needs of the individual in the supported employment job). Company personnel in turn supported the individual whose disability was disclosed in their jobs.

These findings indicate that supported employees and the employment specialists should be sensitive to who discloses information about the supported employee's psychiatric disability, how this information is relayed to the workplace personnel, when to share the information, what information to disclose, and the primary purpose for disclosing information about the mental illness. It is likely necessary for employment specialists and individual supported employees to consider these factors and make sound decisions based on the work culture and individual's preferences when discussing the type and amount of support needed for the individual to have successful outcomes in employment. While disclosure is a sensitive issue that should be discussed with the individual, it may also involve personal understanding of the implications for the supported employee. Employment service providers should explore the following practical suggestions when arranging workplace supports with individuals diagnosed with psychiatric disabilities:

- Help the individual understand his/her rights through the ADA, and the reasonable accommodations allowed for individuals with psychiatric disabilities. Explore any accommodations that may be needed on the job with the supported employee and develop a plan to discuss with the employer any needed accommodations and supports.
- Discuss with the supported employee his/her comfort level and preferences with disclosing the disability at the start of employment services. Realize in some circumstances, disclosure may be necessary in facilitating workplace supports and negotiating accommodations, especially if individuals may experience psychiatric symptoms at work. In other instances, individuals who may not exhibit symptoms that interfere with job performance may not find it necessary to disclose their disability.
- Prepare the individual in answering questions about his/her disability. The individual's choice of disclosing the disability may involve examining personal attitudes and beliefs, and coming to terms with the disability and its chronicity, yet still viewing oneself as a competent, contributing member of the workplace. It is best for the individual to have a comfort level with his/her disability and recognize that the psychiatric disability label is NOT the individual. Rather, the individual may have unique characteristics that require support and accommodations. Help the individual learn to focus on strengths rather than limitations when discussing his/her disability.
- Plan the type and amount of employment support and intervention that is most effective and least intrusive for the supported employee (on-site support, off-site, or support to workplace personnel).
- Examine the workplace culture to understand if it is a work environment that is supportive of diversity, and supports all employees and their various differences.
- If disclosure results from the role of the employment consultant's involvement, use "common language" terms to describe the individual's basic support needs. Never describe the individual in clinical or medical terms, or in ways that draw attention to their limitations. Rather, accentuate the individual's strengths, and his/her skills.
- Develop specific plans for supports from workplace personnel. Identify with the supported employee what kind of support is needed, when the support is needed, who at the workplace can be a mentor, and what issues may trigger stressors (for example, changes to the work environment or increase in productivity demands) that may require support from coworkers and/or the employment specialist.

- Realize that employment specialists can be ambassadors for the individuals they serve through effective communication to educate and alleviate concerns of employers who hire people with disabilities.

Whenever possible, avoid professional interference at the workplace. Use discretion and confidentiality. Using these suggestions can help the employment specialist and the supported employee adequately discuss and agree upon the decisions around disclosure. Through incorporating these strategies, both the employment specialist and the supported employee can be best prepared to negotiate accommodations and access workplace supports.

### Limitations

There are several limitations to this study. These data with a sample of 162 individuals provide only a synopsis of disclosure and associated outcomes. The sample was not randomly chosen and may not be representative of all people with psychiatric disabilities in supported employment. In most situations, the employment provider provided the data, and no inter-rater reliability was used for the natural supports survey or the disclosure supplement. Therefore, some bias may be suspected where employment staff members provided the data. To control in part for this bias in the data, test–retest information was collected on 15% of the natural supports survey sample. In addition, in this study, disclosure results did not relate to age, ethnicity and living arrangements. A larger sample may discover relationships in such data regarding these variables. Future research is needed that investigates the relationship of employment, disability, age, and multicultural issues.

### Implications

This study poses several implications for further research. Further research is needed about the effects of the employment specialist in supporting individuals in the hiring, recruitment, orientation, and training process. How does disclosure affect integration outcomes? Are individuals with psychiatric disabilities more or less integrated socially with coworkers if they disclose their psychiatric diagnoses? Additionally, a better understanding is needed of how individuals adjust to their jobs in lieu of the disability. What is the effect of the employment specialist support on job adjustment? Issues of supported employment, and outcomes are in need of studies related to gender, ethnicity, and multicultural issues. These issues have been rarely studied (e.g., Olson, Cioffi, Yovanoff, & Mank, 2001). In addition, the Association for Business Communication (2005) and Hawley-McWhirter (1999) note the lack of information regarding disability, employment, and multicultural issues.

The above implications are critical in understanding workplace supports and integration. Further research is needed to understand strategies to support individuals with psychiatric disabilities in typical and natural ways in their workplaces and communities.

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# Social Support And Quality of Life Among Psychiatric Patients In Residential Homes

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## Abstract

We examined the relationship between social support (SS) and Quality of life (QOL) among 83 patients suffering from schizophrenia, schizoaffective disorder, bipolar disorder, depression, and other psychiatric conditions from three residential facilities. When controlled for age, gender, type of funding, marital status, residence location, and length of stay, total SS was significantly related to total QOL and QOL subcomponents of finance and self and home maintenance. SS from friends was significantly related to the QOL subcomponent of housing. SS from a significant other was related to the QOL subcomponents of mental situation and services.

**Keywords:** Quality of Life (QOL), Social Support (SS), Residential Home Clients

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## Introduction

The issue of quality of life (QOL) has received increased attention from the medical community due to its importance for patient rehabilitation (Lustig & Crowder, 2000). QOL is known to be indicative of the level of social functioning in mental health patients (Menlowics & Stein, 2000). In an era of deinstitutionalization, the proliferation of community support programs has played a pivotal role in providing basic support structures to patients with mental illness (Jinnett et al., 2001). However, the maximum level of QOL attainable to patients with chronic mental illness is a topic for continued discussion.

QOL can be defined as an overall sense of well-being, comprised of both objective and subjective evaluations of physical, material, social and emotional well-being together with personal development and purposeful activity (Felce & Perry, 1996). Measurement of QOL can be a comprehensive means of evaluating various aspects of care through the exploration of subjective judgments of persons with severe mental illness (SMI) of their own welfare and by objective assessments of their life circumstances by researchers (Clarkson & McCrone, 2000). The subjective QOL refers to the level of satisfaction of a person with his or her living situation and general well-being, while objective pertains to how well the patient functions in social settings and in daily activities (Mares, Young, McGuire, & Rosenheck, 2002). The level of satisfaction with interpersonal relationships and subjective QOL of patients with SMI may be lower than for people from the general population (Tempier, Caron, Mercier & Leouffre, 1998).

QOL derives in large part from social contact (Bigelow et al., 1991). Social contact fulfills the personal needs of mentally ill individuals for affection and promotes self-esteem. Social contact also contributes to a sense of affiliation in people with mental illness (Corrigan, 2003). Patients with SMI who have access to community support services report having acceptable levels of satisfaction with their lives (Trauer et al., 1998). Unfortunately, many activities that can potentially fulfill basic personal needs for social contact are unavailable to people with mental illness in mental health settings. Also, people with mental illness tend to have small, low-density social networks comprised mainly of family members (Brunt & Hansson, 2002). This lack of social networks in mentally ill patients may contribute to the onset of psychopathological symptoms, which can in turn place a burden on psychiatric services and in-patient services.

Previous research has demonstrated that heightened social support can improve the QOL of persons with mental illness (see for example, Yanos et al., 2001; Nelson et al., 1995). Social support acts to buffer the impact of stressful experiences, such as those related to physical health (Swindells et al., 1999). Social support can also moderate the effects of pain, certain functional limitations, and depression (Blixen & Kippes, 1999).

It has previously been shown that the quantity of supportive social relationships is predictive of subjective QOL in persons diagnosed with severe mental illness (Baker et al. 1992; Bengtsson-Tops & Hannson, 2001; Caon et al. 1998; Hannson et al., 2002; Lam & Rosenheck 2000; Rudnick & Kravetz, 2001). Especially when present within a context of large network size (Goldberg et al., 2003), social support can promote recovery in people with serious mental illness (Corrigan and Phelan, 2004). Mares, Young, McGuire & Rosenheck (2002) found that a desirable social climate was positively associated with subjective QOL in mental health patients. Previous researchers have used the Bigelow Quality of Life Questionnaire (Bigelow et al., 1991) to individually measure various components of QOL in mental health patients (Baker et al., 1992; Caron et al., 1998; Goldberg et al., 2003; Mares et al., 2002; Nelson et al., 1995; Skinner et al., 1999 and Yanos et al., 2001). Our study was unique in that we assessed all domains of the Bigelow questionnaire, both subjective and objective, and also assessed the relationship between total quality of life (TQOL) and its individual subcomponents to social support. We also used multivariate models to assess the possible role of age and other variables as potential predictors of QOL and its subcomponents due to their known correlation with satisfaction (Chand et al., 2004; Blenkiron & Hammill, 2003; Clarkson & McCrone, 2000; and Mercier et al., 1998).

## Methodology

## Study Population and Sampling

Convenience sampling was used to select subjects for the study. Participants were recruited through personal appeal, and indirectly through the residential manager at each facility. The study participants resided at three separate residential facilities

Potential participants were informed of the nature of the study, the survey method and the anticipated amount of time required for participation. Patients were informed that their participation was strictly voluntary and that there were no penalties for non-participation. Any confidentiality concerns were also addressed. Patients were also encouraged to discuss any concerns about the objectives of the study.

## Data collection

The modified Quality Of Life Questionnaire Interviewer Rating Version questionnaire was administered to assess QOL. The Multidimensional Scale of Perceived Social Support (MSPSS) was administered to assess social support. Demographic and funding information, as well as information on patients' diagnosis was also collected.

The QOL components assessed in the Bigelow questionnaire are: self and home maintenance ability, financial situation, availability of employment and transportation, available services, physical condition, meaningful use of time, and ability to complete tasks. Acronyms used for the nine subcomponents of QOL are listed in Table 1.

Table 1. Acronyms used for QOL and its nine subcomponents

TQOL = Total QOL
QOLE = QOL subcomponent of employment
QOLF = QOL subcomponent of finance
QOLPH = QOL subcomponent of patient health and services
QOLH = QOL subcomponent of housing
QOLSH = QOL subcomponent of self and home maintenance
QOLM = QOL subcomponent of mental situation and services
QOLT = QOL subcomponent of ability to complete tasks
QOLU = QOL subcomponent of patient use of time
QOLTR = QOL subcomponent of transportation services

For the modified Bigelow QOL questionnaire, a total QOL score was calculated as a sum of the scores on the individual items. Total scores were then projected onto a range of 0 – 212 with the high end representing better quality of life. Subjective and objective domains were reported both separately as subjective QOL and objective QOL scores and together as part of a total score for each of the patients. Not all sections had an equal number of questions, for example twelve questions were asked in the mental health section and only 2 questions were asked in the transportation section. Reliability and validity of the QOL Interview (interviewer rating version) was previously assessed (Bigelow et al., 1990). Fifty-six items had Cronbach's Alpha greater than .70 and more than half the items were above .80. According to the authors of the study the questionnaire demonstrated good face validity in its credibility and acceptance among experienced practitioners. The interview is readily administered and easily scored and was used successfully in several program evaluations (Bigelow et al., 1990).

The MSPSS questionnaire is comprised of 12 items rated on a 7-point Likert-type scale (response format ranges from, 1 = very strongly disagree to 7 = very strongly agree). A higher score signifies increased levels of perceived social support. The score on individual items on the MSPSS were summed and divided by 12. Scores on the four items that comprise each subscale were also summed and divided by 4 (Cecil, Stanley, Carrion, & Swann, 1995).

Canty-Mitchell & Zimet (2000) assessed the reliability and validity of the MSPSS instrument. The Cronbach's Alpha coefficient was .93; the The Cronbach's Alpha coefficient of the three subscales of family, friends and significant

other were .91, .89 and .91 respectively. Correlation coefficients were used to assess the validity of the MSPSS instrument by comparing it to the Adolescent Family Caring Scale (AFCS). The results showed that for the family subscale the correlation was .76, for the friends' subscale it was .33, and for the significant other subscale was .48 (Canty-Mitchell & Zimet, 2000).

In attempting to assess QOL of people with mental illness there is a concern regarding the validity of self-reported ratings by patients. Limitations on the validity of self-reported QOL may be partially attributable to the psychopathology of the patients, which can distort mental, emotional and social judgments (Atkinson, Zibin, & Chuang, 1997). Two safeguards were utilized to minimize any potential bias of patient's self-reported ratings. First, eleven questions from the survey instruments were answered directly by the interviewer in order to offset any response bias on the part of the patient. Secondly, the questionnaire included both objective and subjective criteria.

This study was approved by the Touro University International institutional review board.

### Statistical analyses

All statistical analyses were performed using the SPSS Graduate Pack 13.0 for Windows program.

Total SS and support of friends, family and significant other, together with age, gender, residence location, type of funding, marital status, and length of stay were examined for their relationship to QOL and its subcomponents via multiple regressions and MANCOVA.

## Results

Data was collected on 83 psychiatric patients, 61 men and 18 women (Table 2). The mean age of respondents was 38 years with a range of 20 to 57 years. The average length of stay at the residential facility was 55.5 months (4.6 years). Fifty-nine of the study participants were Caucasian (71.1%), eight were Hispanic, seven were African American, seven were Jewish American, and two were Asian. Sixty-seven patients received Medicaid financial support and 16 received Medicare financial support. Sixty-nine patients were single, nine were divorced and five married. Among members of the study population, 38 patients had been diagnosed with Schizophrenia or schizoaffective disorder, 22 patients had bi-polar disorder, 18 had depression disorder and five patients diagnosed with other psychiatric conditions (Table 2b).

Table 2a. Characteristics of study participants (N=83)

Variables	N = 83	%
Gender		
Male	65	78.3
Female	18	21.7
Ethnicity		
Caucasian	59	71.1
Hispanic	8	9.6
African American	7	8.4
Jewish American	7	8.4
Asian	2	2.4
Marital status		
Single	69	83.1
Divorced	9	6.0
Married	5	10.8
Residence location		
LOCATION1	26	31.3
LOCATION2	23	27.7
LOCATION3	34	41.0

Funding		
Medicaid	67	80.7
Medicare	16	19.3

Table 2b. Characteristics of study participants (N=83) contd.

Variables	N = 83	%
Psychiatric conditions		
Schizophrenia/schizoaffective disorder	38	45.2
Bipolar disorder	22	26.2
Depression	18	21.4
Other psychiatric conditions (Personality disorder, ADD/ADHD, anxiety, panic, impulse control disorder and obsessive compulsive disorder)	5	6.0

Study participants scored highest on QOLM and lowest on QOLE. Participants tended to report low scores on QOLTR (Table 3).

Table 3. Descriptive statistics – QOL and subcomponents (N = 83)

Variable	Mean	SD	# Questions	Mean divided by # questions asked
TQOL	159.9	15.6	56	2.9
QOLM	42.9	4.6	12	3.6
QOLE	14.1	7.5	9	1.6
QOLH	26.9	2.0	8	3.4
QOLSH	18.4	2.2	7	2.6
QOLU	18.8	3.4	6	3.1
QOLT	16.3	3.0	5	3.3
QOLPH	12.3	1.7	4	3.1
QOLF	7.0	0.9	3	2.3
QOLTR	3.3	1.6	2	1.7
QOLsub	55.45	7.58	17	3.3
QOLobj	106.0	9.67	39	2.7

Subjects reported having more social support from friends than from family or from significant other. This is evidenced by the fact that the mean scores on the ‘friends’ subcomponent of social support were significantly higher than the mean scores of the ‘family’ and ‘significant other’ subcomponents (Table 4).

Table 4.

Descriptive statistics – Social support and subcomponents (N = 83)

Variable	Mean	SD	# Questions
Total social support	69.6	14.7	12
Social support subcomponent family	21.3	8.3	4
Social support subcomponent friends	26.4	2.9	4
Social support subcomponent significant other	21.9	7.4	4

Table 5



Results of multiple linear regression using total social support as the main predictor and TQOL and subcomponents as dependent variables (N = 83)

Variable	TQOL	QOLE	QOLF	QOLPH	QOLH	QOLSH	QOLM	QOLT	QOLU	QOLTR
Total SS	.300*	.101	.017*	.024	.023	.040*	.059	.022	.024	-.011
Residence Location										
Location 3 (reference)										
Location 1	5.858	-2.821	.664**	.860	.784	1.494*	.739	1.398	1.803	.936
Location 2	14.128**	3.686*	.964**	.180	.087	1.563**	2.987**	.574	3.552**	.536
Funding	5.491	6.659*	.330	.679	1.263	.278	-.515	-2.795*	-.551	.144
Gender	-2.470	-.340	.494	.410	-.663	-1.378	-.558	.142	-.626	.048
Age	-.040	-.310**	.040*	.004	.017	-.018	.125	.004	.118*	-.021
Length of stay	.201*	.114**	-.005	.001	.028*	.012	.031	.015	-.016	.021*
Marital Status										
Single (reference)										
Married	-6.067	5.179	-.895*	-1.309	-.649	-1.292	-1.876	-2.144	-3.121*	.042
Divorced	-7.262	1.036	-.466	-1.293*	-.892	-1.064	-1.290	-1.357	-2.141	.206

\*\* $p \leq .01$ , \* $p \leq .05$ , beta coefficients are reported

Funding (Medicaid vs. Medicare), Gender (Men vs. Women), Length of stay (months), Age (years), Location 3 is used as a reference, Single status is used as a reference, total social support represents a score made up of family, friends and significant other. The coefficients are the un-standardized coefficients.

Ten multiple regression procedures were performed on TQOL and its subcomponents (QOLE, QOLF, QOLPH, QOLH, QOLSH, QOLM, QOLT, QOLU, and QOLTR) with total social support as a main predictor of both TQOL and its subcomponents (Table 5). Total social support was significantly related to TQOL ( $B = .300$ ,  $p \leq .05$ ). Other significant predictors of TQOL were location 2 ( $B = 14.128$ ,  $p \leq .01$ ) and length of stay ( $B = .201$ ,  $p \leq .05$ ). Significant predictors of QOLE included location 2 ( $B = 3.686$ ,  $p \leq .05$ ), type of funding ( $B = 6.659$ ,  $p \leq .05$ ), age ( $B = -.310$ ,  $p \leq .01$ ) and length of stay ( $B = .114$ ,  $p \leq .01$ ). Total social support was significantly related to QOLF ( $B = .017$ ,  $p \leq .05$ ). Other significant predictors of QOLF were location 1 ( $B = .664$ ,  $p \leq .01$ ), location 2 ( $B = .964$ ,  $p \leq .01$ ), age ( $B = .040$ ,  $p \leq .05$ ), and married status ( $B = -.895$ ,  $p \leq .05$ ). Using QOLPH as the dependent variable divorced status was a significant negative predictor ( $B = -1.293$ ,  $p \leq .05$ ). Using QOLH as the dependent variable length of stay was a significant positive predictor ( $B = .028$ ,  $p \leq .05$ ). Using QOLSH as the dependent variable total social support was a significant positive predictor ( $B = .040$ ,  $p \leq .05$ ). Using QOLM as the dependent variable residence location 2 was again a significant predictor ( $B = 2.987$ ,  $p \leq .01$ ). Using QOLT as the dependent variable, type of funding was a significant predictor ( $B = -2.795$ ,  $p \leq .05$ ) with Medicaid patients exhibiting greater QOLT than Medicare patients. Using QOLU as the dependent variable significant predictors were location, with location 2

having significantly higher QOLU than location 3 ( $B = 3.552, p \leq .01$ ), age ( $B = .118, p \leq .05$ ), and marital status, married patients having lower QOLU ( $B = -3.121, p \leq .05$ ). Using QOLTR as the dependent variable, only length of stay was a significant predictor ( $B = .021, p \leq .05$ ). The  $R^2$  coefficients for predicting QOL and its subcomponents were respectively TQOL – .304\*\*, QOLE – .350\*\*, QOLF – .327\*\*, QOLPH – .116, QOLH – .230\*, QOLSH – .377\*\*, QOLM – .359\*\*, QOLT – .356\*\*, QOLU – .284, and QOLTR – .102 (\*\* $p \leq .01$ , \* $p \leq .05$ ). A MANCOVA analysis was also performed (data not shown). Thus, taking into account all TQOL components as dependent variables at the same time, results were consistent with the results of the linear regression analyses.

When objective QOL and subjective QOL were used as the dependent variable respectively, a significant positive relationship emerged between total social support and objective QOL ( $B = .176, p \leq .05$ ) and between total social support and subjective QOL ( $B = .140, p \leq .05$ ). Longer length of stay was associated with higher objective QOL ( $B = .176, p \leq .01$ ), however, length of stay was not significantly related to subjective QOL.

Linear regressions were also performed using the three subcomponents of social support (family, friends, and significant other) as independent variables of TQOL and its subcomponents. Social support from friends was related to QOLH ( $B = .228, p \leq .05$ ) and tended towards positive association with QOLF ( $B = .075, p = .075$ ). Social support from family tended to be associated with QOLSH but did not reach significance ( $B = .062, p = .059$ ). Social support from family was not significantly related to other components of quality of life. Social support from a significant other was associated with QOLM ( $B = .153, p \leq .05$ ).

## Discussion

This study was focused on the relationship of social support and other potential predictors to QOL and its subcomponents. The study sample size was 83 people, made up mostly of single Caucasian males at three separate residential facilities.

A significant association was revealed between social support and TQOL in patients with mental illness at residential facilities. Furthermore, the study showed positive associations between the different QOL subcomponents, SQOL and OQOL areas, and total social support and its three subcomponents. The results presented here reinforce previous findings on the importance of social support to quality of life for patients with mental illness (Mares et al, 2002; Goldberg et al, 2003; Nelson et al, 1995). This study also showed a novel association between total social support and the QOL subcomponents of QOLF and QOLSH. Other novel features of the study were an examination of the relationship between support from friends and QOLH, as well as an exploration of the relationship between support from a significant other and QOLM. The results presented here suggest that age, gender, facility location, funding, length of stay and marital status may all be significantly predictive of QOL in residential home clients.

As shown in table 3, residential home clients had high TQOL. Out of a possible 224 points on the QOL questionnaire instrument, the patients' mean score was 160 points (72% of the possible points), suggesting a moderate to high self-reported level of QOL. The high QOL could be attributed in part to the quality of mental health services and housing that the patients received. Mental health services and housing were found to be significant predictors of TQOL score.

Multivariate analyses of the data revealed that total social support was related to QOLSH and QOLF. The increased levels of total social support with regards to increased levels of self and home maintenance and finance could indicate that patients put more effort in caring for their personal living spaces and participating in the general care of the residential facility and were more optimistic about their future finances.

Social support from friends was significantly and positively related to QOLF and was almost a significant predictor of QOLH. There was a special significance for social support from friends for most of the study participants. Almost all of the psychiatric patients reported having some form of friendship with other psychiatric patients. Due in part to the enduring nature of their mental illness, most patients did not report having regular contact with their family members; moreover, most did not maintain regular relationships with a significant other. Of the subcomponents of

Social Support, it would therefore be logical to conclude from these results that social support from friends exerted the strongest influence on overall social support in our sample of residential home clients.

Social support from a significant other was only significantly and positively related to QOLM. Social support from family only tended towards a positive relationship with self and home maintenance QOLSH.

Age was not related to TQOL but was positively related to QOLF and negatively related to QOLE. In addition the multivariate test revealed that age was significantly related to QOLU.

In examining the role of gender, we found that female clients received more social support from their families as well as higher QOLSH than male clients (bivariate analyses of data not shown here). However, it should be noted that only 21.7% of the study participants were women, and all female clients were located at location 3. Females may ascribe a higher level of importance to self and home maintenance than do men, which could in principle account for the higher mean QOLSH in female clients than in male clients. Female clients may also have felt a greater stake in contributing to both their personal areas and that of the facility, as compared to male clients.

Length of stay was significantly related to TQOL and QOLH. In addition the multivariate analyses revealed that length of stay was significantly related to QOLE, QOLH and QOLTR. These findings suggest that psychiatric patients who stayed for longer periods of time at the residential facilities were more likely to acclimate to their surroundings, reporting increased levels of satisfaction with both their housing and their quality of life. Patients who stayed for longer periods of time at the residential homes were also more likely to seek employment and transportation services, when compared to their counterparts with shorter length of stay.

The type of patient funding, whether Medicare or Medicaid, was influential upon QOLE and QOLT. Medicaid patients scored higher on QOLE but lower on QOLT as compared to those on Medicare. Medicaid funded 80.7% of the patients in our sample.

No significant relationship was found between marital status and TQOL. However, when examining the subcomponents of QOL, divorced clients had significantly lower QOLPH than single clients. Married clients had significantly lower QOLF and QOLU as compared to single clients. It should be noted that out of the 83 patients in the study, only five patients were married and nine were divorced.

These findings about the role of marital status on quality of life were somewhat unanticipated. Indeed, the results of previous investigations (see for example, Chand et al., 2004; and Lang et al., 2002) suggested a strong positive role of being married as a predictor of overall life satisfaction (in addition to age and higher income). The small number of married participants (5 married patients) in the study could explain this discrepancy. Also, another possible explanation for the lower score for both married and divorced patients regarding the issue of finance, completing tasks and use of time could be related to comparisons of their current activities, or lack thereof, to their former lives.

Reported Quality of Life in subjects varied significantly from one residential home to another. There was a relationship between residence location and QOL with location 1 scoring higher on various QOL components than location 3, while location 2 scored higher on QOLF than location 3. There were notable differences between the three locations with respect to both the gender of patients sampled, and the total number of patients. For example, Location 3 was the only location at which both men and women were housed, and it contained the largest group size. Locations 1 and 2 were similar in design, and both housed an all-male population. Here we speculate briefly as to the reasons why clients at Locations 1 and 2 reported having higher quality of life than clients at location 3. First, the larger number of patients in the home at location 3 suggests that crowding may have some role in reported quality of life; however, we did not measure this factor directly. Secondly, the mixture of men and women at Location 3 suggests that male/female interactions may not be beneficial. Finally, Location 3 was located in a separate geographic location from the other two homes that we sampled. Thus, the geographic location itself may have been

less favorable to clients at Location 3.

The results of multivariate analyses demonstrate that total social support was positively associated with both the objective and subjective domains of QOL. Social support from friends was also significantly related to both objective and subjective QOL. We found that the lower level of reported quality of life in patients who lacked social support was explainable, at least to some extent, by a low level of connection to family members. Further, many of the patients with low reported QOL were unable to sustain a relationship with a significant other. The lack of connectedness to family and significant others suggest that mental patients rely heavily instead upon social support from friends, which affords them higher quality of life.

Previous research (see for example, Bussbach and Wiersma, 2002) suggested that affective bias, poor insight, lack of adaptive processes and persistently unfavorable life circumstances may all influence subjective measurements of subjective quality of life. Further, perceived QOL implies a subjective judgment about satisfaction that can be affected by many variables. It would thus be reasonable to expect a positive relationship between satisfaction with social support and QOL (Caron, Tempier, Mercier, & Leouffre 1998). Previous research by Tempier et al. 1998 suggested that subjective QOL in patients with SMI tended to be lower for welfare recipients than for patients with SMI who were not on welfare

Our findings on the impact of social support upon subjective QOL are thus consistent with those of previous research (see for example, Lam & Rosenheck, 2000). It is our hope that by carrying out our study, the clients accrued some benefits. Indeed, focusing upon a person's subjective view of his or her QOL may be important in terms of empowering that person, and in strengthening his or her involvement and participation in the rehabilitative process (Lustig, Crowder, 2000).

## Conclusions

Total SS was significantly related to total QOL. Of the nine subcomponents of QOL, only two domains (self and home maintenance, and financial services and concerns) were related to total social support.

SS from friends was significantly related to the QOL subcomponent of housing, was close to significance as a positive predictor of the QOL subcomponent of finance, and was also significantly related to both objective and subjective QOL.

Perhaps the most significant finding reported here is that social support from friends has a strong positive impact upon QOL in residential home clients with SMI. For most of the patients, social contact with friends was the most significant source of interaction in their lives. The clients evidently relied more heavily upon that connection than they did a family member or a significant other as a source of social support. This highlighted role of social support from friends is plainly evident upon examination of the social network for many psychiatric patients in residential homes- reduced connection to family members and an inability to sustain a relationship with a significant other.

## Study limitations

Here, we briefly discuss the limitations to our approach. First, many of the items on the QOL questionnaire pertain to the type of services received and satisfaction with the services received by the residential psychiatric patients. Thus, some of these items cannot be largely affected by social support from friends, family or a significant other. In the multivariate analyses the R<sup>2</sup> value was 0.3, or 30% of the variance. In other words, the model did not explain about 70% of the concerns regarding QOL. Areas for further exploration of these influential factors to QOL include measurement of patients' emotions and feelings regarding their specific living situation, and an assessment of the impact of different therapeutic approaches upon mental health treatments. Additionally, factors external to the current lives of patients at the residential facility are perhaps worthy of further exploration for their impact upon QOL.

Second, the instrument that we used to measure QOL did not fully completely assess transportation, finance, or the physical health of the patient. Patients have varied needs, some requiring transportation and financial services while other patients do not; these issues were explored only superficially in our study. We also did not directly measure the direct impact of variations in psychiatric medications prescribed to the patients, type of care received for those with chronic illness, nor the overall impact of chronic illness upon daily life.

Thirdly, some of the personal information that we gathered on patients was not independently verifiable, and could have been influenced by bias. In order to ensure patient confidentiality, we did not seek access to medical records or other documentation required to verify patients' responses to questionnaire items. Lastly, non-normal distribution of the QOL subcomponents and residuals may have affected the study results.

The results confirm the importance of social support to Quality of Life in patients with mental illness at residential home facilities. The findings also suggest a prominent role of marital status, finance, self and home maintenance, and support from friends in this relationship of social support to quality of life.

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# Supported Education Strategies for People with Severe Mental Illness: A Review of Evidence Based Practice

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## Abstract

The article reviews extant literature related to the study of evidence based practice of the provision of supported education to the mentally ill and provides a chronological history of efforts from various institutions and mental health and educational facilities in North America. Priority is given to the studies that operated under controlled situations and randomly assigned their subjects. Comments are included with each review discussing the limitations of the program or study. The discussion includes an overall impression of the limitations of all of the studies such as the tendency toward variance in the description of outcomes used to measure success in education and the cloudiness of definitions of prevocational training. Recommendations are offered in an effort to guide future endeavours to provide education to the mentally ill and some direction is given regarding the development of standards for future research such as the inclusion of sample groups that more realistically represent the functional levels of clients from publicly funded state and provincial hospitals.

**Keywords:** supported education, academic education, severe mental illness, psychiatric illness, supported employment, prevocational training

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## Introduction

Mental Health facilities and prisons in the US and Canada have for some time offered on-site training and academic educational opportunities (Zwicker, N. & Myers, M. A., (1991). As well as increasing proficiencies among inmates, “there is evidence that token economy programs that emphasize vocational and educational training in prison settings

reduce post release recidivism” (Quinsey et al 1998; p.205). Recently, such interventions have moved beyond institutional walls to include academic education programs for clients living in the community. These programs provide one-on-one or small-group education, comprised of Literacy Basic Skills, Secondary School Courses, General Interest Education, Diploma Courses and Computer Skills Training. Programs often fall under the supervision of local school boards or colleges, resulting in mental health consumers, occasionally attending programs within normal campus settings.

Cursory database searches reveal little published information about such programs, making program evaluations elusive and results uncertain. Evaluations are further challenged by the wide range of treatment protocols and outcome measures found within literature searches. For example, some searches for supported education (SEd) identified meta-analyses of studies comparing supported employment (SEm), prevocational training (PVT; a form of education specific to job preparation), and more traditional forms of workplace preparation such as sheltered workshops and transitional employment. Only a few studies clearly looked at the efficacy of supported academic education.

### Objectives

The primary objective of this review was to systematically search available literature databases for relevant information that would guide mental health facilities in more effective provision of academic education for clients both in the hospital and in the community.

The length of sustained employment at a mainstream job was the primary outcome measure consistently appearing for employment success.

However, outcome measures deemed relevant to successful provision of academic education include course or diploma completion, along with the measurement of length of sustained studies thought to contribute to vocation or career choice.

A search for evidence-based practice in the provision of academic education to people with a severe mental illness would be helpful to reassure funding sources that:

- 1) SEd is indeed a necessary part of the client’s overall rehabilitation and contributes to the client’s successful recovery.
- 2) Current SEd is being provided in the best possible venue.
- 3) Methods employed for SEd are drawn from empirically supported approaches.

### Initial Search Strategy

Initial literature searches were as follows:

1. A Pub Med search using the general terms “Academic Education” and “Mental Illness”.
2. A Pub Med search using the MeSH terms “Education, Special” and “Psychiatry” or “Diagnosis, Dual (Psychiatry)” or “Community Psychiatry” or “Biological Psychiatry” or “Forensic Psychiatry”.
3. A Cochrane Collaboration search using the terms “Academic Education” and “Mental Illness”, “Supported Education” and “Mental Illness”.
4. A Psych Lit search using the terms “Academic Education” and “Mental Illness”, “Academic Education” and “Psychiatric Illness”, and “Supported Education”.
5. A Cumulative Index of Nursing and Allied Health Literature search using the terms “Academic Education” and “Mental Illness”, “Academic Education” and “Psychiatric Illness”, and “Supported Education”.
6. A Google search using the terms “Academic Education” and “Mental Illness”, “Academic Education” and “Psychiatric Illness”, and “Supported Education”.

7. A second Google search using the term, “Participatory Action Research”.

As a result of the final “Participatory Action Research” search, the Canadian “Review of Best Practices in Mental Health Reform” (Goering *et al.*, 1997) was identified, and subsequently used to locate a number of additional articles.

### Follow-up Strategies

The literature review began with an examination of the groundwork paper “Review of Best Practices in Mental Health Reform”, that was commissioned by the Minister of Public Works and Government Services Canada and carried out by the Health Systems Research Unit of the Clark Institute of Psychiatry (Goering *et al.*, 1997).

Guided by the finding of the “Review of Best Practices in Mental Health Reform” report, *post hoc* efforts were made to find recent outcome studies (i.e., within the last fifteen years). Searches for randomised controlled trials of approaches to providing academic education to the mentally ill were given highest priority. However, only one such study was found (i.e., Hoffmann & Mastrianni, 1993) where a comparison was made between two different inpatient settings in New York State, one with an SED program and one without. This study, first identified within the above-described “Review of Best Practices” document, will be described briefly, below.

*Post hoc* efforts continued on to a comprehensive review of “The Handbook on Supported Education” by Karen Unger (1998), a book which not only provided guidelines for supported education but also described five different models of supported education: first, within a college, second, a consumer alliance, third, within a clubhouse setting, fourth, within a community services agency, and fifth, a supported education program within a hospital setting. The models set within a clubhouse setting, community services agency and hospital setting will be briefly reviewed below.

Next, additional attention was given to another study by Dr. Unger entitled, “Program of Supported Education for Young Adults With Long-Term Mental Illness” (1991) at Boston University; again, described below.

Also considered was a very unique Supported Education model for students with psychiatric disabilities run within a community college in Houston (Housel & Hickey, 1993). However, it is noted from the outset that this program was difficult to assess, given the lack of a controlled comparison.

In 2004, an article appeared in the *American Journal of Psychiatric Rehabilitation* entitled “Redirection Through Education (RTE): Meeting the Challenges” (Gilbert *et al.*, 2004). This article described a historical RTE program established in 1973 at Lakeshore Psychiatric Hospital in Toronto, Ontario. This program would appear to be one of the earliest supported education programs in North America, begun when Lakeshore Hospital negotiated with George Brown College to provide educational support for discharged clients.

Search criteria for ‘academic education for mentally ill’ commonly identified studies of vocational rehabilitation and found insightful results for related topics such as a Review of Vocational Rehabilitation for People with Severe Mental Illness, a comparison of Supported Employment and prevocational training (Crowther *et al.*, 2001). This meta-analysis will be examined below, with the intent that the protocol used by the reviewers could appropriately guide future studies of Supported Education.

Also considered was a recent *Archives of General Psychiatry* article detailing the “Results of a Multisite Randomized Trial of Supported Employment Interventions for Individuals With Severe Mental Illness (Cook *et al.*, 2005), in which supported employment was compared to services as usual. This study will also be examined briefly.

Various online information was gleaned from the vast web site of the New York State Office of Mental Health, including the values and quality standards underlying all evidence-based practices for the provision of mental health services in the State of New York (“Creating An Environment of Quality Through Evidence-Based Practices”, 2006).

## Results

### The Role of Supported Education in the Inpatient Treatment of Young Adults: A Two-Site Comparison, (Hoffmann & Mastrianni, 1993):

This study compared a convenience sample of inpatients receiving SED with a matched group of patients not receiving SED.

The study was carried out at two sister facilities in New York state. Both facilities were private inpatient psychiatric hospitals providing treatment for patients. Only the Four Winds – Saratoga patients ( $n = 68$ ) were in close enough proximity to a college setting for educational experiences and opportunities to be integrated into the treatment milieu. The control group selected from the Four Winds-Winchester Hospital were matched by age, prior education, and were hospitalized during the same period (September 1986 to June 1986) as the experimental group. Patients treated in the Four Winds-Saratoga College Service were significantly more likely to return to college than those treated at the Four Winds-Westchester (69% versus 47%). Likewise, 88% of College Service patients who had returned to college were full-time at the time of follow-up compared with 58% of Westchester patients, and 55% of Saratoga patients planned to obtain graduate degrees compared with 37% of Westchester clients.

This study has several limitations. First, patients were not randomized to the treatment conditions. Second, the SED treatment was rather elitist in that it necessitated patients residing in close proximity to a college campus. Finally, the study involved subjects with abnormally high levels of baseline education. *Both groups had completed between 12 and 15.5 years of schooling with a mean of 13 years. In comparison, the average education of a group of 29 subjects from a recent study done on the Geriatric Services Program at the Provincial Mental Health Centre in Penetanguishene was 10.7 years* (Bruer et al, 2006) (Bruer et al., 2006).

### “Program of Supported Education for Young Adults With Long-Term Mental Illness” (Unger et al., 1991):

In this program, applicants were recruited from a population of medically stable young adults (ages 18-35) who had experienced a severe disability due to a mental illness. Inclusion required average or above average intelligence and an ability to use a classroom based approach program for career planning. Of the applicants, 52 were accepted into the program and were compared demographically at baseline with 76 applicants who had applied but not been interviewed or accepted. No significant differences were found in age, gender, marital status, employment status or educational level attained. Classes ran for 16 months, three days weekly, for two and one half hours per class and no fee was charged. The program curriculum was comprised of four instructional components related to career exploration and development: profiling vocational potential, researching occupational alternatives, career planning and mobilizing personal skills and resources. Program teachers were master’s-level counsellors who had experience in mental health settings and training in classroom-based interventions. Of the 52 participants enrolled, 2 had less than high school education, 15 had a high school diploma and 83 had post high school education. *Again, the high mean education is a factor for further discussion.* Of the 52 subjects in the program, 35 completed all four semesters, 15 completed less than three semesters and 7 did not complete one semester. Two subjects committed suicide and were not included in the analyses of study outcomes. Before the program 19% were competitively employed or enrolled in educational programs compared with 42% of the students after the intervention. Between the first and last assessments, significant increases were found for employment ( $p < .001$ ,  $N=44$ ), for educational status ( $p < .0001$ ,  $N=43$ ), for self esteem using the Rosenberg self esteem scale, ( $p < .05$ ) and significant decreases were found in hospitalization rates during the first year ( $p < .05$ ). The authors concluded that community integration on a university campus provided an accepting environment for students with psychiatric disabilities to enter into the rehabilitation process and begin to define themselves as students rather than patients.

This study also has several limitations. Again, participants had abnormally high levels of baseline education. Also, unrealistic elitism was suggested by the fact that all instructors had masters’ level education. Finally, while this study did compare baseline demographics between subjects and other general inpatient populations, the study did not compare pre and post outcome measures. Therefore, while the study’s subjects admittedly improved, it cannot be stated whether they improved more or less than, or possibly stayed relatively even with, inpatients not in the program.

Supported Education in a Community College for Students with Psychiatric Disabilities: The Houston Community

College Model, (Housel & Hickey, 1993):

Through a revolutionary partnership, the Mental Health and Mental Retardation Authority (MHMRA) of Harris County Texas, has entered into a liaison with the Houston Community College System (HCCS) to remove the barriers for admission to a postsecondary environment faced by people with a serious mental illness.

In January of 1992 the Office of Supported Education was established at the Central College in response to a needs survey of 1000 local consumers that had indicated an interest in training for a wide range of professions. Initial goals of the Office were to train counsellors, administration and faculty to work with students with psychiatric disabilities, to identify support services to be provided to program participants, market services to the population to be served and establish referral procedures. The development of an active advisory board, representative of the community being served, was paramount to the continued success of the program. The Supported Education Advisory Board included representatives of the College, MHMRA, the Mental Health Association, the Alliance for the Mentally Ill, and students with and without a psychiatric disability. On site support through the Office of Supported Education, that coordinated mobile support in the form of specialized case managers, was viewed as a psychological reassurance to students enrolled in the segregated programs as well as to those consumers engaged in mainstream programs.

In July of 1992 “The Entry/Re-entry Program for Students in Transition was implemented. This program, established in a segregated classroom at the college, accentuated: 1) management of one’s psychiatric disability 2) study skills training 3) Basic English and math 4) vocational exploration 5) building a support network amongst the students 6) assistance in navigating and re-entering the mainstream educational system. Of the 34 consumers enrolled in this program, 28 went on to enrol in regular classes.

At the same time and with the support of the MHMRA, the College also developed a Program to train psychiatric consumers as case management aides. This program called the Community Service Aide Training Program is a one-year program that involved 27 credits, some achieved through in class education, and the balance as part of a 256-hour paid internship. The MHMRA was responsible for screening and selecting students from a large group of applicants (for each person accepted into training, two were turned away), providing psychiatric support to students, and providing employment opportunities to successful graduates. Funding for books, tuition and clothing came from various sources (pg43) and HCCS developed the curriculum, provided instruction and accreditation. Thirteen of the fifteen students (87%) enrolled in the first class completed the internship and were hired as case manager aides. This rate of success was replicated in two subsequent classes.

The three facets of the entire program have assisted over 200 students with psychiatric disabilities to access educational services that had previously been out of reach. These kinds of programs insist on a close working relationship between mental health agencies and community colleges, and demand that the college maintain an open door policy regarding enrolment (Housel & Hickey, 1993, p. 47).

Besides limitations relating to the lack of randomized controlled studies of the above, it should be noted by facilities responsible for whole populations of mental-health consumers that two thirds of applicants were turned away from one component of the above program. Suitable, yet meaningful alternative opportunities would logically be required for the excluded by any facility mandated to service all consumers comparably.

The Handbook on Supported Education (Unger, 1998):

### A Supported Education Program in a Clubhouse

Laurel House in Stamford, Connecticut developed a program in the 1980’s to assist students with admissions, enrolment and obtaining financial aid to students planning to attend a post secondary institution (Dougherty, 1997). The program also provides emotional, psychological and administrative support to the members of the clubhouse enrolled in school programs. One full-time staff at Laurel House is employed to discuss students’ plans to return to school, assist with registration and financial aid, offer or arrange tutoring, help with schoolwork, lead an educational support group and travel to the campus if the student requires any on-campus assistance. One interesting

development of the program is the culture of support for education that has evolved at Laurel House. Staff and fellow members have come to value education and support the educational goals of those enrolled. A review of the program in 1998 found that 70 members of Laurel House had returned to school enrolling in a total of 300 courses. Of these 70 members, several had graduated.

### **A Supported Education Program in a Community Services Agency**

The Kennedy Service Centre, a supported employment program was established in Trumbull, Connecticut in 1989 with the assistance of the State Department of Mental Health. Through this program, students with psychiatric disabilities can pursue their vocational goals by accessing and completing postsecondary educational opportunities (Petella, Tarnoczy, & Geller, 1996). Services offered by the Program include; testing for career interests, skills and abilities; help in formulating a long-term vocational goal and associating it with their educational plan; financial aid planning; education support/discussion groups and summer workshops promoting education; individualized tutoring and the fostering of student support skills such as time management, organizational skills, study skills and stress management with an emphasis on making use of existing supports available on the college campus. A consulting psychologist is also available to help staff contend with situational problems.

### **A Supported Education Program in a Hospital Setting**

The Western State Hospital Patient and Family Education Program, in Tacoma Washington is a program contracted through Pierce Community College, thus providing comprehensive educational services to consumers and their families since the mid 1970's. Client's who had not previously been considered appropriate for the classroom have been observed to be "cogent, focussed and student-like in the classroom" (Gilmur, 1997, pg 29). What is astounding, about this program, is the universality of the services offered and the provision of services to all groups within the hospital including forensic patients, older adults, and all psychiatric diagnoses. The services offered consist of Adult Basic Education, and high school completion/general equivalency diploma; psycho-educational classes; health and wellness; women's health issues; medication education; HIV education; substance abuse; empowerment; symptom management and recovery and family /consumer illness education. The program's staff members include six instructors, a director, and an office assistant. Remarkably, 500 clients are enrolled in education classes each semester, a whopping 62% of the individuals in the hospital. Teaching methods draw from methods used with students with learning disabilities and embrace multimodality teaching, repetition, stimulus reduction, experiential learning, and individualized instruction. A support program has also been developed for students who plan to continue their college education when they leave the hospital.

The book did not indicate that any of the three models reviewed had been studied using an experimental design. However, the programs, each in their own way, suggest relevant and important protocols for effective supported education, and in light of the high level of patient participation, most particularly in the Western State Hospital Patient and Family Education Program (62%).

### **Redirection Through Education: Meeting the Challenges (Gilbert et al., 2004):**

In the fall of 1973 the Rehabilitation 'Through Education Program' was established in a trailer, on the grounds of Lakeshore Hospital in Toronto. Initially the program began with two George Brown College faculty members teaching life skills, refresher English and math every morning. Eventually, a full time program for 20 students was placed on the main college campus, in response to demands to prepare consumers seeking to return to the community and to work. The program was subsequently expanded to help with community support for finances, housing, health care as well as establishing programs to meet social, vocational, academic and recreational needs. The Ministry of Health provided Vocational Rehabilitation Funding for two more full time staff in 1977 and in 1979 George Brown College funded another full time faculty position. By 1979 enrolment had had climbed to 65 consumer/survivor/students and the program continued to undergo changes to respond to social and economic trends. The 1980's saw the organization delineated in three major directions, the first focussing on self-assessment, self-esteem, and confidence building, the second on vocations and offering supportive work placements through the creation of downtown cafes, and the third concentrating on enhancement of vocational skills so as to increase

employment outcomes. More recently, the program has experienced curriculum changes and because of an increasingly competitive job market and the RTE faculty have begun providing post secondary school credit courses that students can complete without charge. These courses include 1) Strategies for Student Success; 2) Society Challenges and Change; 3) English; and 4) The E-course, a mandatory Ontario wide computer course.

In 2002 the RTE program joined the Access Centre of Excellence, a division of the College formed to serve under-prepared students. Because it was grouped with other college programs such as, English as a Second Language, the Academic Bridging Program, pre-programs in Health Sciences, Hospitality, Community Services, and Business, it is hoped that students from the RTE program will readily access some of these courses as well.

#### **RTE Outcomes (2000-2001)**

Phase	Number of Students	To next phase	Extended phase	To work or further education	Withdrew
1	92	61 (66%)	7 (8%)	6 (7%)	18 (20%)
2	89	26 (29%)	40 (45%)	12(13%)	11(12%)
3	26	n/a	n/a	24(92%)	2(8%)

It is interesting to note that after 30 years, RTE is moving to the main campus of George Brown College, thereby offering students access to all of the main campus facilities and providing them with a greater access to other mainstream college courses, a definite step toward further integration into mainstream education.

The article reports that most of the students enrolled in the program had completed high school, some had a college diploma or university degree, and a few had completed graduate work. Therefore, generalization of the above programs is limited by participation criteria, which appear specific to more highly educated students (i.e., mean educational level of 12 years or more).

#### **Review of Vocational Rehabilitation for People with Severe Mental Illness, a Comparison of Supported Employment (SE) and Prevocational Training (Crowther et al., 2001):**

This Cochrane meta-analysis of 18 randomized controlled trials (N=2539) comparing prevocational training, supported employment and standard community care, found that people who received Supported Employment were significantly more likely to be in competitive employment at 12 months (34%) than those who received Prevocational Training (12%). For the purposes of this review, pre-vocational training was described as “any approach to vocational rehabilitation in which participants were expected to undergo a period of preparation, before being encouraged to seek competitive employment. This preparation could involve either work in a sheltered environment (clubhouse approaches and sheltered workshops) or some form of pre-employment training or transitional employment”. Supported employment was defined as, “any approach to vocational rehabilitation that attempted to place clients immediately in competitive, integrated employment with a period of workplace preparation no longer than one month and indefinite follow up or support”. Standard community care was defined as, “usual psychiatric (outpatient) care for patients in the trial, without any specific vocational component”. Outcome measures included: engagement in competitive employment; amount earned in dollars per month; length of employment measured at follow up intervals and health care costs per client. Clinical outcomes were also measured using a variety of scales, listed as: the Global Assessment Scale (Endicott *et al.*, 1976), the Positive and Negative Symptom Scale (Kay *et al.*, 1987), the Brief Psychiatric Rating Scale (Overall & Gorham, 1988), the Self Esteem Scale (Rosenberg, 1965) and the Quality of Life Scale (Heinrichs *et al.*, 1984). A total of 31 studies were excluded from the review because they

did not meet the requirements for the review. (i.e.; not randomised, no vocational component offered, diagnosis unclear) The results of this meta-analysis emphatically pointed out that pre-vocational training was no better at increasing length of employment than standard community care (Crowther et al., 2001), and echoed the findings of Bond *et al.* (1997) that pre-vocational training promoted dependency and deterred clients from finding competitive employment.

One obvious limitation to this otherwise thorough review of the extent literature is the fact that the extent literature (i.e., all rigorous studies to date and therefore included in the meta-analysis) is restricted to the United States. The replication of results in Non-American studies is needed to generalize the conclusions and promote understanding in this area.

Results of a Multisite Randomized Trial of Supported Employment Interventions for Individuals With Severe Mental Illness (Cook et al., 2005):

This trial randomly assigned 1273 outpatients with severe mental illness either to an experimental Supported Employment program, a comparable program, or a services-as-usual condition". The outcome analysis considered three measurable vocational outcomes; competitive employment (mainstream, minimum wage job); working for 40 or more hours in a single month; and monthly earnings. Follow up was conducted after 24 months. Experimental group participants in this study were more likely than those in comparison programs to achieve competitive employment, more likely to work 40 or more hours in a given month and had significantly higher monthly earnings than those in comparison programs.

This study provides admirable standards for future SEd research. Specifically, the study included the use of a large sample, randomization, practical outcome measures, and the comparison of treatment with both a comparable program and "service-as-usual".

Regrettably, while the study goes so far as to include multiple sites and a large study sample, it again is restricted to the continental United States.

## Discussion

The determination of the effectiveness of studies of educational programs is made more difficult by variance in the method of selection of subjects or participants, the differences in site selection or location of the program, and the variety of educational programs offered to psychiatric clients, (hereby referred to as students in this discussion). At first glance studies that showed significant improvement in continued enrolment in post secondary courses and longer terms of competitive employment inspired optimism. However the first three studies, examined above, all include, as part of their selection criteria, students with above average intelligence and students who have a mean education at least 13 years. This is not a random cross section of the population of adults with a psychiatric disability and it would seem that more favourable study results could be expected from a more highly educated and intelligent experimental group. Having said this, the studies are important because they demonstrate that for higher functioning students, an educational approach to rehabilitation both increases the desire to stay in school and results in longer terms of competitive employment.

On the other hand, the meta-analyses of randomised controlled studies, such as the Cochrane Review (Crowther et al., 2001) of Vocational Rehabilitation for People with Severe Mental Illness and the Multisite Randomized Trial of Supported Employment Interventions for Individuals With Severe Mental Illness (Cook et al., 2005), have a more inclusive selection criteria for experimental subjects and are more representative of the entire population rather than dealing with an elite group. One confusing aspect of the Cochrane meta-analysis begins with the definition of Pre-vocational Training. The definition offered for the purposes of this collection of studies perhaps muddies the waters by including transitional employment, sheltered workshops and Clubhouse Approaches along with an "in-class" pre-vocational training model. (*The in-class pre-vocational training model has been described by Unger and Anthony, in the Boston University study in 1991, as having significant effect on high functioning students with psychiatric*



*disabilities*.) These meta-analyses both claimed that supported employment was clearly more effective than pre-vocational training and other approaches to vocational rehabilitation or standard community care (that offered by an outpatient service or assertive community treatment model).

The Houston Community College was unique in the creation of new approaches to SED including the creation of a Consumer Case Management Aide Program, an Entry/Re-entry Program for Students in Transition and an Office of Supported Education designed to provide psychological support, counselling and educational accommodations to students enrolled in the college. These programs, (although still limited to higher functioning psychiatrically disabled students), should be viewed jealously by universities and colleges, both for the creation of new academic programs and for the removal of barriers to enrolment in the college system.

The alliance formed between Western State Hospital and Pierce Community College in Tacoma Washington is another model that waves the gold standard for approaches to supported education within a hospital setting. The sheer numbers of students enrolled in educational events during a quarterly period in this hospital comprised a staggering 62% of the hospital population. The wide variety of educational services offered in the Tacoma program would rival even the in-service staff training for many hospitals. The Tacoma model establishes education as a right, not a privilege, and echoes the writings of more liberal adult educators such as Paulo Freire (1972) who felt that education should be freely provided, regardless of social class, level of intelligence, or current geopolitical location. Underlying Freire's vision of popular education are the following precepts:

- \* Identifying the problems, expectations and expressed needs of a community;
- \* Identifying areas of change relevant to the groups' needs;
- \* Considering the community's history, its local power base and economic distribution;
- \* Understanding why there are those who are disadvantaged, or oppressed.

Certainly the mentally ill inside and outside of a hospital are members of a community who are disadvantaged and (some might argue) oppressed by mainstream educational values that uphold the rivalry for marks and vicious financial and academic competition for entry into learning.

## Recommendations

Provision of an Extensive Variety of Services:

One key to the provision of academic opportunities to the seriously mentally ill lies in the offering of a wide variety of services, so as to challenge and reward each and every individual regardless of mental illness, age, sex, social status or intellectual level. There should therefore exist, an educative and rehabilitative opportunity appropriate for every individual with a psychiatric disability, regardless of functional level. The mainstream community of people are a diverse and heterogeneous lot whose intellects vary greatly. We should not expect the population of mentally ill to be any different. This concept became more evident as articles were searched for this review, with successful academic programs commonly restricted to the more highly educated mental health consumer.

Within a hospital and community setting, the cross-sections of mental health consumers are microcosms of society at large. The provision of psychiatric services must therefore mirror this diversity. Whether dual diagnosis, forensic, geriatric or acute care, each hospital ward embodies not only different diagnoses but also contains many types of individuals of different economic, social, intellectual and educational backgrounds.

The student service should address the needs of the individual student. Sometimes the needs are limited by the nature of the residential program or ward a client is assigned to. For example, forensic clients are often in hospital for longer periods and do not have privilege levels that allow them to travel to other areas of the hospital or outside the hospital grounds. Education should therefore be available in an acceptable format within their restricted territory; otherwise we risk the pitfall of condemning the offender to a worse fate, that is, of being uneducated simply because of his incarceration.

Similarly, a short-term client on an acute care ward, struggling through a complex of crisis events may find short-term guidance vis-à-vis viable educational pathways to be a crucial component within the parcel of critical care services offered. For this student, educational counselling and psycho-educational support might highlight the need for a new or changing direction in continuing education or career.

In dual diagnosis clients with low baseline educational levels, assessment of individual needs can be followed-up with basic literacy and numeracy instruction which provides structure to daily living, while remediating lost math and language skills necessary for successful independent living. In a group setting, such learning in a classroom environment builds social skills through the normalizing influences of “appropriate school behaviour”.

#### **Match the Intervention to the Students Ability and Preference:**

Effective college and prevocational training programs that persist for more than one month in length have been found to benefit high functioning clients with mean educational attainments of at least 13 years (Unger et al., 1991), (Hoffmann & Mastrianni, 1993). It is possible therefore, that many issues addressed in prevocational training programs may be too challenging for clients whose language reasoning and other academic skills are inadequate or whose preference is to work but not to attend training sessions. Prerequisite cognitive abilities can be assessed through transcript information or academic testing. Lack of pre-course screening for functional level result in lower-functioning students feeling alienated from the rest of the group, leading to negative effect such as depression and disruptive behaviour. Clients with poorer educational backgrounds who are found unsuitable for an extended prevocational training period could instead be offered adult basic education to upgrade skills. Some of these properly-assessed students might even progress on to secondary school courses, with courses containing subjects of unique interest to them rather than subjects that the instructor feels they need to take. Clients with low functional ability may at the same time, be served better by shorter prevocational preparation periods of no longer than one month and assisted by a job development specialist and a supported employment specialist to find and keep a personally meaningful job. Sheltered workshop environments may be more appropriate for the lowest functioning clients, who may never be able to reasonably compete for mainstream employment because of chronic psychiatric disability and/or profound cognitive disability.

#### **Integrate into Mainstream Education System Whenever Possible:**

Repeated examples of on-campus supported education such as the Houston Community College Model (Housel & Hickey, 1993) emphasize the need for high functioning clients with psychiatric disabilities to move towards describing themselves as students rather than patients. Such transformations, from being a passive recipient of treatment to becoming an active learner who purposefully and independently seeks out experiences for erudition do not logically occur within a hospital setting, where clinicians commonly reward absence of volition. Such transformations to active learning are, at the same time, not magical processes, nor do they happen over night. Instead, they require coaching, instruction and encouragement from a supportive teacher who also possesses the counselling skills necessary to facilitate change (Unger et al., 1991).

#### **The Development of Working and Funding Partnerships Between Community Colleges and Hospitals:**

In most of the settings examined, community colleges and universities were located in the same community and therefore retained an obvious advantage over mental health facilities located in rural areas (i.e., away from post secondary institutions). Wherever possible, mental health facilities need to foster close ties with colleges and universities to provide on-campus courses and broaden educational opportunities for psychiatrically disabled students both in mainstream and special education classes. The Boston, Houston, Tacoma, Saratoga Springs, and Toronto models all demonstrate a close and interactive participation between mental health facilities and colleges and universities that demand inventive approaches to joint funding. These funding approaches may incorporate separate provincial ministries or state departments or offices into the funding formula and, as with the Houston model, may involve municipal, community college, private industry, federal and state/provincial government funding. The

challenge may, in some cases, be to overcome the barriers to inter-ministry cooperation. It may also be more cost effective for one ministry (because of existing programming) to provide educational and prevocational opportunities to clients who's training is normally funded through another ministry (because of psychiatric diagnosis or developmental challenge).

### An Emphasis on Developing the Role of the Job Development and Supported Employment Specialists:

Because of the wide body of literature and the large number of controlled, randomised trials comparing supported employment to other methods of vocational rehabilitation, it was inevitable that searches for supported education would reveal much in the literature in the area of supported employment. Without exception, all such meta-analyses stress the value and efficacy of supported employment over other methods of vocational rehabilitation. "Clients who were placed directly into jobs with training and support had higher rates of employment than those who had extended prevocational preparation" (Goering et al., 1997). Some information suggests further research into the role and effectiveness of the "Job Development Specialist" separating this role entirely from that of the "Employment Support Specialist". Employment support should be ongoing and should only cease when both the employer and the employee mutually agree that support is no longer needed.

### Further Research

Little formal research exists in the area of SED, especially in the area of randomized controlled experiments. However, within the limited research that does exist, there is much to suggest hope that future research would in fact find SED to be both popular and effective. Future research should clearly determine the benefits of supported education, while individual studies should take into account the functional level of the subjects through the careful matching of controls and treatment subjects. In particular, more attention should be given to education as an intervention for lower functioning students with psychiatric disabilities. Most of the existing studies involved clients with mean levels of education of 13 or more years. Such academic levels are not representative of publicly funded state or provincial psychiatric facilities. Except for the meta-analyses reviewed here, most study samples have been somewhat small. Therefore larger studies are needed.

Another concern is the clouding of definitions and the uncertainty over protocols for outcome measurement. Researchers need to work more closely together to develop definitional consensus around what is meant by terms such as pre-vocational training and community care, thus studies related to educational interventions will more precisely target each individual intervention. Similarly, increased standardization of outcome measures is needed so that future studies can continue to replicate and validate results.

### Conclusion

Many of the cited approaches to academic education were drawn from pristine examples where unrealistically ideal conditions exist for supported education. These centres of pre-eminent practice champion unrealistic paradigms of funding, cooperation, and multi-service provision. Many are located in areas where hospitals are in close geographical proximity to educational facilities and can easily accommodate on-campus education. In the real world, such conditions rarely if ever exist. Instead, practical solutions should be formulated to provide potential students having a psychiatric disability, with effective educational opportunities within the hospital setting and should always strive for the ultimate aim of integration into mainstream education. The flexibility of the educational programming should allow for careful planning based on an assessment of the patient populations needs, specific to its particular history, problems, expectations and expressed needs.

Educational or psycho-educational planners and facilitators should keep in mind the quality practices underlying evidence-based practices, specifically that the nature and quality of the therapeutic relationship will remain crucial to success; and that quality practices of necessity must be inclusive, continuous and individualized, thus matching services to the needs, strengths, preferences and values of the recipient. Quality practices in supported education should also be dynamic, promote responsible partnerships, involve quality practitioners, be culturally competent and outcome oriented ("Creating An Environment of Quality Through Evidence-Based Practices", 2006).

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# Integrated Psychological Intervention for Schizophrenia

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## Abstract

**Objective.** Studies have demonstrated the independent effectiveness of cognitive retraining and family interventions in schizophrenia. The improvements in cognitive functions following the retraining are poorly sustained, which could be due to the absence of a supportive and congenial family environment to sustain the gains of the retraining program. The present study aimed to develop a treatment program for schizophrenia, which integrated cognitive retraining with family intervention, and test its clinical effectiveness.

**Design and methods.** The sample consisted of three outpatients diagnosed as having schizophrenia and their caregivers. Cognitive retraining for the patients targeted the functions of attention, information processing, executive functions, learning & memory, comprehension & production of emotions. Family intervention consisted

of psychoeducation, improving communication and problem-solving skills, lowering expressed emotions and modifying expectations. The treatment lasted 6 weeks, with cognitive retraining being given everyday and family intervention in bi-weekly sessions. The patients were evaluated on a battery of neuropsychology tests and Global Assessment of functioning scale and the caregivers on the General Health Questionnaire, and Burden Assessment schedule at pre intervention, post intervention and at two-month follow-up.

**Results.** Following intervention the cognitive and global functioning of the patients improved. The psychological distress and subjective burden of the caregivers decreased. Two patients sustained the gains on neuropsychological functions and global functioning at the follow up. At the end of three months all the three patients were in fulltime gainful employment.

**Conclusion.** The integrated psychological intervention has shown promise and merits further evaluation of its efficacy.

**Key words:** *Neuropsychological assessment, Cognitive retraining, Family Intervention, Global functioning.*

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## Introduction

Schizophrenia is a disabling disease that continues to pose challenges in understanding its etiopathology. Cognitive deficits are a manifestation of the neuropathology in schizophrenia (Gold & Harvey, 1993). Cognitive deficits have been reported in sustained attention, switching attention and working memory, auditory and visual information processing, verbal memory, executive impairment, set shifting, and planning (Morris, et al., 1995; Cadenhead et al., 1997; Nelson et al., 1998; Smith et al., 1998; Pantelis et al., 1999). Cognitive functioning has a significant bearing on the parameters of functional outcome such as work performance, social functioning, social problem solving and social skill acquisition (Green, 1996; Bellack et al., 1999; Twamley et al., 2002). Therefore improvement of cognition has a therapeutic role in schizophrenia.

Cognitive retraining uses graded tasks to improve specific cognitive functions. Cognitive retraining studies in schizophrenia have followed two approaches. The first approach includes studies carried out in laboratory settings with the aim of improving performance on individual tests. Examples are the following studies. Retraining was given on the Wisconsin Card Sorting Test (WCST), incorporating strategic training, positive and monetary feedback. However the improvement was not sustained and failed to generalize to other problem solving measures (Goldberg et al., 1987; Bellack et al 1990; Summerfelt et al., 1991) The functions of attention (Benedict et al., 1994; Medalia et al., 1998) working memory (Bell, Bryson & Wexler 2003) and emotion perception (Gaag et al., 2002) have also been improved in schizophrenic patients through cognitive retraining. However, a review of nine cognitive retraining studies in schizophrenia provides inconclusive evidence of the effectiveness of retraining. (Suslow, Schonauer & Arolt 2001). The second approach comprises of studies done in clinical settings, which in addition to improving performance on a variety of tests, have also, examined the generalization of the improved cognition to daily activities. This approach has number of different types of cognitive retraining programs, such as paper pencil task, computer based task also group activities (Wykes, 2000). Examples are the following studies. The Integrated Psychological Therapy (IPT) developed by Brenner et al., is a highly structured group therapy approach for schizophrenia,

which incorporates cognitive retraining. Studies evaluating the IPT have been inconclusive in stating the specific role of cognitive retraining on improved cognitive functions (Hodel & Brenner, 1994). Another individualized program developed by Van der Gaag (1992) uses paper pencil tasks. The program consists of three separate modules targeting cognitive flexibility, working memory and planning. The program improved concept formation and set shifting as on the WCST performance, following treatment, with questionable improvement in social functioning (Delahunty et al., 1993). Other controlled studies of cognitive retraining programmes have shown improvements in cognitive functioning but poor generalization of the improvement to global functioning (Wykes, 2000).

The reason for poor generalization may be the slow and gradual pace of improvement of cognitive functions during the retraining process. Family members may be unable to perceive the gradual and subtle improvements and hence fail to provide positive feedback to the patients. On the other hand, those families, which recognize the improvements, may develop overly high expectations about the patients' level of clinical improvement and their general functioning. Either way the consequences are likely to result in high expressed emotions, which could then have deleterious impact on the gains acquired through the retraining programme. A way out of this intractable situation would be family intervention.

Family interventions enhance understanding of the illness among the caregivers and foster supportive relationships in the family (Bellack, 2000). The anxiety, distress and burden of the caregivers reduce and their acceptance of the patient's illness improves after family intervention (Xiong et al., 1994). Thus to optimize the clinical benefits for the patient, a combination of cognitive retraining and family intervention would be desirable since this approach would improve the cognitive functions of the schizophrenic patient and sustain the gains with a congenial family environment. The present study aimed to develop a treatment programme for schizophrenia, which combined cognitive retraining with family intervention, and to examine its clinical efficacy.

## Method:

### Participants

The sample consisted of three unmarried male patients from urban background diagnosed as having paranoid schizophrenia (ICD- 10; WHO 1992) and their caregivers. Patients were identified in the out-patient department of the adult psychiatry units, National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore, India. Case 1 was 29 years old, educated up to BA, from upper socio economic status, with illness duration of 8 to 10 years. Case 2 was 29 years old, educated up to B E, from a low socio economic status, with illness duration of 14 years and case 3 was 26 years old, educated up to B. E, from upper socio economic status, with illness duration of 8 to 10 years. The caregivers were brother and sister-in-law for case 1, mother in case 2 and parents in case 3. On the Brief Psychiatric Rating Scale (Bech, Kastrup and Rafelsen, 1986), the scores for case 1, 2 and 3 were 7, 8 and 8 respectively. All patients were stabilized on atypical antipsychotic medication and the dosages were not changed during the course of the study and follow up period. Case 1 and 2 were never in gainful employment and Case 3 had been unemployed for 2-½ years prior to the recruitment to the study. None of the patients had sensory or motor deficits, clinical evidence of mental retardation, psychiatric co-morbidity, neurological or neurosurgical disorder. The caregivers had no present or past history of psychiatric illness. Patients and caregivers gave written informed consent to participate in the study.

### Procedure

The study employed a single case study method. Prior to and after cognitive retraining, each of the three patients was assessed on a comprehensive battery of neuropsychological tests, and a measure of

global functioning. The caregivers were screened for presence of minor psychiatric disorders and evaluated for their perceptions of family burden. The cognitive retraining program was administered daily to the patient for six weeks, while the caregivers underwent family intervention twice a week, for the same duration. Two patients and their caregivers were reassessed after a period of two-months, while the third patient and his caregivers were not available for the follow up assessment.

#### Assessment of patients:

The patients were assessed for their overall level of functioning using the Global Assessment of Functioning Scale (GAF) (DSM IV, APA 1994). The following neuropsychological functions were assessed; Sustained attention was assessed using Digit Vigilance Test (Lezak, 1995), focused attention using Colour Trails 1 and 2 (D'Elia et al., 1996), psychomotor performance and information processing speed using Digit Symbol Substitution (Wechsler, 1981) and motor speed using Finger Tapping Test (Spreen & Strauss, 1998). Executive functions assessed were: response inhibition using Stroop Color-Word Test (Stroop, 1935), working memory using Self-Ordering Pointing Test (SOPT) (Petrides and Milner, 1982), set-shifting ability using Wisconsin Card Sorting Test (WCST) (Milner, 1963) and planning using Tower of London Test (TOL) (Shallice, 1982). Verbal learning and memory was assessed using Rey's Auditory Verbal Learning Test (AVLT) (Maj et al., 1994) and visual learning and memory using Rey's Complex Figure Test (RCFT) (Meyers & Meyers, 1995).

The scores on the neuropsychological tests were compared with norms appropriate to that of the subject's gender, age and education. The normative data was derived from a group of 540 normal healthy volunteers (Rao et al., 2004). Healthy volunteers were recruited from relatives of patients admitted at the hospital, students, and from the community at large. Healthy volunteers who obtained a score of > 2 on the General Health Questionnaire (GHQ-12) developed by Goldberg and Williams (1988) were excluded, as these persons met criteria for psychological distress, which itself could influence cognitive functioning. Healthy volunteers were also excluded if they had a previous history of neurological, neurosurgical or psychiatric illness or substance dependence and family history of alcohol dependence, schizophrenia or bipolar disorder. The normative sample was divided into three age ranges (16-30, 31-50 and 51-65 years) and three education groups (no formal schooling, 1-10 years, and greater than 10 years of formal education) separately for males and females. For each test variable, percentile scores were calculated. The 15th percentile score (1 SD below the mean) was taken as the cut off score (Heaton et al., 1995). Cutoff scores were then calculated for each group based on age, education and gender. A deficit was defined as a test score falling below the 15th percentile (Heaton et al., 1995). Validation for each of the tests has been carried out on patient groups with focal lesions, refractory epilepsy, head injury and Parkinson disease (Rao et al., 2004).

#### Assessment of caregivers:

The caregivers of the patients were assessed before and after the period of intervention using General Health Questionnaire-28 (GHQ-28) (Goldberg & Hillier, 1979). This is a screening tool aimed at detecting those with probable psychiatric disorders (depression, anxiety, social dysfunction and somatic symptoms). The responses are endorsed on a 4-point rating scale and the cut off score is 4/5. The scale has been found suitable for use in the Indian context (Shamasunder et al, 1986). Burden Assessment Schedule (BAS) assessed the family's experience of burden in various domains (Thara, Padmavathi, Kumar & Srinivasan, 1998). It has 40 items rated on a 3- point scale. The scores range from 40 to 120, with higher scores indicating higher burden. It assesses burden in areas of financial aspects, patient's behavior, social relations, caregiver health, caregiver occupation, leisure activities and emotional burden. The scale has an inter-rater reliability of 0.80 (kappa,  $p < 0.01$ ) (Thara et al 1998), test-retest reliability of 0.91 while the alpha coefficient is 0.92 (Rammohan et al 2002).

## Integrated Psychological Intervention

### Cognitive retraining programme:

The cognitive functions reported to be deficient in schizophrenia (Gold & Harvey, 1993) were chosen as targets for retraining. Tasks to ameliorate these deficits were introduced in the retraining program in a graded manner, according to the following schedule. The functions of attention, fluency, information processing, working memory and response inhibition were targeted in week 1. Tasks to improve the functions of visual immediate memory and spatial encoding were added in week 2. Finally, tasks to improve the functions of set-shifting, planning, comprehension and production of emotions were added in week 3. The cognitive retraining was carried out daily for 1 ½ to 2 hours. Feedback on the performance of the retraining tasks was given at the end of each session.

*Attention:* Tasks of letter and symbol cancellation and dictation were used to improve attention. The letter/symbol cancellation task required the patient to cancel any two target letters or symbols from an array presented in an A4 size sheet. Time taken to complete the task and errors of commission and omission were recorded. Decreasing the font size and increasing the number of letters or symbols in the given sheet achieved increased task difficulty. Letter cancellation was given till week 5 and symbol cancellation in week 6. In weeks 4 and 5, music played during the task performance as was used as a distracter. In week 6, during symbol cancellation, phonemic fluency task was used as a distracter. In the Dictation task, the patient wrote 20 words to dictation. Number of correctly written words formed the score. Dictation was discontinued after 2 weeks as the patients obtained the maximum score.

*Information processing:* The task was to sort grains of various sizes, with the type of grains ranging from two to four. There were two types of big grains in week 1, 2 types of small grains in week 2, 3 types of small grains in week 3-4, four types of small grains in the weeks 5-6. The patient listened to music while sorting grains in the weeks 4-6 to increase task difficulty. The quantity of grains sorted in 30 minutes was measured.

*Response Inhibition:* The patient colored increasingly complex drawings using pencils from weeks 1-6. Emphasizing careful regulation of pressure and direction of strokes as well as neatness increased response inhibition. Time taken to complete the task was recorded. Stop-start task was introduced in the week 5 and 6 of the retraining programme. In this task while the patient was performing a motor sequence for e.g. clapping hands, he was instructed to stop suddenly without a prior signal and then asked to restart the same sequence when the start signal is given. The start-stop signal is given randomly. The task was performed for 5 minutes in each therapy session.

*Working memory:* Mental arithmetic (10 problems) and jumbled sentences (10 sentences) were administered in week 1 and 2. The tasks were discontinued subsequently as the patients reached the ceiling level. Tasks for improvement of visuo spatial encoding and visual memory for locations required the patient to reproduce the location and sequence of an arrangement of objects on a table, from memory. An increasing number of objects were exposed for 10 seconds. Following maintenance in memory for another 10 seconds, the patient was asked to reproduce the arrangement. The task was given from weeks 2-6, with accuracy of reproduction as the score.

*Set-shifting:* Categorization of beads, categorization of playing cards and motor set-shifting were administered. In week 3, 50 beads of various shapes, colours and sizes were combined

together. The patient's task was to categorize the beads employing a different rule everyday. In weeks 4 -5, two decks of playing cards were sorted. Week 4 required the patient to identify the sorting rule of the therapist, while in week 5 the patient generated a sorting rule. Weeks 4-5 also included the motor set-shifting task for 5 minutes. The patient suddenly shifted from one motor sequence such as clapping hands to another sequence such as tapping feet.

*Planning:* In weeks 3 and 4 the patient was given real life situations and asked to narrate the steps taken to achieve the desired goal. For example, a situation such as planning for a picnic within a given budget was given. The therapist suggested improvements to the plan. In the weeks 5-6, the patient wrote essays on topics of his interest. The therapist corrected the sequence and planning of the essay.

*Comprehension and Production of emotions:* In week 3, the therapist depicted basic emotions of joy, anger, sorrow, fear, surprise, disgust and disappointment. The patient was asked to identify the depicted emotion. Week 4 required the subject to depict various emotions. In week 5, the patient depicted an emotion to an imagined social situation.

*Immediate visual memory:* In the weeks 2-6, the patient recalled from memory, 10 abstract designs, which had been sequentially presented 10 seconds before and remembered for another 10 seconds. Increase in task difficulty was achieved by increasing the number of components in each design over the weeks. The correct number of designs formed the score.

*Family Intervention Programme:* Bi – weekly family intervention sessions for the patient and the caregivers were held concurrently with the 6-week cognitive retraining programme. These 12 one-hour sessions were broadly divided into four phases. Phase one, comprising of three sessions, focused on assessment of current functioning of the family as well as the difficulties being experienced by the caregivers in various areas. Two sessions of phase two focused on psychoeducation about the illness. In phase three, comprising of three sessions, caregivers were helped to normalize the family routines disrupted due to the illness and appraised about the importance and the need to lower expressed emotions directed towards the patients as well as helping the patients to develop a structured schedule of daily activities. Three sessions in phase four were devoted to improving the communication and problem solving skills of the family members, clarification of their roles and attempted to enhance their social networks and support systems. Finally one session was held for preparing the families for termination and for clarification of any further queries that the caregivers had.

## Results

### Pre intervention assessment of patients:

#### *Neuropsychological assessment:*

Table 1 gives the normative percentiles of the raw scores on the neuropsychological tests. In the pre training assessment, all three patients had deficits in at least three domains of cognitive functions out of the nine cognitive domains assessed. All three cases had deficits in concept formation and set-shifting ability. Case 1 and 3 had deficits in information processing speed. Case 1 and 2 had deficits in visual memory and case 3 had deficits in visuo-spatial construction.

**Table 1. Neurocognitive Functions of the three cases**

**Normative Percentiles corresponding to the raw scores**

<i>Neuropsychology Test name</i>	<i>Variable</i>	Case 1					Case 2					Case 3		
		Pre	Post	(a)	F/u	(b)	Pre	Post	(a)	F/u	(b)	Pre	Post	(a)
DVT	Time in seconds	27	57	+	57	=	19	84	+	41	-	11	38	+
CT 1	Time in seconds	97	100	=	100	=	44	50	=	38	=	38	56	=
CT 2	Time in seconds	77	100	=	100	=	65	97	+	47	-	65	41	-
DGST	Time in seconds	10	90	+	63	-	38	53	+	33	-	3	23	+
FT (right hand)	Mean No. of taps	70	95	+	50	-	70	85	+	95	=	40	25	-
FT (left hand)	Mean No. of taps	20	70	+	30	-	30	70	+	85	=	75	40	-
SOPT (words)	Total No. of Errors	100	100	=	78	=	78	100	=	100	=	78	100	=
SOPT (designs)	Total No. of Errors	59	94	+	94	=	59	100	+	94	=	100	100	=
Stroop color word test	Stroop effect in seconds	81	65	-	84	+	48	94	+	45	-	19	23	=
WCST	% Error	18	100	+	91	=	3	94	+	97	=	6	85	+
	% Perseverative Responses	9	100	+	79	=	3	64	+	88	=	15	79	+
	Failure to maintain set	12	100	+	100	=	46	100	+	100	=	46	100	+
	No. of categories completed	25	95	+	95	=	10	100	+	100	=	10	95	+
TOL	Total No. of problems solved with minimum moves	80	80	=	95	=	80	95	=	90	=	60	90	+
AVLT	No. of words recalled in Trial 5	50	100	+	100	=	95	95	=	95	=	95	95	=
	Immediate recall No. of words	50	95	+	95	=	80	95	=	80	=	95	95	=
	Delayed recall No. of words	50	95	+	95	=	95	80	=	80	=	80	80	=
	Long Term Retention	50	75	+	75	=	60	50	=	50	=	50	50	=
RCFT	Copy	100	100	=	100	=	100	100	=	100	=	5	100	+
	Immediate Recall	5	75	+	80	=	25	85	+	95	=	20	75	+
	Delayed Recall	5	85	+	80	=	10	100	+	90	=	15	75	+

Pre: Pre Cognitive retraining Assessment; Post: Post cognitive retraining Assessment; F/u: Follow-up assessment; (a): Changes of percentile score from Pre intervention assessment and post intervention assessment; (b): Changes of percentile score from Post intervention assessment to Follow-up assessment  
Quartile change: +, Percentile increase of a quartile or more; -, Percentile decline of a quartile or more; =, No change in the quartile  
Percentile score < 15 indicates deficit.

*Assessment of Global functioning:* Global functioning was average in all the 3 cases i.e. scores were in the middle range. (Table 2).

Table 2. Global Assessment of Functioning Scale scores (GAF scores)

CASE	Pre- Intervention	Post- Intervention	2- month Follow-up
1	53	75	57
2	51	67	61
3	45	57	-

Score Range: 0- 100. Higher score indicating better overall functioning

Pre Intervention assessment of caregivers

Table 3 gives the scores of GHQ and BAS. At pre intervention assessment, the GHQ scores of the caregivers ranged from 0 to 14. Presence of a probable psychiatric problem was indicated for two of the caregivers, as their scores equaled or exceeded the cut off score of 4. The brother of Case 1 reported problems related to anxiety, somatic symptoms and insomnia while the mother of Case 2 reported predominantly somatic symptoms. The scores on the BAS were high for all the caregivers, indicating the presence of increased burden. Analysis of the items of BAS found that burden was experienced with regard to concerns about the patients' future and their social and occupational functioning. During the family assessment interviews, caregivers expressed concerns regarding patients' negative symptoms, nature and course of the illness and apprehension in choosing the issues to be discussed with the patient in the everyday family interaction.

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Table 3. Scores of the caregivers on General Health Questionnaire (GHQ) and Burden Assessment Schedule (BAS)

Caregiver		Pre-intervention	Post-intervention	Follow-up
Brother	GHQ	14	3	2
(Case1)	BAS	57	62	63
Sister-in-law	GHQ	2	1	1



(Case1)	BAS	59	66	64
Mother (Case2)	GHQ	4	0	3
	BAS	68	47	53
Father (Case3)	GHQ	3	0	-
	BAS	65	65	-
Mother (Case3)	GHQ	1	0	-
	BAS	70	70	-

GHQ: (cut off score – 4/5)

BAS: (Score range 40-120; Higher the score, higher the burden)

### Changes after Intervention

#### Comparison of Pre-Post Retraining Assessments of patients:

*Neuropsychological assessment:* Change in the neurocognitive functions was characterized as normalization, improvement or decline. Normalization was defined as a shift of percentile from the deficit range to the normal range, improvement was defined as shift of percentile to a higher level by one quartile or more and decline was defined as a shift of percentile to a lower level by one quartile or more. (Table 1)

In Case 1 the post retraining assessment did not show deficits. Comparison of the pre and post intervention neuropsychological assessment showed that the functions of information processing, set-shifting as well as visual memory were normalized after retraining. The functions of sustained attention, motor speed as well as verbal learning and memory improved. Other functions such as focused attention, working memory, planning and visuo spatial construction remained status quo. There was a decline in response inhibition..

In Case 2 the post intervention assessment did not show deficits. The functions of visual memory and set-shifting were normalized. The functions of sustained attention, focused attention, information processing, motor speed, working memory and response inhibition improved. There was no decline in any of the cognitive functions.

In Case 3 the post intervention assessment did not show deficits. The functions of information processing, set-shifting, planning and visual memory were normalized while sustained attention and planning improved. Cognitive functions of working memory, response inhibition, and verbal learning and memory remained status quo. The functions of focused attention and motor speed declined from the pre-assessment.

*Global Functioning:* The scores on the global functioning scale increased between the pre and post training assessments in all 3 cases. Qualitatively, all the 3 patients improved minimally in self-care, in performing household chores and helping other family members. The occupational status did not improve.

Comparison of Pre-Post Intervention assessment of caregivers: The mental health of caregivers of case 1 and case 2 improved. Table 3 shows the scores on the GHQ scale, which indicate non-caseness in all the caregivers. There were variable changes in the scores on the BAS among the caregivers (Table 3). The caregivers of cases 1 & 3, who had had very high occupational expectations for the patients, lowered their expectations to more realistic levels. Qualitatively the caregivers continued to be worried about financial liabilities, issues of long-term care giving and the lack of gainful employment of the patient. However, they reported a feeling of being supported by the therapist, as well as better awareness and acceptance of the fact that the process of improvement observed in the patients would be a slow and gradual process. All the caregivers reported decreased psychological distress and subjectively reduced feelings of burden. Improvement was observed in the emotional interactions between patient and the caregivers.

#### Maintenance of Improvement

Comparison of Post intervention- follow-up Assessment of patients:

#### *Neuropsychological assessment*

There were no cognitive deficits either at the post or the follow up assessments in cases 1 & 2.

In Case 1 the improvement of sustained and focused attention, working memory, set-shifting, verbal learning and memory as well as visual memory were sustained. Response inhibition improved from the post assessment to the follow-up assessment. There was a decline in information processing and motor speed.

In Case 2 the improvement of focused attention, motor speed, working memory, concept formation and set shifting, planning, verbal learning and memory as well as visual memory were sustained. The functions of sustained attention, information processing and response inhibition declined.

Case 3 was not available for the follow up assessment.

#### *Global functioning:*

At follow up, the GAF score declined significantly in Case 1 and marginally in case 2 compared with the post-retraining score. However the follow up scores remained higher than the pre training scores in both cases (Table 2).

All the 3 patients were able to obtain full time paid employment within 3 months after completing retraining. While Case 3 joined gainful employment in one month, Cases 1 & 2 joined within three months after completing the cognitive retraining.

Comparison of Post Intervention -Follow up assessment of Caregivers:

The caregivers of cases 1 & 2 were available for follow up. Case 3 and his caregiver did not report for follow up. The GHQ scores of the caregivers of cases 1 & 2 indicated non-caseness and hence absence of psychological distress. Scores on BAS increased very minimally from the post-intervention assessment levels in caregivers of Case 1 and 2 (Table 3). Qualitatively, the improvement observed after the intervention in the emotional interactions between the patients and the caregivers was maintained. The caregivers showed increased tolerance towards the patients' problems and had realistic expectations in the social and occupational functioning of the patients. The caregivers reported that the psycho education had been very beneficial.

## Discussion

We developed and examined the clinical efficacy of an integrated intervention programme, which included cognitive retraining and family intervention in the present study. Cognitive retraining targeted improvement of cognitive functions. Family intervention aimed to reduce the feeling of burden and improve psychological well-being of the caregivers.

In the present study, all three patients had cognitive deficits. However, it was not uniform. Prior to the intervention, all three patients had deficits in concept formation, set shifting. In addition to the deficit of concept formation and set shifting, Cases 1 and 2 had deficits in visual learning and memory and cases 1 and 3 had deficits in information processing. Assessment following the intervention showed improvement in the cognitive functions that were initially assessed to be in the deficit range. Sustained attention, which was in the non-deficit range in all three patients prior to intervention, showed further improvement in all the three patients. Improvements in other functions were again, not uniform across the three subjects. For instance, in case 1, there was improvement in motor speed, verbal learning and memory; in case 2 there were improvement in mental speed, information processing, working memory and response inhibition; and in case 3 there was improvement in planning. Cognitive functions improved following intervention and remained in the normal range at the post intervention assessment in all the 3 cases. At two-month follow up all the cognitive functions remained in the non-deficit range in both case 1 and 2. The sustenance of improvement was not uniform. For instance in Case 1 response inhibition improved. However, in case 2 there was decline in sustained attention and response inhibition from the level observed at the post assessment. About two thirds of the cognitive functions sustained this improvement at the two-month follow-up in cases 1 & 2. Improvements in cognitive abilities following cognitive retraining are similar to the finding of other studies. Cognitive retraining was found to improve sustained attention (Medalia, 1998) and executive functions (Lopez Luengo, Va'zque, 2003). Improvements in attention, memory and executive functions have occurred following cognitive retraining, which was given as part of Integrated Psychological Therapy (IPT) (Spaulding et al., 1999).

The pre-intervention assessment of the caregivers indicated significant psychological distress in two out of five caregivers as indicated on the GHQ (brother of case 1 and mother of case 2). At the post intervention and follow up assessments there was a significant reduction in their distress levels. Qualitatively too, there was a substantial reduction in their subjective reports of distress following the intervention. Similarly in the pre assessment all the caregivers reported significant burden. The BAS scores have remained in the same range during the post-intervention and at the 2-month follow-up assessment, indicating that caregivers experienced burden even after family intervention. However it is noteworthy that despite the high scores, all the caregivers have subjectively reported a decline in the feelings of burden, and an improved mental health. In order to understand the discrepancy between the subjective report and the objective scores a qualitative analysis of responses on the BAS was carried out. It was seen that the objective scores on the BAS decreased in the domains of patient behavior, caregiver health, caregiver's occupation, leisure activities and emotional burden. The scores did not change in the domains of financial burden and social support. As these two are critical areas, lack of improvement in these areas could have led to the perception of burden. Changes in the families' financial position or in their social support network are unlikely to show quick or marked changes within a short span of time. The 6-week duration of family intervention in the present study is perhaps insufficient to effect a change in these two domains.

Although the level of burden did not change objectively, decreased psychological distress may have contributed to the perception by the caregivers of an improved ability to cope with problems. Greater tolerance of the patients' symptoms and acceptance of the gradual pace of improvement were evident in the caregivers' subjective reports. This in turn may have contributed to an overall congenial family

environment, reflected in the subjective reports of decrease in the sense of burden. The results of family intervention in the present study are similar to those of Budd and Hughes (1997). In their study, following family intervention, the family members reported an increase in the knowledge about the illness, feeling supported and reassured and encouraged by the helpful nature of therapeutic alliance. In a study of a family psycho educational support group, the family members showed greater satisfaction with the services provided. However there was no change in the objective scores on psychological distress, coping behaviour and family satisfaction. (Posner et al., 1992) .

An improvement in the global functioning of all the three patients during the post-intervention assessment has been observed. Improvements following intervention and changes in cognitive flexibility are known to have positive effect on social functioning as well as self-esteem (Wykes et al., 1999). It is significant to note that the improvements in the cognitive functions and the family environment have generalized to the daily functioning of the patient as reported by the patient themselves and their caregivers. It is equally significant to note that in the present study all three patients obtained gainful employment. One patient obtained a job one month after the retraining and two patients within three months after the retraining. Of the three patients, case 3 had not worked for the previous 2-½ years and the other two patients had never been in a gainful job. It is also pertinent to note that medication dosages for all the three patients remained constant in this period and they were not treated with any other additional therapy. Therefore the improvement of global functioning could not be attributed to changes in medication. Further, as the illness in all the patients was a long-standing one (exceeding six years duration), the changes in the global function cannot be inferred as occurring spontaneously. Therefore the improved global functioning and gainful employment of the patients can be attributed to the integrated intervention. It is likely that remarkable changes have occurred due to the improved cognitive functions, which have been sustained in a supportive family environment and probably generalized to day-to-day functioning. This in turn could have aided in the acquisition of job skills. The gradual changes in the patients' day to day functioning as well as the families' improved understanding of the illness are likely to have contributed to a reduction in the levels of criticism, intrusiveness and over involvement on the part of the family members and helped in modifying their expectations towards more realistic levels. The emergence of a more tolerant and positive family environment could have supported and encouraged further improvements in the patients' functioning. Thus a recursive cycle of positive changes appears to have been initiated.

The present exploratory study is the first to integrate cognitive retraining and family intervention. . The small sample size is a limitation of this study. A randomized control study with larger samples would establish the efficacy and generalizability of the results and remove any expectation biases. The Integrated psychological intervention has shown promise and encouraging results that merits further investigation.

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# The Problem of Stigma during End-of-life Care at a Psychiatric Institution

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## Abstract

The literature on palliative care for individuals with a mental illness is scant and there is a complete absence of work available on the issue of stigma at this interface. The following discussion makes a start to addressing this important topic by presenting findings on the nature and impact of the stigma associated with mental illness from a qualitative research project on end-of-life care for patients in a mental health institution called The Park, Centre for Mental Health, located in Brisbane, Queensland, Australia. The findings reported in this article affirm the difficulties associated with the stigma of mental illness and point to the obstacles created for psychiatric staff in accessing the services of mainstream palliative care.

**Keywords:** Stigma; Mental Health; Palliative Care; Attitudes; Service Delivery.

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## The Problem of Stigma during End-of-life Care at a Psychiatric Institution.

Stigma is associated with a wide variety of groups including those that experience mental illness (Link, Phelan, Bresnahan, Stueve, & Pescosolido, 1999; McGrath & Jarrett, 2004; Schneider, 2004), the dying (Epley & McCaghy, 1978), those imprisoned (Aday, 2005 -2006), the aged (Wade, 2001), those with illnesses like AIDs (Buseh, Kelber, Hewitt, Stevens, & Park, 2006) and disabilities (al., 2005). Individuals with a terminal illness in psychiatric facilities can have multiple stigmatised social identities as they are not only considered mentally ill, but are often imprisoned, aged, and have other illnesses or disabilities apart from the fact that they are also dying. The impact of multiple stigmatising social identities may affect not only the institutionalised individual with a mental illness seeking end-of-life care but also the service providers who care for them. However, to date, there is an absence of literature on the topic of stigma and terminal illness in relation to individuals who are inpatients of psychiatric institutions. Indeed, the literature on palliative care and mental illness is scant (McGrath & Forrester 2006; McGrath and Holewa 2004) and there is a complete absence of work available on the issue of stigma at this interface. As Baker notes (2005) those individuals facing the final stages of their life in psychiatric facilities have to date not been studied.

The silence within the palliative care literature over this issue pre-empt questions around whether individuals who suffer from the stigma of mental illness are marginalised and discriminated against in relation to mainstream palliative care service provision.

The following discussion makes a start to addressing this important topic by presenting findings on the nature and impact of the stigma associated with mental illness from a qualitative research project on end-of-life care for patients in a mental health institution called The Park, Centre for Mental Health, located in Brisbane, Queensland, Australia.

## The park, centre for mental health

Situated in the Brisbane suburb of Wacol, The Park, Centre for Mental Health (TPCMH) provides mental health and psychiatric services to the people of Queensland and was one of the largest psychiatric facilities in Australia (Finnane 2002). Established in 1865, TPCMh has recently decentralized its extended care services as provisioned by the Ten Year Mental Health Plan for Queensland (The Park 2006) through adopting a paradigm focused towards rehabilitation and recovery. Currently, TPCMh provides five clinical and rehabilitation services programs to 192 clients from central and southern Queensland, including, Extended Treatment and Rehabilitation, Dual Diagnosis services, Extended Secure Services, High Security/ Forensic Care Services and Adolescent Rehabilitation Services. Support Services available at TPCMh include General Health Services, School of Mental Health and Library, Centre Management and Research Services.

## The research

Mindful of the lack of research on palliative care in a mental health setting, the principal aim of the research project was to document the experience of providing end-of-life care to patients for health care workers in an institutional mental health setting at TPCMh. The work was carried out by a Central Queensland University post-doctoral research fellow with a background in palliative care research and infrastructure links to TPCMh.

Ethical consent to conduct the study was obtained from the West Moreton Health Service District Human Research Ethics Committee. Participants were verbally informed of their rights in research and written consent was obtained for participation in the research.

## Methodology

The theoretical framework for the research is situated in descriptive phenomenology, defined by Spiegelberg (1975) as “direct exploration, analysis, and description of particular phenomena, as free as possible from



unexamined presuppositions, aiming at maximum intuitive presentation”. The phenomenon in this case is the experience of providing terminal care for patients with a physical illness in an institutional mental health setting. Descriptive phenomenology is particularly appropriate where little is known about a group of people (Krathwohl 1993; Polit & Hungler 1995) and so is well suited to the study of palliative care in a mental health facility where there is no previous research literature. The experience of providing terminal care is documented through qualitative research using open-ended interviews conducted with health care workers at TPCMH by a post-doctoral fellow experienced in palliative care research.

### Sample population

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

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

### Demographics

Because of the sensitive nature of the topic under investigation and the fact that the interviews were completed in a closed institutional setting, extra precautions needed to be taken and promised to participants during informed consent procedures. Such procedures were important in order to build a sufficiently safe environment where the interviewees could participate with confidence. Thus, it is an ethical imperative that the information provided for demographics will need to be provided in generalities so that participants cannot be identified.

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

### Data collection and analysis

The time and location of the interviews were of the participants choosing. The interviews lasted for approximately one hour, and the interviews were conducted in interviewing rooms in the hospital. Participants were encouraged to tell their experience with caring for a terminally ill patient with the initial question of “Could you tell me in your own words and in your own way of your experience as a health professional caring for a patient in a mental health facility with a terminal illness?” Of particular interest was an exploration of factors that the participant believed either facilitated or hindered the provision of optimal end-of-life care. The

momentum of the interviews was maintained by the descriptive phenomenological method of ‘imaginative listening’ (Colaizzi 1978). The challenge in descriptive phenomenology is for the researcher to follow the ideas of participants rather than impose preformed assumptions on data collection (Holloway 1997).

The interviews were audio-recorded and transcribed verbatim. The language texts were then entered into the NUD\*IST (Nonnumerical Unstructured Data Indexing Searching and Theorizing) computer program, computer software available to facilitate cutting and pasting interview transcripts into codes (Mays & Pope 1995), and analysed thematically. As descriptive phenomenology is an inductive process which seeks to record experiences from the viewpoint of the individual who had them without imposing a conceptual framework, the thematic analysis was driven entirely by the participants’ insights (Polit & Hungler 1995). The coder read all of the transcripts, then created codes from every statement made by the participants. The title of each code was usually from the exact words of the participant. As Grbich (1999) explains, such coding practices use minimal underpinnings to avoid data being forced into predetermined frames and to encourage uncontaminated themes to emerge from the data. There were thirty five (n=35) free nodes created. Once all of the participants’ comments were coded into free nodes, the list of nodes were then organised under thematic headings. Only the data relevant to the issue of stigma are presented in this manuscript. Further findings from the study on ethico-legal issues (McGrath & Forrester 2006) and the compatibility between the perspectives of mental health and palliative care professionals (McGrath & Holewa 2004) are published elsewhere.

## Findings

The following findings need to be set in the context of further data from the study that indicates that the provision of palliative care in a mental health institution is challenging at best because of a range of problems including lack of staff knowledge of palliative care, limited resource, legal restraints, and problems interfacing with palliative care services. The findings presented here focus on one of the central problems impacting on end-of-life care: that of the stigma attached to mental health patients.

### The Mental Health Stigma

Palliative care services for their clients is the stigma attached to mental illness.

- There is nothing you can do about the stigma. Nothing you can do about it. It would be lovely if there was something but there isn’t.

The stigma is reported to be attached not only to mental health patients but also the health professionals who care for them.

- I suppose the stigma is still attached to ‘psych’ nursing isn’t it. All mental health.

The stigma for both the patient and the health professional is described as unfounded.

- I can understand if they are aggressive, on the whole they are not usually.

### A Caveat: the stigma works both ways

Although the findings indicate that there is a definitive stigma about mental health patients by palliative care staff, it also needs to be noted that some of the mental health professionals made statements that were indicative of a stigma towards palliative care.

- I believe a lot of staff would be very comfortable with knowing what palliative care means but also a lot of staff would be quite resisting to the idea on the ward.

The important point is that issues of stigma are not one way: lack of familiarity with and knowledge about the work of other disciplines can create barriers of stigma that provide obstacles for patient care. The findings point to the importance of avoiding simplistic dichotomies of ‘them’ and ‘us’.

However, as published elsewhere, in many cases the psychiatric staff shared similar ideas of philosophy and practice to palliative care specialists (McGrath & Holewa, 2004) and saw the involvement of palliative care as the preferred option.

- I would have thought that towards the end probably the most appropriate thing in some instances is for that individual to go in an in-patient palliative care in a hospice setting where experts who deal with it every day of their lives and know how to do it.

### Suggested causes for the mental illness stigma

The reason for the stigma is seen to be generated by a number of inter-related factors including fear,

- It is fear. Is the person going to be dangerous to her own life?

Ignorance,

- They look at us and say ‘Well we can’t handle these people no way. We don’t want anything to do with them’ ... they don’t understand enough about it.

Lack of experience with dealing with mental illness.

- I think the stigma comes from fear and that people haven’t been confronted by them enough. And maybe they should come and do a day here.

The alienating nature of many difficult mental illness behaviours,

- He had done things in the past which had alienated him from a lot of people which is so typical of people with a mental illness. Through no fault of their own they become alienated from society a bit like alcoholics

The sense of estrangement associated with different world views,

- They have been ill for so long that their experience of the world is not like ours

And, the inability to see the person behind the illness.

- It suddenly dawned on me ‘this man had a life before he got unwell’, whereas so many people just see the incredibly debilitating illness

### Implications of mental illness stigma for end-of-life care

The outcome is that staff find it difficult to access appropriate end-of-life services,

- People with mental illnesses are not welcome with at the General Hospital.

At times the refusal by mainstream services to care is complete and final, for example,

- ... there is no way he will come here and die here.

At times it comes after a trial period.

- I rang them and they said we will give it a go, and then they took him a few days and said, no we are going to send him back.

At best the refusal is accompanied by helpful offers of alternative assistance.

- Anyway a social worker at palliative care did some remarkable work and found a place for him at a nursing home.

The lack of availability of services was seen as confounded for this group of patients by the fact that they were involved in institutional, rather than community based, care.

- I can't see why we aren't entitled to the same service as a community. We are a community care unit or are we? We are an extended treatment and rehabilitation unit. We are funded by the government. See I don't know really what our status is. But we are certainly not entitled to that service.

Thus, participants indicated that institutionalised mental health patients are not provided with equal rights to appropriate end-of-life care.

Positive experiences: Finding ways around the stigma

The participants also spoke about the positive experiences they had with some service providers who did find ways of overcoming the resistance to care caused by the stigma.

### Trained health professional accompanying the patient

One solution was for the institutional facility to provide trained mental health staff as full time support at the hospital or palliative care facility to care for the individual mental health patient.

- They were saying we are not equipped to deal with disturbed people. And I said we are happy to leave our staff here 24/7 and they said okay.

Bringing palliative care expertise in to the psychiatric facility

Another solution was to organise for sympathetic palliative care providers to visit the institutional psychiatric facility. The role of the palliative care providers in this case was to provide professional advice and support.

- Once the palliative care people would come out every couple of weeks and people would interrogate them - What do we do? How do we do...?

The arrangement for palliative care staff to visit, rather than send the patients to the palliative care facilities, is reported as the best option because the patients needed the familiarity of remaining in institutional care. It was noted that individuals in institutional psychiatric care depend on a familiar environment in order to have some control over their, at times, difficult behaviour.

- They got sent back because in a totally strange environment they become more difficult to manage so they send them back.

In some cases this issue is based on a legal requirement necessitating custodial care.

- From medium and high security it would not be possible to send them off.

For others, it was because they had been in psychiatric care for so long they were institutionalised and required the comfort of repetitive familiarity, for example.

- Because some of them have been here a long time so they are institutionalised. Could you imagine being here for maybe 16 years how hard it is to be out there in the big world? Could be a cruel world for them sometime. Here they are safe, they got their friends, they get everything provided for them, there is no fear like there is out in the community.

But mostly, it was noted that patients in the psychiatric facility came to rely on the familiar relationships with the staff of the facility.

- He would not let a lot of them do things for him. ... he liked people that he knew as well.

As one participant summed up, this is a particularly poignant issue during end-of-life care.

- People can't help themselves. If they find themselves in an unfamiliar environment they would be phobic or more psychotic. Because they just do not want to be there. So this is another issue which has to be definitely pointed out. Shift these people somewhere else and that is how they operate. The mental health

issues are also part of palliative care. It is not like you can separate it.

The issue was not just about familiarity, but also about training. It was noted that people with a severe mental illness require the care of trained mental health professionals.

- We have the expertise to deal with their mental illness which is an overriding factor when they are physically ill.

Training and knowledge in dealing with disruptive behaviour is noted as particularly important with individuals who are likely to be violent.

#### Ad hoc nature of solutions

However, the important point was made that in the cases where ongoing support was provided by mainstream services it was usually after a period of expressed desperation and usually because of the sympathetic response of an individual health professional. The significant point is that there is not an automatic system response; rather, end-of-life care for mental health patients in an institutional facility is ad hoc. It depends on finding a sympathetic person in mainstream services who is prepared to go out of their way to help.

- Palliative care said we will not accept this man until he is on death's door. And he could live for another three months. In the end it was only that I spoke to someone who was just really tuned in I think and I said, you got to help us. With this we are struggling here. And she said okay. Your connection with most services is not the service it is the person.

#### The limited nature of even the positive assistance

In most cases the assistance was only advisory rather than hands-on practical help. Although such advice was appreciated, it was only periodically available.

- They were very supportive in that respect but they weren't here all the time.

Also, advice over the telephone, although helpful, is seen as less valuable than service delivery assistance.

- The other one is the lack of close palliative care support. I mean nobody would look at once a fortnight. They were always available on the phone if you wanted to talk to them, but that is not really the same. Somebody that knows exactly what is supposed to be being done and then you didn't have anyone available to do it.

The difficulties associated with end-of-life care were seen as very challenging and so more ongoing reassurance and support was reported to be needed.

- The consultations and reassurance: yes you are doing it right or this is the way to do it. We could have used more consultation in that department (pain management). I suppose more reassurance.

#### Mental health staff stress in caring for dying patients

As the health professionals at the psychiatric facility were not trained in palliative care and had limited resources and support in dealing with dying patients, caring for terminally ill patients is described as highly stressful. As can be seen by the following examples, participants used words such as 'hard', 'traumatising', 'angst', and 'stress' to describe the experience.

- It is incredibly traumatising for the people who have to do it. I am certainly aware of the angst in the staff.

#### **You could see the stress. You could feel the stress.**

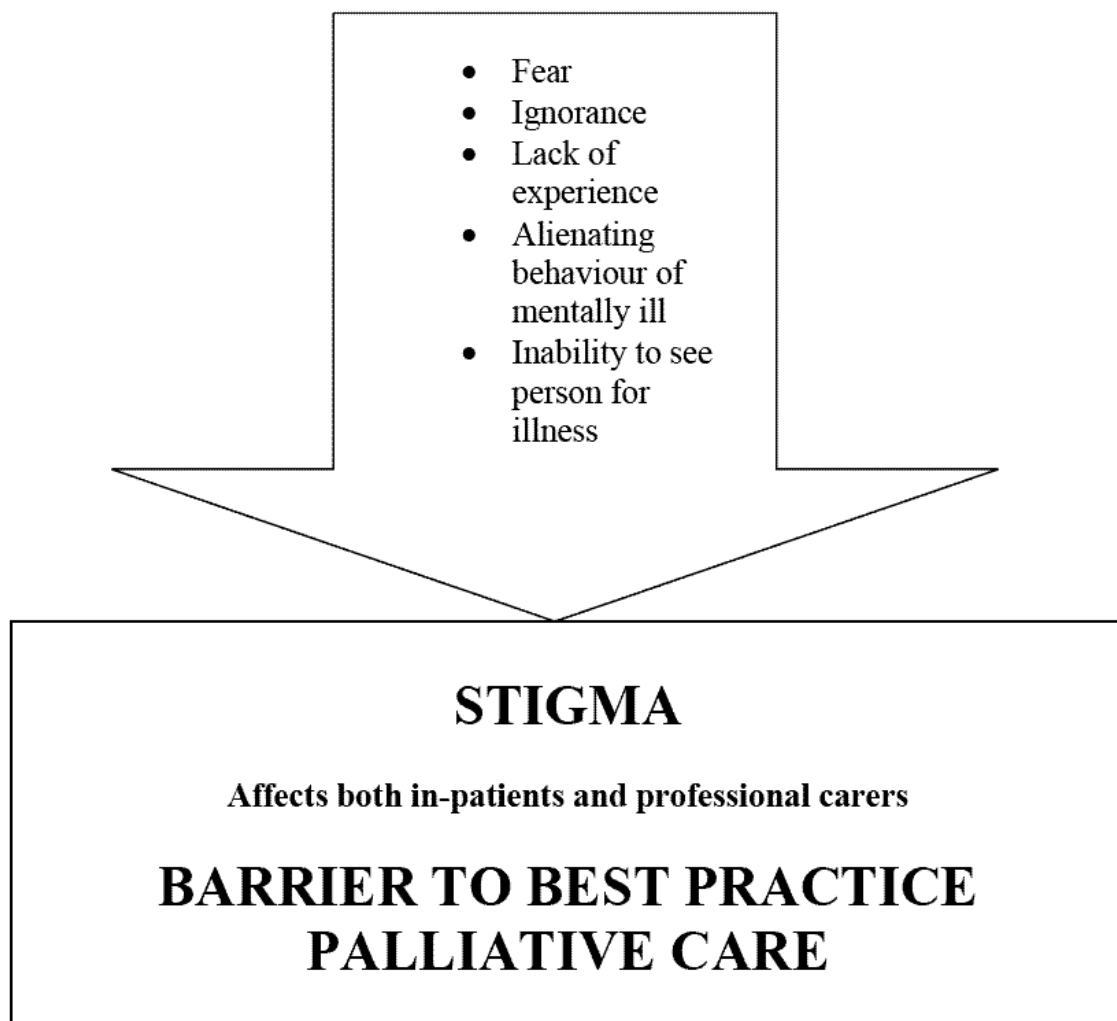
For some, the distress was exacerbated by issues of loss associated with the strong relationships that develop with long term patients. Bureaucratic difficulties and lack of resources added to the stress.

- It was stressing watching him without having the facilities to give him, what we needed to give him.

## Discussion

Although research is available on the negative sequelae of the stigma attached to mental illness, there is no work on this topic in relation to end-of-life care for patients in a psychiatric institution. Indeed, although over the last decade there has become increasing interest in palliative care, as yet caring for the seriously mentally ill dying population is an area within this field consistently overlooked (Baker 2005; Chochinov 2004). The findings reported in this article affirm the difficulties associated with the stigma of mental illness and point to the obstacles created for psychiatric staff in accessing the services of mainstream palliative care. Corrigan and Penn (1997), also support the idea that services provide a source of discrimination for those with mental illness. Figure 1 outlines the factors posited by the present study that contribute to stigma and thwart access to appropriate palliative care for in-patients in a mental health institution.

**Figure 1 - Factors contributing to stigma for in-patients of a psychiatric facility**



The findings resonate with Allport's (1954) account of stigma where decisions are made based on the negative stereotype without knowing about the individual. Link and associates (Link, Cullen, Frank, & Wozniak, 1987) affirm the findings that the difficulties surrounding end-of-life care for

those with mental illness are increased because of the fear of dangerousness that is associated with the negative stereotype of being mentally ill. Phelan's research (cited in Link 1999) similarly highlight the fear associated with beliefs that mentally ill people are dangerous. This fear has been shown to be unfounded (cited in Link, 1999).

Studies over the last decade in Australia (Highet, Hickie, & Davenport, 2002) and New Zealand (Green, McCormick, Walkery, & Taylor, 1987) have found that stigma is still a problem and that despite many campaigns to improve community awareness, that there is still misunderstanding of mental illness. The findings from the present study indicate that the strong negative sequela of the mental illness stigma is the obstacle to accessing mainstream palliative care services for the patients of the psychiatric institution. The evidence points to the fact that the links between the mental health and palliative care system are not yet established. The outcome is that access is ad hoc, rather than automatic or systematic. The situation is serious in view of the profound needs of this group of dying patients as stigma is likely to be greatest for those who are most vulnerable with chronic and incapacitating mental illness (Corrigan & Penn, 2004, Link, 1987), and it is also likely that this stigmatized group will suffer more from physical illnesses (Farnam, Zipple, Typrrell, & Chittinanda, 1999).

A caveat to the discussion is that in end-of-life care, the stigma can work both ways with psychiatric staff recording a stigma in relation to the discipline of palliative care. Most of the participants interviewed, however, did have a positive orientation to palliative care and sought such best practice terminal care for their patients.

The link to the palliative system relies on the good will of individual professionals acting singularly within mainstream care, and usually after the display of severe signs of exasperation by mental health professionals. Alternative strategies used to foster liaison between psychiatric and palliative care recorded include the provision of mental health staff to accompany psychiatric patients to mainstream facilities or the involvement of palliative care staff in an advisory capacity in the psychiatric institution. Predominantly, however, where help is offered it is usually advisory rather than hands on service provision and is periodic and limited. The outcome is a high level of stress recorded by mental health professionals during times of end-of-life care. This is exacerbated for those with long term relationships with dying patients. Lack of knowledge, insufficient resources and bureaucratic difficulties compound the distress.

## Conclusion

Previous findings published from the project (McGrath & Holewa, 2004) point to the great similarities between the palliative and mental health philosophies and practices, demonstrating that both share a patient-centered and holistic focus. The clear indication from the present findings is that there is a strong need to start to build the links between these two quite similar, but presently alienated, systems for the sake of both the patients and the staff who care for them. As Baker (2005) argues, palliative care provides a unique opportunity for mental health nurses, particularly the nurse practitioner in psychiatry, to fill the need of helping this group of individuals to experience a "good death".

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# Psychiatry Morbidity Among Inmates of the 'Beggar Home'

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## ABSTRACT:

With aim to know prevalence of psychiatry morbidity among the beggars, we study socio-demographic variables and assessed the psychiatric morbidity and distress among the inmates of 'Beggar Home'. The Subjects were 49 inmates of Beggar Home situated in Vadodara(Gujarat), India. We gave them a semi-structured questionnaire of socio-demographic details and also gave General Health Questionnaire-28. We also interviewed them personally to diagnose the psychiatric illness and to know their begging patterns. We found that 38.8 per cent of inmates were suffering from one or other types of psychiatric disorders. The study also revealed the high scores on GHQ among the beggars suffering from the psychiatric illness.

## **INTRODUCTION:**

A 'beggar' or a 'cadger' (Oxford Dictionary, 2001) is, a person who lives by asking people for money or food. It is roughly estimated that there are about 2 million beggars of all category in India (Planning Commission, 1963). A Beggar Home is a statutory organization that functions in collaboration of State Government and Municipal Corporation of that particular city. It works under 'The Bombay Prevention of Begging Act', 1959. The beggar's home provides shelter, protection, and training of vocational skills to the inmates. Thus, Beggar Home is a good source of sample when beggars are to be studied. This study was aimed to assess psychiatric distress and morbidity and also to study socio-demographic variables of beggars among the inmates of beggar home in Vadodara. In this study we have tried to find any significant association among presence of psychiatric illness, distress, begging patterns and socio-demographic variables.

## **METHODS:**

### **Data collection**

The subjects were 49 inmates of Beggar's Home, Vadodara, Gujarat. After receiving permission from The Superintendent of Beggar Home, we interviewed the inmates of beggar home on one to one basis, using DSM-IV criteria, to diagnose any mental illness. We also prepared a semi-structured questionnaire that included questions about socio-demographic details and begging patterns of beggars. We used General Health Questionnaire-28 (Goldberg, 1978) and translated it in Gujarati language to find out distress among inmates of beggar home.

### **Data analysis**

We analyzed all the data by using SPSS (Statistical Package for the Social Sciences, Version 8.0). We collected the data along a nominal level, and then we used chi-square test for the main statistical analysis. The demographic variables we studied were age, sex, geographic distribution, residence (rural/urban), education, marital status, family (nuclear/joint), and family income.

## **RESULTS:**

The sample consisted of 49 inmate beggars from 'Beggars Home', Vadodara. Their Age ranged from 16 to 60 years (mean= 35.14, SD=11.02). Among forty- nine inmates, age of 11 beggars ranged from 16-25 years; 16 were from 26-35 years age group; 14 were from 36-45 years age group and remaining 8 were of more than 45 years of age. Their duration of begging in months ranged from zero to 48 months (mean=3.82, SD=1.13).

Of 49 beggars we studied, 41 beggars were male and only 8 were females. There was no significant association between, gender and presence of psychiatric illness. Twenty beggars were from urban locality whereas 29 were from rural locality. When asked about literacy level, 23 beggars did not answer anything; 1 beggar said he was illiterate; 15 beggars had studied up to primary education level and 10 had studied up to secondary education level. While replying about their marital status, 28 beggars said they were married and 21 said they were unmarried. Among 21 inmates with distress, 14 were unmarried ( $p=0.009$ ).

Seventeen beggars were begging for less than month duration. Thirty-one were begging by their own wish while forty-four attributed their begging to unemployment or financial crisis. Thirty-three were farmers or laborers earlier. Fifteen beggars reported guilt feeling related to begging, while 15 inmates denied having any guilt because of begging. Twenty-eight beggars wished to quit begging if given any opportunity to earn.

Of forty- nine inmates, 28 of the inmates were feeling happy in Beggar's Home. When inquired about earning, 17 beggars said that 'they earned just sufficient to have their two meals', while 32 beggars declined to reply. The income of these beggars varied in between zero to 9000 rupees (0 to100 pounds) per annum (mean=1706.12, SD=1973.1).

Thirty-five beggars reported addiction to one or other substances, mainly chewing or smoking tobacco (65 per cent) and alcohol (13.6 per cent). Association of act of begging and history of addiction of a substance was statistically significant ( $p=0.04$ ). Twenty beggars had some relative with history of substance abuse in their home; distress was present in eight among these 20 beggars. It was statistically significant that distress was present more in the beggars who had positive family history of substance abuse ( $p=0.017$ ). Two beggars had attempted suicide at least once in their lifetime. Four beggars had tried theft before and among them two had positive GHQ findings. Beggars who had tried theft before, had distress present in them ( $p=0.001$ ).

Twenty-three beggars came from joint family, 21 from nuclear family and 5 were separated from their family. Family members of 28 beggars were unaware of their begging. Forty-two beggars reported overall good attitude of family members towards them. Out of thirty-two beggars who answered very good or good family attitude, 10 had distress present in them. Nine out of twelve beggars who answered somewhat good, bad or very bad attitude of family members towards them, had distress present in them. When we studied association between psychiatric illness and family attitude, we found that there was significant association in between them. Seven beggars had someone with physical disability in their home; distress was present in 3 among these 7 beggars ( $p=0.05$ ). Ten beggars had one or other permanent physical disability; whereas 37 beggars did not have any permanent physical disability. Six beggars accepted having homosexuality.

When we applied DSM-IV criteria to find out any psychiatric illness in the beggars, we found 19 (38.8 percent) beggars among 49 were suffering from one or other psychiatric illness. Exact number of different illnesses present in beggars is described in TABLE-1. We observed significant association in positive family history of psychiatric illness and presence of psychiatric illness in beggars ( $p=0.04$ ). Distress was also present significantly in the beggars who were suffering from psychiatric illness ( $p=0.05$ ).

**TABLE-1: Psychiatric illnesses present among inmates.**

Psychiatric illnesses	No. Of beggars	% Of sample
Psychosis	11	22.4
Mental retardation	3	6.1
Adjustment disorder	2	4
Bipolar I mood disorder	1	2
Major depressive disorder	1	2
Dementia	1	2
Total	19	38.8

#### **DISCUSSION:**

We were unable to find any study done on beggars, especially the one that assesses psychiatric co-morbidity and distress among them. In our study we tried to find out any association present among socio-demographic variables and psychiatric co-morbidity; socio-demographic variables and distress; and psychiatric co-morbidity and distress. We found significant association between marital status and presence of distress in beggars, whereas association between marital status and presence of psychiatric illness in beggars was non-significant. Association of act of begging and history of addiction of a substance was statistically significant. It was statistically significant that distress was present more in the beggars who had positive family history of substance abuse ( $p=0.017$ ). Beggars, who had tried theft before, also had distress

present. Nine out of 12 beggars who answered somewhat good, bad or very bad attitude of family members towards them, had distress present in them ( $p=0.009$ ). When we studied association between psychiatric illness and family attitude, we found that there was significant association in between them ( $p=0.04$ ). Seven beggars had someone with physical disability in their home; distress was present in 3 of these 7 beggars ( $p=0.05$ ). We observed significant association in positive family history of psychiatric illness and presence of psychiatric illness in beggars ( $p=0.04$ ). Distress was also present significantly more in the beggars who were suffering from psychiatric illness ( $p=0.05$ ). Dean et al in 2000 also observed that 74 per cent of subjects had troubled family background.

The beggars with psychiatric illness had high prevalence of addiction, family history of psychiatric illness, poor attitude of family members towards them and high score of GHQ (TABLE-2). In our study, we found that 35 beggars reported addiction problem in other words 71% of the inmates agreed to have addiction of some kind (TABLE-3). The result were similar to the cross-sectional study done by Dean and Melrose in 2000, in which 68 per cent of subjects admitted current or past involvement with drugs and/or alcohol. In other comparative study done by Danczuk (2000), 45 per cent reported having addiction problem. In our study 13 per cent beggars admitted alcohol dependency, while in Fitzpatrick study in 2000, 33 per cent reported alcohol dependency. The high prevalence of psychiatric morbidity among beggars is not a startling revelation if we examine the findings in light of testimony given by Congressman Ted Strickland in front of 'House Judiciary Committee' on crime (Strickland, 2000). He said, 'deinstitutionalization movement' in which large number of mentally ill patients were released in society, was well intended. But it is not deinstitutionalization but trans-institutionalization because large number patients have shifted from mental hospital to jails, prisons and homeless shelters.

**TABLE-2**

<b>GHQ</b>	<b>DISORDER PRESENT</b>	<b>DISORDER ABSENT</b>
POSITIVE	13 (68.4)	12 (40)
NEGATIVE	6 (31.6)	18 (60)
<b>TOTAL</b>	<b>19</b>	<b>30</b>

**TABLE-3**

<b>ADDICTION</b>	<b>DISORDER PRESENT</b>	<b>DISORDER ABSENT</b>
SMOKING	7 (36.8)	15 (50)
TOBACCO CHEWING	7 (36.8)	14 (46.7)
ALCOHOL	3 (15.8)	6 (20)
OTHERS	0 (0)	0 (0)
D.N.A.	8 (42.1)	6 (20)
<b>TOTAL</b>	<b>19</b>	<b>30</b>

There was significant association between female sex and distress in inmates of Beggar Home, which might be because of the lack of privacy in beggar home. There was no female servant or caretaker in the Beggar home.

Majority of the inmates had started begging because of unemployment and financial crisis in the family. Sixty three percent had started begging by their own wish. Sixty Eight per cent of beggars felt badly about begging and also reported feeling of shame and a loss of pride and dignity. In one previous study done by Dean and others (2000), they found that 63 percent did not start begging out of choice. In one study, Simon Walk mentioned that only 6 per cent of beggars started begging because of homelessness.

This data suggests that it is necessary to facilitate de-addiction and other educational programs for beggar inmates. We found that occupational guidance and training would help beggars to regain confidence to earn bread. They required access to appropriate accommodation and work opportunities. Fitzpatrick (2000) also

recommended individualized, flexible support provided through key workers as one way of promoting a holistic approach at service delivery level. The most inmates also required help to overcome drug and alcohol misuse, social isolation, mental and physical health problems, and deep-seated low esteem. These needs can only be met in an integrated way through effective policy co-ordination at both national and local levels, with responsibilities accepted by all the key players and the necessary resources attached.

#### **SUGGESTIONS:**

- Criteria for admission to be reconsidered
- Periodic visit by a psychiatrist
- Adequate number of staff members to be recruited
- Awareness and education of staff members regarding psychiatric illnesses
- Vocational training for beggars.
- Female attendants and staff for the female inmates of beggar home.
- The policy of a deinstitutionalization and releasing mentally patients in society without making alternate arrangement needs rethinking.

#### **LIMITATIONS:**

Interpretation of the findings in this study is limited by the small size of the sample. Nevertheless, analysis reported in this article reached the standard accepted levels of statistical significance. This is a cross sectional study. It provided an idea about the condition of inmates of the Beggar Home. A prospective study is required to get more information about any improvement or worsening in the condition of the beggars till they stay in the Beggar Home. A prospective study can also help in the follow up of the beggars who had psychiatric illness or distress present at the time of our study. We have faced language problem while communicating with the beggars who could not understand Gujarati or Hindi. There was no relative or informant present while interviewing the beggars, so information given by the beggars could not be verified. The sample we studied was of inmates of the Beggar Home, so the results of this study cannot be generalized to the whole beggar community. We performed this study at Beggar Home in Vadodara city; the findings may differ if the same study is performed in the Beggar Home somewhere else.

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# The positive effects of religiousness on mental health in physically vulnerable populations: A review on recent empirical studies and related theories

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## Abstract

Since Freud and other famous mental health scholars have put forth their postulations concerning the neurotic influences of religion in mental health, many of the 20<sup>th</sup> century mental health professionals have been influenced to hold skeptical and even hostile attitudes toward religion. However, the past two decades have increasingly found more empirical evidence supporting the beneficial effects of religiousness on mental health that apparently contrasts with the postulations of Freud. Evidence in research was nonetheless mainly based on physically healthy populations. Studies addressing the relationship between religiousness and mental health in physically vulnerable populations, such as the aged, ill and disabled, have been insufficient. For this reason, this paper reviews recent empirical studies published in peer-reviewed academic journals concerning these relatively neglected populations. Consequently, although the number of studies concerning these vulnerable populations is less than research on the general healthy populations, well-conducted studies did point out the beneficial effects of religiousness on physically vulnerable people. Apparently, religion is an important aspect of life in these populations during the times of suffering and stress. Finally, relevant theories explicating the relationship are reviewed and some theoretical implications are also addressed.

**Keywords:** religiousness, mental health, physically vulnerable populations, theoretical implications

## Introduction

The relationship between religion and mental health has been debated for centuries. History shows that religious organizations were often the first to offer compassionate care to the vulnerable groups, including the medically ill, the elderly and the disabled. The first hospitals for patients with mental health problems established in the fourteenth century were church-sponsored and priest-managed (Alexander & Selesnick, 1966). Towards the end of the Middle Ages, religious scientists first suggested that biological mechanisms rather than supernatural powers were responsible for mental illness (Kroll, 1973). The idea and approach of moral treatment of individuals with mental health problems actually originated from the religious people. Benefited from this approach, individuals with mental health problems were treated much like normal persons (Taubes, 1998). Hence, religion had played a significant role in shaping the form of mental health care known as 'moral'.

However, the postulations of Freud and other mental health scholars concerning the neurotic influences of religion have had an enormous impact on the field of mental health in the 20<sup>th</sup> century. Freud had been skeptical, if not antagonistic toward religion. He suggested that the less religious people were more mentally healthy (Ellis, 1980, 1988). Wendell Watters, another well-known psychiatrist, also stated that religious beliefs were responsible for the development of low self-esteem, depression, and even schizophrenia (Watters, 1992). In fact, during much of the 20<sup>th</sup> century, mental health professionals tended to either deny the religious aspects of human life or consider religiousness as old-fashioned or pathological. They anticipated that religious issues would disappear as mankind matured and developed. Scientific and systematic research lending support to a positive relationship between religiousness and mental health emerged only in past twenty years.

Recently, ideas about the relationship between religiousness and mental health have changed dramatically. Obviously, a great multitude of psychological, psychiatric, medical, public health, sociological and epidemiological studies conducted during the past two decades proved the beneficial and protective effects of religious involvement (the term "religious involvement" will be used interchangeably with other terms such as "religious engagement" and "religiousness" in this review, and this will be elaborated in the part on method later in this paper) on people's mental and physical health as well as on their longevity. These studies also showed religion is an important aspect of human life. Evidence supporting these findings emerges from both cross-sectional and longitudinal studies, as well as from studies based on both clinical and community samples (George et al., 2002; Plante & Sherman, 2001). This empirical evidence apparently contrasts with the skeptical and hostile attitudes towards religion of Freud and earlier mental health scholars, which were largely formed and based on their negative experiences with religion and their encounters with the psychiatric patients (Meissner, 1984; Zilboorg, 1958; Koenig, 2001).

Over the past two decades, a lot of studies have uncovered a strong positive association between religiousness and mental health. This association has extended across various populations, including samples of the young, adults, older people, general community residents, immigrants and refugees, college students, the sick, addicts, homosexuals, persons of parenthood, individuals with mental health problems and personality disorders (Alvarado, et al., 1995; Baline & Croker, 1995; Braam et al., 2004; Chang et al, 1998; Donahue & Benson, 1995; Idler & Kasl, 1997; Jahangir et al., 1998; Kendler et al., 1996; Koenig, George & Titus, 2004; Levin & Taylor, 1998; Mickley et al., 1995; Miller et al., 1997; Pardini et al. 2001; Plante et al. 1995, 2001; Richards et al. 1997; Selway et al., 1998; Thearle et al., 1995; Woods et al, 1999).

Past research and reviews on the religiousness-health relationship tended to have focused more on the physically healthy populations, such as adolescents and youths, family members, college students and the

general public (Koenig & Larson, 2001; Gall & Grant, 2005; Mahoney, 2005; Marks, 2005; Regnerus, 2003). There is a lack of the review on this relationship among the physically vulnerable populations, such as the old, the ill, and the disabled. If religious involvement contributes to health outcomes among the healthy populations, would this effect be equally relevant to the physically vulnerable groups? As people become ill and physically vulnerable, they experience great stress as a result of the changes in life caused by adverse conditions they are undergoing. Research pointed out that many people who were not religious previously might turn to religion for comfort (Koenig, 2001; Koenig, & Larson, 2001). This often involves in beliefs in a living and caring God, private religious activities, reading religious scriptures for direction and encouragement, or looking for support from pastors or members of faith community. In fact, many studies commonly reported that religiousness was powerful resources of hope, meaning and purpose in life, comfort and solace. These protective and beneficial effects are particularly strong in people with illness and disability (Ehman et al., 1999; King, 2000; Koenig et al., 1998; Koenig et al., 2004; Mueller et al., 2001).

Due to the special meaning and importance of religion to the physically vulnerable populations, this literature review would focus on research studies investigating the relationship between religiousness and mental health among the vulnerable populations. They include people who are ill, aged, and people with disabilities. The review also addressed current theories that depict the relationship between religiousness and mental health. Finally, the implications of this review on therapeutic treatment and future research on the relationship between religiousness and mental health will be discussed.

## Method

The current review is not a meta-analysis, which is typically characterized by tables of positive and negative effect sizes. This article aims mainly to summarize the more representative studies investigating the relationship between religiousness and mental health among people who are ill, aged, and people who are disabled. Relevant studies were searched and collected through a number of databases, including the Social Sciences Citation Index, the Medline, the PsycInfo, and the PAIS International, using keywords like 'religion and mental health', 'religiousness and mental health', 'religiosity and religious effects'. After relevant research articles were identified, further efforts were made to scan through the references of these articles as a 'springboard' to locate other relevant research articles for the review. Among all the studies that were identified, those with standard quality and representation in terms of design, method and sampling were included in the review.

Although a substantial number of empirical studies addressing the association between religiousness and mental health were identified through the aforementioned databases, most of the studies did not fulfill the purpose for review. Studies which are excluded are those that do not fall into either the targeted populations (the ill, the aged and the disabled), those which do not treat religiousness as a predictor variable, or those which apparently do not control for confounders and other covariates. In addition, empirical research articles adopted for this review were defined as studies that included in their methods and findings with at least the application of one inferential or correlation statistics to investigate the association between religiousness and mental health. All identified articles must include one or more measures of religiousness or religion-related spirituality as predictors and one or more mental health measures as outcome variables. Among these, those which only used descriptive statistics, percentages or frequencies, or those which did not treat religiousness as a predictor variable were excluded. Consequently, not all pertinent studies would be addressed in this review for the reasons that they were either not highly relevant, or were to our knowledge questionable in design, or simply a result of our negligence of them. The final sample for this review consists of twenty-one empirical studies across the years from 1987 to 2006 (asterisks marked at the articles in the reference). The classification of these 21 articles is presented in Table 1.

Table 1: Summary of reviewed studies classification		
Category	Number of Studies	Reference Sources
The Old	7	Bienenfeld et al., (1997); Braam et al., (1997); Braam et al.(2004); Ellison, (1995); Idler, (1987); Nisbet et al., (2000); Seidlitz et al., (1995)
The Ill	9	Ai et al., (2002); Harrison, (2005); Koenig, (1998); Koenig, (2004); Koenig et al., (1998); Ma et al., (1998); Pargament et al., (2004); Rippentrop et al., (2005); Tarakeshwar et al., (2006)
The Disabled	5	Idler & Kasl, (1992); Idler & Kasl, (1997); Koenig et al., (1992); Reingdal (1996); Treloar, (2002)

Review refers to a broad range of religious engagement and involvement. Apparently, related research to date has rudimentarily focused on the seven dimensions of religious involvement. They are public religious participation (e.g. church attendance), religious affiliation (e.g. involvement in a religious organization/ denomination), private religious practices (e.g. prayer and reading religious materials), and religious coping

(turn to his/her religion/belief system for assistance), daily religion-related spiritual experiences (e.g. one's subjective perception of the transcendent in daily life), religious commitment (times and resources involved in religious activities and beliefs), and self-rated overall salience of religion (importance of religion in one's life)(George et al., 2002; Mueller et al., 2001). Religiousness is often delineated with reference to these dimensions. As such, religiousness may connote religious involvement in the context of this review. Interestingly, recent studies showed that these dimensions are apparently correlated (Francis, et al., 2004; Nooney, 2005). As for the term 'mental health', it refers to both the positive aspects of psychology, such as life satisfaction, optimism, sense of hopefulness, meaning and purpose of life, mental as well as emotional adaptiveness, and the negative aspects of psychology, such as depressive symptoms, anxiety, suicidal ideation and attempt, illness-related burden, psychological instability and emotional negativity.

This review had not taken a rigid that discerns religion-related spirituality from the scope of religious involvement. Taking this stance is thought to more appropriately tally with theoretical rationale and empirical findings in previous literature. In fact, many characteristics that are common to religiousness may also be found in spirituality (Jones, 2004; Idler, 2003). In addition, other social researchers espoused that a search for the sacred can be deemed as the common ground between religion and spirituality (Gall & Grant, 2005; Idler et al., 2003; Koenig et al., 2001; Muller et al., 2001). Hence, spirituality and religion have been often used interchangeably in prior research and less is known about spirituality outside the context of religion. It is apparent that at its core spirituality is related to all the value orientations, beliefs, actions and behaviors or activities by which adherents attempt to link their lives to God, the Divinity, or a higher power. More than that, religion is the outward substantiation of one's spiritual system of beliefs and values and is reckoned as the podium of expression of spirituality (Speck, 1988; Sloan, Bagiella & Powell, 1999). Essentially, the sacred core is what is central to both religious and spiritual experience (King, 2000; Koenig et al., 2004; Zinnbauer, 1999). Therefore, three empirical studies of the ill population included in this review consist of religion-related spirituality (Koenig et al, 2004; Pargament et al., 2004; Rppentrop et al., 2005). The spiritual measures used in these studies contain concrete and obvious religious elements. For instance, the subscale Daily Spiritual Experiences (DSE) of Brief Multidimensional Measure of Religiousness/ Spirituality (BMMRS) employed in the research by Rippentrop et al. (2005) to measure spirituality is comprised of certain religious elements, which mainly taps in one's perception and experience with the transcendent (God or the divinity).

## Findings

### The old

Recent research revealed that people become more religious when they are getting older. In comparison with young people, older people think that religion is more important for them, especially for those who are toward the end of life (Koenig et al., 2004; Moreira-Almeida, 2006). There exist different explanations as to why older persons are apparently more religious than younger people, such as for psychological compensation after retirement. Whichever explanations are more salient in depicting the relationship, religious involvement is obviously a critical factor for older people to cope better and have better social and psychological adjustments while facing the debilitating process of aging. Undoubtedly, there have been increasing empirical evidence in gerontological, medical, social psychological and psychiatric literature that support the positive effects of religiousness on mental health in the older population (Ayele et al., 1999; Braam et al., 2004; Strawbridge et al, 2001), especially the positive relationship between religiousness and depression in old ages.

Braam and his colleagues conducted two notable studies investigating the relationship between religious involvement and depression in the older population (Braam et al., 1997, 2004). One study confirmed the inverse association between the elderly religious involvement and depression (Braam et al., 1997).

Controlling for socio-demographics, physical impairment and social network of the elderly participants did not affect this inverse association. Besides, the researchers identified two subgroups of elderly whose religious involvement was of particular importance in attenuating their depression. They were aged people with small

social network and those with low sense of mastery.

Another recent and more salient longitudinal study of aged residents in Amsterdam by Braam et al. (2004) also reported an inverse relationship between religious involvement and depression. The findings reveal that religiousness, in terms of church attendance and religious importance, was inversely related to depression in a representative sample of 1840 community-dwelling older people. The relationship remained significant even after adjusting for physical health, self-perceptions, social integration, urbanization, and level of alcohol use. Over the 6-year period, depressive symptoms were significantly lower or reduced in frequency for those who attended church more frequently, compared to those elderly participants who had less church attendance or never attended church. Controlling for possible confounding variables did not change this relationship. For this, Braam et al. (2004) explained that :

***“Religion may offer a frame of reference toward questions of life, suffering and death, and may help to accept a decrease in physical functioning in light of religious and spiritual values (p. 485).”***

Similarly, the study by Ellison (1995) also found a negative relationship between church attendance and depressive symptoms measured by the Diagnostic Interview Schedule (DIS) in a sample of older Americans. The result was significant after controlling for the respondents' physical diseases and perceived illnesses. Likewise, the study by Idler (1987) pointed out a significant negative relationship between religiosity and levels of depression measured by the Center for Epidemiologic Studies Depression Scale in older women (CES-D), after adjusting a number of psychosocial factors and demographic characteristics, such as measures of intimate relationship, optimism and pessimism, physical health, and social contact. Moreover, although religious denomination was not an apparent and consistent predictor of the inverse relationship between religiousness and depression in the elderly (Idler & Kasl, 1992; Schnittker, 2001), people's perceived importance of religion was (Braam et al., 1997, 2004; Koenig et al., 1998). This result was consonant with other studies pointing that intrinsic religiousness was more powerfully predictive of depression and remission of depression after experiencing stress from critical life events, et al., 2002; Coryn & Benda, 2000; Koenig & Larson, 2001).

Bienenfeld et al. (1997) surveyed a group of retired Catholic sisters, examining the contributions of psychosocial factors and religiousness to life satisfaction, psychological distress, and depression. As a result, they found that sense of mastery, social support, physical functioning, and religious commitment were important factors contributing to life satisfaction in the older population. The finding supported that elderly religiousness was conducive to mediating the psychological impact of impaired functional status.

A number of studies pointed out that suicide ideation and attempt are more prevalent in the older population (Koenig, McCullough & Larson, 2001; Seidlitz et al., 1995). Religiousness is an important factor to prevent suicidal thought and ideation in older people. A study by Nisbet et al. (2000) using logistic regressions as a method of data analysis found that church attendance could reduce the likelihood of the elderly participants to commit suicide. In comparison, elderly people who did not engage in any religious activities at all were four times higher than those who took part in religious activities daily to commit suicide. The relationships did not alter even controlling for other confounding factors, such as socio demographic characteristics and social contact. Another study revealed that older people who viewed religiousness as salient in their lives were more likely to disagree with statements approving suicidal decisions and attitudes (Seidlitz et al., 1995). Their disagreement toward approval of suicide remained significant after controlling for participants' socio-demographic differences, self-rated health and contentment with interpersonal relationship by multivariate logistic regression analysis. The study concluded that religious salience in one's life was a concrete predictor of disapproval of suicide.

### **The ill**

Being ill, especially for those with severe and chronic illnesses, is a life-threatening experience that taxes on a

person's psychological and social resources and coping capacity. Religiousness could help a patient to withstand psychological, physical and social impacts resulted from these adverse experiences (Mueller et al., 2001; Pargament et al., 2004).

In a study by Koenig's et al. (1998), the researchers attempted to investigate the effect of religious belief and activity on remission of depression in medically ill hospitalized older patients. The depressed patients were followed up by telephone at 12-week intervals four times after hospital discharge. Consequently they found that religious variables were significant predictors of reducing depressive symptoms over time. More evidently, depressed patients with higher intrinsic religiosity scores had more rapid remissions from depression than patients with lower scores. Therefore, the researchers concluded that religiousness was a predictor of successful recovery from depression in the ill elderly.

In another research by Koenig (1998), 455 cognitively unimpaired patients admitted to the general medicine, cardiology and neurology services were studied. Information on their religious affiliation, religious attendance, private religious activities, intrinsic religiosity and religious coping was collected for purpose of investigating the prevalence of religious beliefs and practices among the medically ill hospitalized older persons and examining how these factors were related to social, psychological and health characteristics. The results showed that religious attendance was associated with less burden in medical illness and lower depressive symptoms in the patients. Moreover, the results in this study pointed out that religious practices, attitudes and coping behaviors were prevalent among hospitalized medically ill older adults and were significantly predictive of social, psychological and physical health outcomes.

Similarly, Ma et al. (1998) examined the effect of religious activity on depressive symptoms among community-dwelling elderly persons with cancer. In this two-wave longitudinal study, measures of religiousness in the form of service attendance, religious devotion, and watching or listening to religious programs were adopted. The findings indicated that religious activity was related to lower levels of depressive symptoms in participants with cancer. However, the effects of religious activity on alleviating depressive symptoms were stronger among Blacks than Whites in the study.

Recently, Ai et al. (2002) investigated the use of private prayer as a way of coping and the relationship between prayer and optimism among 246 patients waiting for cardiac surgery. The measure of prayer included three aspects in the study; they were 1) belief in the importance of private prayer, 2) faith in the efficacy of prayer on the basis of previous experiences, and 3) intention to use prayer to cope with the distress associated with surgery. Data on patients' religious and controlling variables were collected 2 weeks before the surgery, and those on optimism were measured the day before the surgery. The findings showed that private prayer was predictive of optimism in the cardiac surgery patients. The result did not alter even after controlling for age, socioeconomic resources, and healthier affect.

In a more recent study, Koenig (2004) surveyed 838 patients admitted to the general medical service wards. Various religious and spiritual measures were recorded. The measures of religiousness and religion-related spirituality included organizational religious activity (ORA), non-organizational religious activity, intrinsic religiosity (IR), self-rated religiousness, and observer-rated religiousness (ORR), observer-rated spirituality (ORS), and daily spiritual experiences. In this study, the self-rated and observer-rated social support, depressive symptoms, cognitive status, cooperativeness, and physical health among the patients were used as dependent variables. After analyses by regression models controlling for age, the results revealed that religiousness and spirituality consistently predicted greater social support, fewer depressive symptoms, better cognitive function, and greater cooperativeness in the patients. In addition, the association between religiousness and spirituality on the one hand, and physical health on the other, was weaker than the psychological one, although there existed between them a significant relationship. At the same time, patients who categorized themselves as neither spiritual nor religious had severer self-rated and observer-rated health

problems and greater medical co-morbidity. Conclusively, the findings showed that religious and spiritual involvement was prevalent in hospitalized patients, and they were apparently associated with greater social support, better psychological health, and to some extent, better physical health. Awareness of these relationships may improve health care.

Although there have been substantial efforts on examining relationship between religiousness and mental health outcomes in medically ill patients, there is comparatively lack of studies addressing the role of religiousness in those patients with chronic illnesses. Harrison (2005) recently conducted a study and found that patients with sickle cell disease (SCD) who were more religious demonstrated better quality of life. In this study, it has been shown that church attendance was significantly associated with measures of pain. The patient participants who attended church once or more weekly appeared to have the lowest scores on pain measures in comparison of those with less frequency of church attendance. This positive association remained significant after controlling for patients' age, gender and disease severity.

Another recent research took a group of 122 chronically ill patients suffering from musculoskeletal pain as study sample to investigate the relationship between religiousness and religion-related spirituality on the one hand, and physical and mental health on the other (Rippentrop et al., 2005). Hierarchical regression analyses revealed that there were apparently significant linkages between patients' religiousness and spirituality (measured by Brief Multidimensional Measure of Religion/Spirituality) and their mental health as well as physical health. In this study, religious coping, forgiveness, daily spiritual experiences, religious support and self-rated of religious/ spiritual intensity were significantly related to the mental health status of the patients.

It needs to point out that religiousness does not necessarily bring about positive mental health outcomes in patients. A two-year longitudinal study with a sample of 268 medically ill hospitalized elderly indicated that use of negative religious coping, such as viewing God or a higher power as punitive, would have hazardous effect on patients' psychological and physical health (Pargament et al., 2004). On the other hand, patients who adopted positive religious coping to deal with their illness, such as seeking spiritual support and religiously benevolent reappraisal of their situations, showed concrete improvements in mental and physical health two years later. The relationships between positive religious coping and better mental and physical health outcomes was significant after controlling for demographic characteristics, the baseline health measures, and selective attrition as well as mortality.

The number of research studies exploring how religiousness functions in patients with critically life-threatening illnesses is very limited. A recent study examined the effects of religious coping on quality of life in 170 patients with advanced cancer (Tarakeshwar, et al., 2006). After taking patients' socio-demographic variables, lifetime history of depression, sense of self-efficacy into account, it was found that positive religious coping was linked to better overall quality of life (QOL), and the existential and support dimensions of QOL. The use of negative religious coping was predictive of poor overall QOL, and its existential and psychological dimensions. The findings of this study are consonant with a review by Koenig et al. (2001), in which the authors reckoned that positive aspects of religiousness were substantially conducive to maintaining mental health in medically ill patients, especially among those with serious illnesses. In the review, the authors concluded that when people became medically ill, they might turn to rely on religious beliefs and practices to alleviate psychological instability, obtain sense of control and hope as well as life meaning, which were beneficial to their mental and physical adjustments and prevented them from being defeated by these negative health experiences.

### **The disabled**

Although there is a well-established literature on the positive relationship between religiousness and mental health, little is known about how people use religious beliefs and practices to establish meaning for and



respond to life with disability. Previous studies have put more emphasis on how the role of religiousness in alleviating emotional stress and enhancing the well-being among caregivers of disabled persons rather than to investigate the role of religiousness in influencing mental health of the disabled themselves. Most of these studies revealed that negative psychology was common among caregivers of disabled persons, and religious involvement was important and useful in reducing their emotional negativity and promoting their perceived well-being (Chang, Noonan, & Tennstedt, 1998; Zunzunequi et al., 1999). However, little is known about whether religious involvement would contribute to better adjustments and well-being among those who are religious but are with disability.

A 12-year longitudinal study found that engagement in religious services was a strong predictor of better physical functioning among a large, prospective and representative sample of elderly residents in New Haven (Idler & Kasl, 1997). This positive association was still significantly evident even when taking confounding variables of health practices, social ties and perceived well-being into account in the analysis. In the study, the researchers reckoned that religious involvement had particular significance for well-being and health of elderly people with disability. Another longitudinal study of Idler and Kasl (1992) showed that public religious involvement was a protective factor against disability among elderly men and women, and private religious involvement was a beneficial and protective factor for recently disabled men to fend off depression resulted in their functional disability.

Another 3-year prospective study conducted by Ringdal (1996) found that higher levels religiousness measured by the importance attached to religion, and the use of religious coping were related to higher life satisfaction and sense of hope in a sample of 253 patients who had been seriously disabled by suffering from cancer. The researcher employed multiple regression analyses to control covariates and evidenced that religiousness might be important in maintaining mental health among the seriously disabled patients who were suffering from life-threatening illnesses.

In addition, Koenig et al. (1992) examined the beneficial effects of religiousness on depression in 850 older patients with disability and other chronic health problems. The results indicated that religious coping was significantly and inversely related to depressive symptoms in the sample even after controlling for a set of confounding variables. More notably, the interaction term between the extent of disability and religious coping was significant, which denoted the negative association between religiousness and depression was strongest for patient participants who were with more serious disability.

Furthermore, there has been limited number of explorative qualitative research available for investigating how disabled individuals employed their religious faith to cope with challenges and difficulties they encountered. One research conducted by Treloar (2002) reported that religiousness stabilized the lives of the disabled, providing meaning for the experience of disability, assistance with coping and bolstering other benefits to the participants with physical disabilities. In addition, the participants reported that increased assistance by the church in promoting theological understanding of disability and religious support in using a continuing model of caring were important in keeping them feel mentally healthy. Although this kind of qualitative studies are disadvantageous in their generalizeability, they could provide insightful implications for mental health professionals in the issues of holistic care.

## Theoretical Implications and Conclusion

This review aims to draw studies that are more representative, typical, and sound in design and method for an overview of the beneficial effects of religiousness on mental health in certain physically vulnerable populations. As a result of their efforts in the past two decades, social scientists have gradually come a consistent view on the positive relationship between religiousness and mental health. Koenig et al. (2001) have recently completed a systematic review of studies on religion and mental health in their *Hand Book of Religion and Health*. They identified 850 relevant studies conducted in the 20<sup>th</sup> century addressing the

relationship between religious involvement and mental health. Although they used a broad term to define mental health and well-being, which include psychologically perceived well-being, life satisfaction, hope, optimism, purpose and meaning in life, depression, anxiety, and suicidal ideation, most of the studies reported the positive role of religious involvement in maintaining mental health. For example, about two-thirds of the 93 observational studies examining the relationship between religiousness and depression identified by the authors revealed that the more religious individuals had lower levels of depressive symptoms. Of another 22 prospective cohort studies that had identified and examined this relationship, 15 studies found that religiousness was significantly and inversely related to depression. Besides, five out of the 8 identified clinical trials reported that religious intervention hastened the recovery processes in depressed participants compared with those who only received secular intervention methods.

Among the 850 studies identified by Koenig et al. (2001), one hundred investigated the association between religiousness and perceived well-being. Seven-nine of these 100 studies reported that religiousness was significantly related to higher life satisfaction, more positive affect, and greater happiness. Among these studies, 12 belonged to prospective cohort studies, 10 out of these 12 studies found a positive relationship between religiousness and well-being. Moreover, the association of these two dimensions was reported to be stronger than the relationship between well-being and other psychosocial factors, such as social support and marital satisfaction. The rest of the identified studies that did not find a significantly positive association between religiousness and mental health are apparently underrepresented in number compared to those with a positive relationship. In addition, these studies either reported a mixed relationship, or found no relationship, or demonstrated a negative relationship between the two dimensions. However, most of these studies were documented as with substandard quality in design, measurement, method and lack of control for covariates (Koenig, 2001).

Empirical evidence on the relationship between religiousness and mental health is very concrete in current literature. However, there is still much room for further research about this relationship in certain vulnerable social groups, such as the ill, the disabled and the aged. In fact, over the past two decades, although there have emerged a large number of research supporting the relationship between religious involvement and mental health, relevant theories to elucidate this relationship are still in its tentative and developmental stage (George, et al., 2002; Jones, 2004). A more noticeable theoretical explanation proposed by Smith (2003) suggested that the beneficial effects of religious involvement on health outcomes were through nine distinct factors that are clustered under three dimensions of social influence. The first dimension is Moral Order, which consists of the factors of moral directives, spiritual experiences and role models. The second dimension is Learned Competencies; it includes the factors of community and leadership skills, coping skills, and cultural capital. The last dimension called Social and Organizational Ties consists of the factors of social capital, network closure and extra-community skills. Although originally developed for elucidating the relationship between religiousness and health outcomes in children and youths, most of the theoretical contents could be adopted as a paradigm to delineate the relationship between religiousness and mental health in various populations.

According to Smith (2003), moral order provides people's normative ideas about what is good and bad, right and wrong, worthy and unworthy, just and unjust and the like, which are beyond an individual's own desires and standards, and could be conducive to the developments of oneself and the society as a whole. Learned competencies may enhance people's social skills and knowledge, which are in turn contributory to their overall well-being and life chances. For the dimension of social and organizational ties, religious people could meet many other members in their religious communities who care about and give guidance to them. This constructive relational network would be helpful for human growth and developments in long run. Obviously, Smith puts more emphasis on the socialization process of religious involvement.

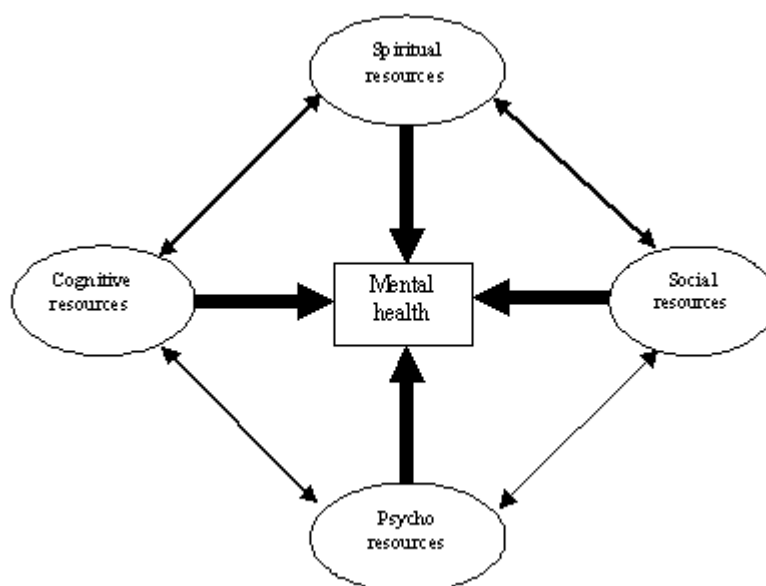
On the other hand, George et al. (2002) also suggested the thesis of the health-promoting effects of religiousness. They proposed four psychosocial mechanisms through which religious involvement could

promote positive health outcomes. These mechanisms are health practice, social support, psychological resources (e.g. self-esteem and self-efficacy), and belief structure (sense of coherence). Their conclusion on these four psychosocial mechanisms was based on the findings of prior relevant studies, and regarded religiousness that might facilitate and enhance these four mechanisms. Apparently they regarded these four mechanisms could act as robust mediators to influence a variety of health and behavioral outcomes.

Similarly, Jones (2004) also proposed a set of mediators through which religiousness could enhance mental and physical outcomes. They are the increase in 'relaxation response' to stress, decrease in unhealthy behaviors, increase in social support, more compliance with physician's treatment, a sense of coherence, more positive self-concept (e.g. higher self-esteem and less anxiety), and the positive interaction between mental and physical well-being (a potentiating interaction effect). However, Jones (2004) did not regard all religious positive effects consisted in the attainment of good health outcomes through these mediators. He considered that religion must have unique contributions to human well-being, which is beyond the explanation of aforementioned ordinary/ secular mediating channels. Hence, he corresponded his theoretical work to many recent prospective studies (e.g. Mahoney et al., 1999; McCullough et al., 2000), many of which, after controlling for most of these mentioned secular mediators, the relationship between religiousness and health outcomes was still significant. Conclusively, Jones (2004) deemed that there must be some unique religious effects that were beyond the recognized social-psychological factors and could not be accounted by secular mediators. These unique religious effects might be thought as something peculiar to religion only, such as ultimate concern, eternal life after death, spiritual character and significance, spiritual support, religious coping and the like. They were regarded as unique psychological-spiritual contents.

It is possible to accept that religious involvement may exert its positive effects through both the psychosocial and unique psychological-spiritual processes (Jones, 2004). Hence, it is not strange that secular models cannot totally account for the variance of religious effects on health outcomes, especially for mental health. So, it is why we find that certain social groups who are apparently under deprived, distressful and undesirable circumstances could still keep mentally healthy. For the purpose of explaining this association based on the theoretical implications mentioned above, a diagram depicting the mediational channels through which religious involvement exerts its positive effects on promoting mental health is presented in Figure 1.

**Figure 1 : Mediational channels of the positive effects of religious involvement on mental health**



Religiousness can promote various resources, including spiritual, cognitive, psychological and social resources. Not only do these resources have unique positive effects on mental health, they also interact and mutually reinforce each other. Spiritual resources could be something particular to religious involvement. They may be hope, ultimate concern, eternal life after death, spiritual support, and assistance and solace from an omnipotent and caring God. These spiritual resources could be helpful and beneficial enough to change one's worldview and cognition from an apathetic, competitive and meaningless worldview to a world with hope, warmth, and meaningfulness.

To see the world and lives in it as hopeful, optimistic and warm and meaningful can become people's cognitive resources, which may be helpful in keeping them mentally healthy when encountering stressful and critical life events. Such a worldview confers religious people a sense that the world they are living in it is desirable, warm and friendly, and life is meaningful. Hence, when problems and difficulties in life come up; they may see these adverse encounters as solvable and surmountable through assistances from an omnipotent and caring God. For people with a religion, they tend to regard God's help, grace and blessing, and mercy, as well as unfailing love may be powerful enough for them to withstand any adversities in lives they face. Taken together, these cognitive resources may cause them to have greater self-confidence, internal locus of control, positive affect and better self-image while facing and undergoing stressful life events. Research show that positive individual traits may assist people to foster the development of more extensive and supportive social network and relationships (Brissette et al., 2002; Lakey, 1989), which are conducive to buffer against stress resulted from adversities. Therefore, more social resources, such as greater supportive social network derived from one's faith and beliefs, will further enhance people's religious involvement and in turn reinforce their spiritual resources. It is because people having greater sense of belonging and having close relationships in the faith community they belong to will be more willing to conform and follow the religious values, norms, teachings and traditions, which may in turn further intensify and magnify their reliance and beliefs in the God/ a higher power.

However, such an interdependent and mutual reinforcement process among the respective resource dimensions (from spiritual resources to social resources through cognitive and psychological resources) may not necessarily emerge and proceed in a counter-clockwise direction. It could also be clockwise. For example, through engaging in a faith community and beginning to profess and pursue a set of religious beliefs, not only people will increase their spiritual resources, such as the concepts and notions of ultimate concern, God's omnipotence and grace and delivery, eternal life after death. They will also augment their supportive social network and relationships simultaneously through their contact and interaction with other adherents with the same beliefs. Having a more cohesive and supportive social network and interpersonal relations derived from their religious involvement and spiritual resources will in turn enhance their psychological and cognitive resources because a cohesive and supportive social network will strongly socialize an individual to have similar psychological and cognitive characteristics (Hewitt, 1991; Peterson & Hughey, 2004). Therefore, people will learn to be more confident, optimistic and hopeful, and see the world less apathetic and more joyful, even when life stressors emerge. This explains why the mutual reinforcement process of the respective religious resource dimensions that need not be unidimensional/ one-dimensional, or either clockwise or counter-clockwise, but could be in an interdependently and mutually reinforced nature.

Through this review and analysis of the related literature, it is hoped to illustrate that religious involvement would result in a set of religious resources, such as spiritual, cognitive, psychological and social resources, which will mutually interact and reinforce one another through the 'chain reaction'. Through this process of mutual interaction and reinforcement, religiousness is considered hypothetically to contribute to mental health in believers. Though these theoretical explanations are at best hypothesis to be tested at the present stage, something more concrete is that most religious resources are thought to be beneficial in human mental health. Nevertheless, there is much room for researchers to conduct research to find out a clearer picture about

mediational mechanisms linking the relationship between religious involvement and mental relationship. Theoretical concepts suggested in this paper may be or may not be one of the mediational relationships between religiousness and mental health.

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# Discontinuation of an Integrated Treatment for Schizophrenia Disorders: One-Year Outcome

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## Abstract

Introduction: Retrospective and prospective studies reveal that the course of schizophrenia is not a uniform process, and may be altered by or benefit from integrated and continuous treatments. Objective: To study the impact of discontinuing an integrated treatment conducted in a non-experimental setting. Method: In order to show

that the person who have schizophrenia condition has improved or worsened, clinical, social and family evaluations were conducted at three points in time: at the start of the intervention, on post-treatment and after one year. The intervention was applied to people with less than five years on schizophrenic disorder (DSM IV) and their families. Results: On post-treatment both psychotic symptoms and degree of disability and family stress level changed favorably with differing averages as compared to the start of 1,50 ( $p=0.006$ ), 1,07 ( $p=0.046$ ) and 1,43 ( $p=0.000$ ) respectively. A year after the intervention ended, all the main results had worsened, although none of the outcomes reached the mean scores of the starting point. Discussion: Unfortunately the lack of continuity of the treatment programme has led not only to the loss of benefits therefore preventing better levels of recovery, but it is also possible that it has produced a iatrogenic effect by increasing risk situations as interrupting anti-psychotic medication, substance misuse and dropping out of the out-clinic regime. Conclusions: Until Institutional commitment adopted and implemented mental health policies capable of creating organizational and financial initiatives, it would be recommended to include reminder sessions as well as the organisation of support groups within the study design itself.

**Key Words:** Integrated Treatment, Family Intervention, Recovery, Schizophrenia

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## Introduction

For many clinicians and researchers schizophrenia is still regarded as a chronic illness with persistent, recurrent and debilitating symptoms with no expectations of sustained remission or functional recovery. However both retrospective and prospective studies reveal that the course of schizophrenia is not a uniform process, and may be altered by or benefit from integrated and continuous treatments. An increasing amount of empirical studies informed that recovery from schizophrenia is possible under two conditions: at onset, with an integrated approach and rational use of medication and in those cases of greater severity or with frequent relapses, using treatments that combine biological, psychological and social strategies, applied continuously in the form of coordinated services (Lenrort et al, 2003).

One of the most significant areas over the past decades for the treatment of schizophrenic psychosis has been intervention in the family setting. Almost thirty controlled studies have revealed that family psycho-educational methods enhance relatives' capacity to cope with problems and improve family atmosphere, reduce the risk of relapse (Pharoah & Steiner, 2003) and hospital readmission, increase therapeutic compliance and reduce relatives' burden (Sellwood et al, 2003). The findings in this field generally suggest that relatives who support a person with schizophrenia with reasonable expectations for their improvement and with aids focused on achieving gradual progress may be a critical factor in the long-term outcome (Falloon I, 2004).

Experience gained in recent years indicates that beneficial effects are greater in initial episodes and in those cases of most recent onset (Mausser et al, 2001). Despite initial treatment is usually intensive a fall in the overall economic cost of care has been observed (Chisholm et al, 2005).

A study of initial episodes shows that integrated treatment not only proved to be effective, but was also more beneficial for patients than standard treatment, with significant clinical implications (Petersen et al 2007). Following decades of research the time has come to put these interventions into practice (Torrey, et al 2001). However the transfer of beneficial effects detected in experimental studies to clinical practice is a challenge for the mental health services. Not only is there a need for a sufficient number of appropriately well trained professionals but also continuity of care delivery. Both aspects are the foundations on which to base the effectiveness of any scientifically compared psychosocial intervention (Tormicroft & Susser, 2001).

To the best of our knowledge there is no information available regarding the outcomes arising from the discontinuation of an effective integrated treatment. This is particularly significant when the majority

of programmes and studies published in the literature have been conducted within the framework of a research project. At the end of the study the experience gained has not been incorporated into the routine practice of mental health services.

The implementation of an integrated treatment for people with schizophrenia and their families was unexpectedly discontinued due to lack of institutional support. This provided an opportunity to study the impact on the clinical and social state of the patient and his or her support group.

## Material and Method

It is a simple follow-up study of people with schizophrenia and their families who received integrated treatment in the clinical practice setting. The study design makes it possible to show the clinical and social benefits linked to therapy intervention outside the experimental setting as well as effects linked to the interruption of the treatment twelve months later.

The intervention was offered to people diagnosed with schizophrenia (DSM IV R) attended by the mental health team from a mental health center in Valencia (Spain). A minimum duration of 2 yrs of intervention was estimated and was geared towards patients with a history of the illness of no more than 5 yrs who presented psychotic relapse or a first episode in the past 12 months. All participants understood what the procedure involved and gave their informed consent.

No other selection procedure was applied, neither depending on level of family Expressed Emotion (EE), severity of symptoms or ethnicity, except for insufficient language skills for following the sessions. The subjects were able to drop-out in the event of side effects, if it was considered to be in his/her best interests or if he/she decided not to continue.

## Therapy Intervention

The main objective of the integrated treatment was to reduce deficiencies and incapacities as much as possible and achieving the best recovery level. It follows community psychiatric care guidelines, provides integrated care involving therapy shown to be effective with scientific evidence, is delivered by a multi-disciplinary team, guarantees the continuity of treatment, focuses on the person and their relatives' needs, offers carers a well defined role and is of a flexible and ambulatory nature (Table1).

Table 1.- Strategies Applied

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| <ul style="list-style-type: none"><li>▪ Training in the development of strategies to<ul style="list-style-type: none"><li>○ Increase compliance and adherence with maintenance regime</li><li>○ Minimization and prevention of side effects</li></ul></li><li>▪ Information and education on schizophrenia and its management</li><li>▪ Regulation of emotional interaction<ul style="list-style-type: none"><li>○ Promote communication and listening</li></ul></li><li>▪ Training in management of stressful situations<ul style="list-style-type: none"><li>○ Training in RP aimed at reducing adverse family atmosphere</li></ul></li><li>▪ Training in everyday life skills</li><li>▪ Early detection and crisis interventions</li></ul> |
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The intervention was conducted by a team of specifically trained professionals in each of the therapeutic strategies to be implemented, followed by supervised sessions. The therapeutic sessions, each lasting one hour, were held in the patient's home, initially on a weekly basis and subsequently

less frequent.

All patients and their families were informed that the intervention was to be discontinued and spent the final session reviewing achievements, constructive changes and work carried out and preparing for treatment to be continued in a different context. Likewise, the families were put into contact with the local Family Association. (AFEM)

### Assessment

In order to present recovery patterns or otherwise, a series of clinical, social and family evaluations were carried out as well as use of resources at three different points in time: at the start of the intervention, at the end and one year later.

The instruments used are based on those previously employed in the international multi-centre project with the object of making results easier to compare. (Falloon et al, 2004)<sup>10</sup>

Clinical state was appraised using the Mental Functions Impairment Scale MFIS (Guy W) This measure focuses on evaluating the amount of daily time that psychotic symptoms are present, independent of the degree of disability and level of distress that psychotic experiences may produce. The Disability Index, ID (Roser & Kind) was applied to assess the overall degree of disability and social maladjustment. In order to assess level of family perceived stress, a semi-structured scale was used Carer's Stress Scale (Falloon). Relapses were defined according to clinical criteria: "significant increase in psychotic symptoms requiring greater clinical measures for their control" and readmissions as the "number of hospital admissions associated with mental disorders".

The information was extracted by two evaluators independent of the treatment team with clinical experience and prior training in the administration and measurement of the different instruments.

### Statistical Analysis

Multiple and repeated measurements were used for comparing changes in the clinical, social and family stress outcomes, at the three evaluation points (0= pre-treatment, 1= post-treatment, 2= follow-up). This analysis of these differences was carried out with the Student t for related samples and variance analysis (Anova) for multiple comparisons.

## Results

A total of 15 patients (10 men and 5 women) and their families took part in the programme until it was discontinued. Average age was 23.47 (ds 2.85) and except for one patient who was separated, the rest were single and all lived with their family, with the majority (66.7%) unemployed. The age of onset of first symptoms was 21 years with a range of 19 to 28 and the average history of illness was 2 years (range 1 to 4 years) and almost half (46.6%) had previously been hospitalised.

In the initial evaluation all people who have schizophrenia showed productive psychotic symptoms, with severity and intensity index placed at 3.13 (ds 1.4). Likewise disability index was 2.72 (ds 0.79), indicating a moderate level of disability. Stress level reported by relatives was between moderate and high, reaching average scores of (2.47 ds 0.74).

As the entrance to the programme was dynamic the number of sessions differs between cases, ranging from 24 sessions in those who joined the programme early on, to just six sessions in the last case to join.

One patient decided to drop-out of the intervention after the first three sessions, stating that no improvement had been noted, leaving a final sample of 14 cases.

At the point of discontinuation all indices analyzed had improved as compared to the start. No relapses or worsening of psychosis and only one hospital admission took place, a decision taken in agreement with the patient in order to undergo treatment for cocaine-addiction. During the intervention process no adverse effect was detected that could be linked to the intervention itself.

A year after discontinuation, all the main results had worsened, although none of the outcomes reached the mean scores of the starting point of the 14 patients followed up. Five people (35.7%) relapsed after discontinuation of the intervention with one requiring hospital admission. A metabolic syndrome was detected in one case, there was an increase of substance misuse, 42.8% of the cases dropped out of anti-psychotic maintenance treatment and 28.5% of the ambulatory regime. (Table 2)

**Table 2. Means and percentages of clinical, discapacity and family stress scores at three points in time.**

	Pre-intervent (n=15)	Post-intervent (n=14)	Follow-up (n=14)
Clinical index ( means,ds)	3,13 (1,41)	1.57 (1.519)	2.93 (2,13)
Discapacity index (means,ds)	2,73 (0.79)	1,64 (1,49)	2,43(1.45)
Family stress(means,ds)	2,47 (6,60)	0,93 (1,07)	1,57 (1,28)
Relapses (n, %)	---	0 (0%)	5 (35,7%)
Hospital admissions (n,%)	6 (40,6)	1 (6,6)	4 (28,6)
Non-adherence to medication (n,%)	1 (6,60)	0 (0)	6 (42,8)
Substance misuse (n,%)	2 (13,3)	1 (7,14)	3 (21,4)

Table 3 shows the analysis' results of changes in clinical status, discapacity and family stress at the three points in time, where a clearly negative impact in the three results can be observed. By comparing the differences in changes between follow-up, that is a year after discontinuation of the intervention, with those detected at the start of the treatment scores are similar to those detected at the start. One exception was family stress level that fell significantly during the intervention, increased after the end of the intervention, and subsequently fell again ( $t=2.065$ ,  $p=0.059$ ).

**Table 3. Results of the analysis of the differences in changes brought about at three points of evaluation**

		Mean	sd	CI 95 %	t	Follow-up
Clinical Severity	Pret-post	1.50	1.69	(0.52 - 2.48)	3.30	0.006
	Post-follow	-1.38	1.86	(-2.43)-(-0.28)	-2.73	0.017
	Pre-follow	0.14	2.53	(-1.32)-(1.61)	0.21	0.836

Discapacity	Pret-post	1.07	1.82	(0.02 - 2.12)	2.21	0.046
	Post-follow	-0.78	1.53	(-1.66)-(0.09)	0.69	0.077
	Pre-follow	2.86	1.54	(-0.64)-(1.17)	-1.17	0.500
Family stress	Pret-post	1.43	1.02	(0.84 - 2.01)	5.26	0.000
	Post-follow	-0.64	1.45	(-1.47)-(0.19)	-1.66	0.120
	Pre-follow	0.79	1.42	(-0.04)-(1.61)	2.06	0.059

Pre-post= start - time of discontinuation

Post-follow= discontinuation - one year later

Pre-follow= start - one year after discontinuation

No correlation has been observed between the number of sessions and the therapy response on ending the intervention nor in follow-up, which could be explained by the small size of the sample along with lower frequency of the sessions. However, unlike the case of anti-psychotics and anti-depressants, where both therapeutic responses as well as side effects are related to dose, the dose-response relationship of psychosocial interventions is less well known

## Discussion

As in all naturalistic studies the greatest shortcoming is being able to attribute the changes to the effect of the treatment or in this case to its unexpected discontinuation. However, the inclusion of a control group would currently pose problems of an ethical nature and the possibility of including a control group consisting of a waiting list would imply logistical problems regarding duration of the project. Concerning the use of equivalent historic cohorts there are too many uncontrolled variables to be able to establish valid comparisons.

Despite the small number of cases where significant differences were not detected in some analyses, the results in general point in the same direction: loss of benefits gained during the integrated treatment as compared to the year following discontinuation of the programme. The levels of clinical and social deterioration reached were very similar to those detected at the start of the intervention.

Family stress shows a tendency to fall rapidly after the first sessions increasing after discontinuation but with lower scores than before starting the intervention. It is possible that information received and the feeling of being supported are capable of reducing stress level faced with the information received and the feeling of being supported. But all this appears to indicate that this is a slow process, time must be allowed for mourning to take place, there is a greater understanding of the illness and the resources for handling it. As in other psychotherapy approaches, the most definitive changes take place with time (Montero et al, 2006). However, we cannot lay aside the possible support provided by the Family Association

As the general trend is to not publish negative results so we are prevented from comparing our data with other similar studies. So, to estimate the significance that discontinuation has represented both for the person who have schizophrenia as well as for their families, we have compared our results with a prior study with integrated treatment applied continuously over a two-year period (Falloon et al 2004). By applying the same therapy strategies as well as identical measuring instruments a more orientate comparison can be made, despite the different study sample characteristics. In fact, the majority of cases in the international multi-centre study (OTP) had a long history of illness, as opposed to our study sample. This factor could explain the differences in initial scores between both studies.

In the OTP study the mean clinical index was 3.57 (sd 1.57) at the start, falling to 2.12 (sd 1.46) after two years, whereas in our case this fell from an average of 3.13 (sd 1.41) to 1.57 (sd 1.51). The improvement noted by the disability index was greater in the OTP study: from 3.16 (sd 1.32) to 1.94 (sd 1.25) vs 2.73 (sd 0.79) to 1.64 (sd 1.49). On the other hand, reduction of family stress was somewhat greater in the present study than in the OTP: 2.47 (sd 0.74) to 0.93 (sd 1.07) vs. OTP: 2.29 (sd 1.34) to 1.09 (sd 1.14)

The improvement detected up until the intervention was discontinued, obtaining in some results greater benefits than in the comparative study, strengthens the idea that this type of approach is more effective during the first years of illness. Likewise it reports on the quality with which the therapy strategies have been applied in this study, increasing its validity.

Unfortunately the discontinuation of the treatment programme has led not only to the loss of benefits therefore preventing better levels of recovery, but it is also possible that it has produced a iatrogenic effect by increasing risk situations. Such situations include: interrupting anti-psychotic medication, substance misuse and dropping out of the mental health services, although the absence of a control group prevents this outcome from being confirmed.

Unlike other studies that claim further studies with larger samples in order to validate the results, our recommendation is to include reminder sessions as well as the organisation of support groups within the study design itself. Just as antipsychotic medication can have a prophylactic effect when administered, psychosocial treatments must also be provided over extended periods of time and be accompanied by reminder sessions to sustain the therapeutically and rehabilitating benefits (Kopelowicz & Liberman, 2003).

#### Conclusions

The importance of combining psychosocial and pharmacological interventions in the treatment of schizophrenia is currently acknowledged. The factors that influence recovery are mainly vulnerable to change by means of treatment, which may often lead to sustained remission of the symptoms and to normal or almost normal performance levels.

All patients are entitled to receive the best treatment available. Our study shows that it is not enough for the evidence to be acknowledged by professionals and interpreted as relevant and methodologically reliable. According to Goldman (Goldman et al, 2001) it is also required from institutional commitment to the adoption and implementation of mental health policies capable of creating organizational and financial initiatives.

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# Investigating the Assistive Technology Skill and Need for Knowledge of CPRPs

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## Abstract

Certified psychiatric rehabilitation practitioners (CPRP's) work with people who have psychiatric disabilities to help them achieve their maximum functional potential. Assistive technologies are "products that enable persons to perform a function that would otherwise be difficult due to some disability." Although there are many benefits to using assistive technology (AT), there are also many barriers preventing its use such as lack of knowledge. Without knowledge of AT, CPRPs may limit their client's ability to access AT. This study investigates the AT-related knowledge and skill that CPRPs have and need. The findings have implications for developing educational programs.

**Keywords:** Psychiatric Rehabilitation practitioners, assistive technology

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## Introduction

Certified psychiatric rehabilitation practitioners (CPRPs) are clinicians whose goal is to “enable individuals to compensate for the functional deficits, interpersonal barriers and environmental barriers created by the disability and to restore ability for independent living, socialization and effective life management” (Hughes, 2003). These practitioners work in a variety of settings such as hospitals, institutions, and mental health clinics, and work with a variety of people who have coexisting psychiatric disabilities, substance abuse and physical and social difficulties (USPRA) (formerly International Association of Psychosocial Rehabilitation Services (IAPSRS), 1997). Individuals with psychiatric disabilities may benefit from the use of assistive technology (AT) because these tools can help an individual compensate for problems with memory, sequencing, time management and organization among other things.

Assistive technology has been described as “products that enable persons to perform a function that would otherwise be difficult due to some disability.” (US Dept of Commerce, 2005, pg 6). AT provided through computers, video cameras, e-mail reminders, and telephone can improve the performance for individuals of all ages with a psychiatric disability (NAMI, 2005). Other AT devices that may be useful for people with psychiatric disabilities include cuing devices, speech output devices, medication aides and safety devices such as GPS locator systems and anti-scalding devices (LoPresti, Mihailidis, & Kirsch, 2004; Cook and Hussey, 2002; Souma, Rickerson, & Burgstahler, 2001).

Although there are many benefits to using assistive technology, there are also many barriers impeding its use, such as funding, availability, quality of the device and lack of knowledge by health care and other service providers (Scherer, 2005; Edyburn 2004, Laki T, 2002). Without knowledge of AT, CPRPs similar to other healthcare and service providers are more than likely limiting their client’s ability to access devices that could enhance their participation in meaningful activities and roles.

A study by Gitlow and Sanford (2003) investigated the knowledge and skills regarding AT by healthcare professionals such as physicians, nurses, psychologists, physical therapists (PT), occupational therapists (OT), and speech language pathologists. The study found that these practitioners did not have the knowledge and skill necessary to adequately provide AT related services to their clients. Based on these findings and others reported in the literature, (PL 108-364, 2004; Healthy People 2010, 2000), we suspect a similar lack of knowledge regarding AT among CPRP’s. Therefore, the hypothesis of this study is CPRPs have a low level of knowledge and skill regarding AT.

## Review of the Literature

More than 45 million people in the United States have psychiatric disabilities that interfere with their ability to engage in day to day activities including going to school, working or daily living tasks (Jans, Stoddard and Kraus, 2004). The literature reports the “employment rate for people with a mental illness is much lower than the national employment rate and is especially low for people with more serious disorders” (Jans, Stoddard and Kraus, 2004, Section 2). The use of assistive technology and other accommodations in the workplace, such as flexible leave policies; computer support, adjusting work schedules, restructuring jobs, and modifying the environment can accommodate those with a psychiatric disability (Butterfield & Ramseur, 2004).

Lower employment rates for people with psychiatric disabilities are also an international problem. For example, statistics provided by Crosse (2003) shows that 85% of those with psychiatric disabilities, such as schizophrenia, rely on welfare benefits, 72% do not have regular occupations, and 45% live in institutions, hostels, supported housing, crisis shelters, or are homeless. An American health interview survey provided by Healthy People 2010 states the use of assistive technology can aid an individual to become self sufficient, and enable someone with a disability to work, attend school, and participate in community life (Healthy People 2010, 2000).

People who have psychiatric disabilities also frequently experience cognitive disabilities. Of people with schizophrenia, 85% have a cognitive disability (Medalia & Ravheim, 2002). Cognitive disabilities can include difficulty in thinking clearly, paying attention, sequencing and memory. Verbal reasoning, problem solving skills, orientation, perceptual and analytic abilities, social reasoning and executive barriers are also difficult for those with psychiatric and/or cognitive disabilities (Medalia & Ravheim, 2002, Levine et al., 1992). Assistive technology improves the day-to-day performance of people with such problems (Gentry, 2005; [www.brainaid.com](http://www.brainaid.com); Assistive Technology Partners, 2005).

Many psychiatric disabilities can be classified as a combination of more than one disability. This is referred to as dual diagnosis. The two most common dual diagnoses identified are mental illness and developmental disability and substance abuse (Pratt et al., 2002). Assistive technology can be beneficial for people who have dual diagnoses along with those who have traumatic brain injury, schizophrenia, anxiety disorders, bipolar, depression, mood disorders, and OCD (Lopresti, Mihailidis, & Kirsh, 2004; Butterfield & Ramseur, 2004; McReynolds, 2002; Pratt et al. 2002).

AT used by individuals with psychiatric disabilities includes a wide variety of devices ranging from low to high technology items. Low technological devices are inexpensive, easy to use, require little training, and may or may not have moving parts. Some examples of low technological devices include day planners, communication boards and lighted or print enlarging devices such as magnifying glasses. High technological devices have greater complexity and are also usually more expensive and contain an electrical component (Cook and Hussey, 2002). Some examples of high technological AT devices are augmentative communication devices that allow individuals with psychiatric disabilities to communicate with others using synthetic or digitized speech programs, modified or alternative keyboards, or computer hardware and software for educational tasks (Hammel, 2003; Blake & Bodine, 2002; Parette, 1997; DeJorge, Rodger & Fitzgibbon, 2000). One of the most frequently used devices in the workforce today is the personal computer. Computers have many features that can help and people with and without disabilities (<http://www.microsoft.com/enable/default.aspx> and <http://www.apple.com/accessibility/>). There are also additional software programs to help individuals organize their thoughts, such concept mapping programs ([www.smartdraw.com](http://www.smartdraw.com) and [www.inspiration.com](http://www.inspiration.com)) as well as programs specifically designed to accommodate individuals who need assistance in order to complete their jobs and be effective workers such as the Planning & Execution/Assistant and Training System (PEAT), by Attention Control Systems (<http://www.brainaid.com/>) which is classified as a cognitive prosthetic (Butterfield & Ramseur, 2004; LoPresti et al. 2004). Another example of AT that has increased in popularity is the Personal Digital Assistant (PDA). This device can serve as a memory aide and task reminder for those with a disability related to memory as PDA's feature a built in alarm system which is useful for daily planning and medication management (Sterns and Sterns, 2006; Gentry, 2005; LoPresti et al., 2004; Hammel, 2003; Blake & Bowdie, 2002).

CPRP's are positioned to have a significant impact on clients who could benefit from AT. If CPRPs were aware of, and prepared to provide, AT related services, they may be better able to provide intervention to improve the well being of their clients and enable them to live more independent lives.

## Methodology

The research design of this study is a quantitative, non-experimental, exploratory, descriptive design (Portney and Watkins, 2000). The Husson College IRB, because of minimal risk to participants, exempted the study from review. A questionnaire was mailed to CPRPs. A mailing list of licensed CPRPs was obtained from an international organization formerly called IAPSRs (International Association of Psychosocial Rehabilitation Services), but today known as the United States Psychiatric Rehabilitation Association (USPRA). The

inclusion criterion for this study was active certification as a CPRP. In order to obtain information regarding the knowledge and skills CPRPs have about AT, a questionnaire previously used for a study by Gitlow (2003) was adapted for this study. Reliability of the questionnaire was not insured in this study, although content validity was, as the questionnaire was pre-tested by AT professionals and CPRPs.

The questionnaire's purpose was two fold. First, to assess the current knowledge CPRPs perceive themselves as having, and secondly to assess what their perceived needs were regarding assistive technology. When questionnaires were received and compiled, statistics were used to summarize the data using the Statistical Package for Social Sciences (SPSS, 1999). A total of 430 questionnaires were mailed with a cover letter explaining the purpose of the study, and an assurance of confidentiality. A total of 117 usable questionnaires were returned for a response rate of 29%. The questionnaire is four pages in length and includes general demographic information questions and questions about perceived knowledge and need for knowledge about assistive technology. Prepaid preaddressed envelopes were provided and confidentiality of the respondents was assured.

### Data Analysis:

Descriptive statistics were used to detail the demographic characteristics of respondents such as gender, education, profession, and work setting. To understand the types of knowledge CPRPs perceive themselves as having about assistive technology, frequency distributions of the proportion of responses in each topical area were used. In the questionnaire respondents were asked to rate their knowledge and need for information in each topic area as expert, basic or novice. In order to assess how much education is needed in each topical area, and how open the respondents are to learning about each area, the items were ranked from the highest to lowest percentages of perceived experts knowledge and need.

### Results:

The majority of respondents (64%) were female and well educated. Most respondents held master degrees (63%). In terms of professions, close to half reported (41%) working as occupational therapists, administrators, or directors. Respondents also reported working as case managers, nurses, educators, and social workers. In terms of work setting, respondents were found to work in a variety of places. The largest proportion (26%) worked in a community mental health center or in other mental health organizations (18%). See Table 1 for detailed findings.

**Table 1: Characteristics of Respondents**

<b>Gender</b>	<b>N</b>	<b>Percentage</b>
Female	74	64%
Male	41	36%
<b>Education</b>		
High School Diploma	2	2%
Associates Degree	6	5%
Bachelors Degree	23	20%
Masters Degree	72	63%

Doctorate Degree	10	9%
Other	2	2%

**Profession**

Other	47	41%
Vocational Rehab	23	20%
Social Worker	19	17%
Case Manager	12	10%
Educator	10	9%
Nurse	3	3%
Physician	1	1%
Residential Worker	0	0%

**Work Settings**

Community Mental Health Center	29	26%
Other Mental Health Organization	20	18%
Other	17	15%
Government	11	10%
School/University	11	10%
Psychiatric Hospital	11	10%
Vocational Services	9	8%
Group Home	4	4%
General Hospital	2	2%
Nursing Home	0	0%

The questionnaire asked participants to rate their knowledge about specific topical areas regarding assistive technology and their need for knowledge in the same area. Table 2 details the topical areas and percentages of respondents who rated their knowledge and need for information as expert, basic, or novice in each area. For many of the areas, respondents have a basic level of knowledge concerning assistive technology. Similarly, respondents felt they needed at least a basic level of understanding of the information in most areas.

**Table 2: Levels of Current Perceived Knowledge and Information Needed**

	Current Perceived knowledge			Information Needed		
Topical Areas	Expert	Basic	Novice	Expert	Basic	Novice
Technologies that improve ADLs	19% (22)	64% (74)	17% (20)	22% (24)	48% (51)	30% (32)
Technologies to improve communication	29% (34)	52% (60)	19% (22)	27% (29)	49% (52)	24% (26)
Technologies to improve independence in vocational activities	27% (31)	56% (65)	17% (20)	38% (41)	42% (45)	19.6% (21)
Technologies to improve independence in recreational activities	13% (15)	62% (72)	25% (29)	17% (18)	52% (55)	31% (33)
Technology to improve positioning	6% (7)	43% (50)	51% (59)	18% (19)	42% (44)	41% (43)
Technologies to decrease visual impairment	5% (6)	36% (42)	59% (68)	13% (14)	48% (50)	39% (41)
Technologies to decrease hearing impairment	7% (8)	41% (48)	52% (60)	15% (16)	48% (51)	37% (39)
Technologies to help with learning disabilities	14% (16)	57% (66)	29% (34)	27% (28)	51% (53)	23% (24)
Information on assistive technology needs	8% (9)	37% (42)	55% (62)	19% (19)	53% (53)	29% (29)
Information on sources of funding AT	7% (9)	47% (55)	45% (52)	30% (32)	47% (50)	23% (24)
Information on team membership collaboration in addressing AT	18% (21)	57% (66)	25% (29)	27% (29)	50% (53)	17% (25)
Information on funding	1%	28%	71%	20%	42%	38%

appeals process	(1)	(32)	(82)	(21)	(44)	(40)
Information on teaching and learning self advocacy	45% (51)	43% (49)	12% (13)	39% (41)	45% (47)	16% (17)
Information on incorporating consumer perspectives into a final AT decision	27% (31)	42% (47)	31% (35)	28% (29)	45% (46)	27% (27)
Technologies to enhance functioning of memory problems	9% (10)	42% (48)	50% (57)	29% (30)	50% (52)	22% (23)
Technologies to enhance time management	20% (23)	57% (65)	24% (27)	35% (37)	48% (50)	17% (18)
Technologies to enhance self medication management	23% (27)	52% (60)	25% (29)	40% (42)	43% (45)	18% (19)

Table 3 presents the areas of knowledge in which respondents felt that they were experts. These areas include teaching and learning self advocacy (45%), technologies that improve communication (27%) and technologies that improve independence in vocational activities (27%). The areas respondents most frequently reported themselves having basic knowledge were technologies that improve ADLs (64%), technologies that help with learning disabilities (57%), and information in team membership collaboration in addressing AT (57%). Refer to table 3 for more detailed findings.

**Table 3: Knowledge of CPRPs**

Expert Knowledge	Percentage	Basic Knowledge	Percentage
Teaching self advocacy	45%	Improve ADL's	64%
Improve communication	29%	Learning disabilities technology	57%
Improve vocational activities	27%	Team membership collaboration in AT	57%

The five areas of perceived knowledge in which most respondents reported having only novice or lowest levels of knowledge included funding (71%), visual impairment (59%), and assistance in technology need (55%), deaf impairment (52%), and positioning (51%). The areas in which respondents reported the greatest need for information were medication management (40%), teaching self advocacy (39%), improving vocational activities (38%), enhancing time management (35%), and funding devices (30%). See table 4 for more details.

**Table 4: Areas of Novice Level Perceived Knowledge and Need for Expert knowledge related to Assistive Technology**

Knowledge		Information Needed	
Funding appeals	71%	Medication management	40%
Visual impairment	59%	Teaching self advocacy	39%
Assistance on technology need	55%	Improve vocational Activities	38%
Deaf impairment	52%	Enhance time management	35%
Positioning	51%	Funding devices	30%

In order to see if knowledge deficits and information needs differed by type of work setting, namely psychiatric and non psychiatric settings, responses were compared between the two groups. Psychiatric settings included psychiatric hospitals, community mental health centers, and mental health organizations. Non-psychiatric settings included school/university, vocational settings, government, group homes, nursing homes and “other”. Table 5 lists the top five areas of knowledge deficits and information needed. Similarities between the respondents in the two settings are apparent. The top five areas of novice levels of knowledge include funding appeals in both psychiatric and non-psychiatric settings. The remaining four areas include AT for visual impairments, assistance on technology need, AT for hearing impairment and positioning.

**Table 5: Top Five Areas of Low Knowledge Base According To Work Setting**

Psychiatric Setting		Non Psychiatric Setting	
Area	Percentage	Area	Percentage
Funding appeals	81%	Funding appeals	64%



Visual impairment	61%	Visual impairment	57%
Assistance on technology need	57%	Assistance on technology need	56%
Deaf impairment	54%	Deaf impairment	50%
Positioning	54%	Positioning	50%

Turning to the results pertaining to information needed and what practitioners felt that they should have expert levels of knowledge were also very similar, but in a slightly different ranked order. In the psychiatric setting the top areas of need for knowledge were medication management, improving vocational activities, enhancing time management, teaching self-advocacy, and enhancing memory. In a non- psychiatric setting the top five areas included teaching self advocacy, improving vocational activities, medication management, enhancing time management, and funding devices. See table 6.

**Table 6: Top Five Areas of Expert Information Needed By Work Setting**

Psychiatric Setting		Non Psychiatric Setting	
Area	Percentage	Area	Percentage
Medication management	44%	Teach self advocacy	37%
Improve vocational activities	41%	Improve vocational activities	33%
Enhance time management	40%	Medication management	32%
Teach self advocacy	39%	Enhance time management	30%
Enhance memory	37%	Funding devices	27%

### Limitations:

Several limitations regarding this study should be noted. Although the names and address of CPRPs were obtained from IAPSRS, many of the listings were not accurate and the response rate suffered as a result. In addition, reminder postcards were not sent out. Also, the response rate was probably adversely affected by the length of the survey, as it was four pages in length. The instructions on how to complete the survey could have also been clearer. For example, several respondents selected more than one knowledge level for each topical area and some participants checked between boxes, or more than one box for each category. A final limitation of the questionnaire was it did not include definitions for the categories expert, basic, and novice.

### Discussion:

Overall, there is a need for training and education regarding AT for CPRPs. Less than thirty percent of the respondents regarded themselves as experts on AT in any one area except for the area of teaching and learning self-advocacy where 45 % reported being experts. This is not surprising given that one of the key underlying

principles of psychosocial rehabilitation is empowerment (International Association of Psychosocial Rehabilitation Services, (n.d.). Interestingly, this was also an area respondents identified as an area where they needed to more knowledge. Again this is not surprising given the importance of this underlying principle of psychosocial rehabilitation. Work setting does not show any particular significance to need and level of knowledge regarding AT among CPRP's. Areas in which most respondents reported having only novice levels of knowledge such as funding, assistance in identifying AT need, AT for visual and hearing impairments and positioning make sense. Funding is one of the biggest challenges in getting AT to the people who can benefit from it (Public Law 108-364, 2004). Anyone who has ever tried to secure AT for those who need it are acutely aware of the ongoing need for knowledge in this area (O'day et. al, 2000). Another area of little knowledge identified by this group as well as others is how to identify the need for AT. Matching a person with the correct AT solution is critical to the success of AT intervention (Scherer et. al.,2005). This finding is consistent with the literature that confirms a lack of professionals trained in this area (Edyburn, 2004; Gitlow and Sanford, 2003). In regards to AT for those with a hearing or visual impairment, people who need AT for these disabilities may be seeing practitioners who specialize in these areas. It is interesting to note that in the state of Maine, CPRPs in community mental health settings are using the text messaging function of their cell phones to communicate with hearing impaired clients and staff (personal communication with John Painter, CPRP March 09, 2006). Finally AT for positioning is often considered for those who have physical disabilities. However, as the people with psychiatric disabilities live longer, this may be a consideration that becomes more relevant to those who work with this group.

The areas in which respondents reported needing the most education are related to technologies for medication management, vocational activities and time management, information about self advocacy, memory devices and funding approaches. Medication management in particular is an issue for this population. Many of the symptoms of psychiatric disability as well as the side effects of many medications used by those who have psychiatric disabilities impair memory and thinking abilities (Hughes and Weinstein, 2002; APA, 1994). The literature reports that non-adherence and forgetting medication is one of the main reasons that people with mental illness become hospitalized and unable to carry out every day life tasks. (Personal communication with John Painter, CPRP March 10, 2006; Pies, 2002). As mentioned above, a number of studies have identified the value of AT devices for those who have memory and other cognitive problems, which can affect medication compliance (LoPresti, Mihailidis, &Kirsch, 2004; Wilson, Emslie, Quirk & Evans, 2001). Technologies to improve medication management include pill-dispensing watches, watches with alerts and timers, beepers, ([www.epill.com](http://www.epill.com)) and practical devices such as cell phones and PDA's that have multiple alarms for reminders. In addition to providing education about the technologies available to help with medication compliance, continued research studying the application of AT for medication management for this population is certainly needed (Department of Veterans Affairs, 2005-7; Cramer and Rosenback, 1998).

Given the importance of employment to health and well being and its stabilizing effect for person with mental illness ((Krupa, LaGarde & Carmichael, 2003; Tyrnsenaar, 2002; Marrone & Golowka, 1999) it is not surprising that CPRP's have a need for more AT related knowledge in this area. It may be that once a practitioner has some awareness of the impact that AT can have on the performance of a client, they want to continue to keep abreast of the advances of AT as it relates to this area. Education in these areas can help CPRPs provide the right types of assistive technology solutions to help their clients attain their goals.

In helping educate people how to manage their time better, there are many resources which describe the use of planners, calendars and/or PDAs.

<http://www.biausa.org/Pages/AT/index.php?PHPSESSID=022658be412e2f1340a21f7a2b21c5e1>.. AT that can help those people with their vocational activities include different computer programs such as "Inspiration" which is a concept mapping program, lightened or enlarging devices such as magnifying glasses,

wall calendar with clock, adaptive tools, and adaptive work environments and schedules (<http://www.jan.wvu.edu/soar/index.html>). To enhance memory, devices include cuing props, tape recorders, and text to speech systems. In the area of funding and self advocacy computer software as well as the Internet will give step by step instructions on ways to advocate for self, and how to fund for AT. The educational options are ongoing.

For future research, how to deliver educational programs to best meet the pre- service and continuing education needs of CPRPs will help us design programs that will be accessible to this group.

## Conclusion:

CPRPs like many other practitioners who work with people who have disabling conditions, have the need for AT related education in order to meet the AT related needs of their clients. This study has given us some guidance on how to begin to prioritize that huge area of AT education to meet the needs of this group of practitioners. Much benefit could be derived from educating CPRPs about AT and providing training on funding and determining the need for AT and AT devices such as memory aides, medication management devices, time management planners, computer programs and other adaptations that can enhance a clients productivity.

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# The Recognition Of Fatigue

## A qualitative study of life-stories from rehabilitation clients

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## Abstract

This article gives a qualitative analysis of symptoms of fatigue in a historical and contemporary perspective. After an historical review, starting with the concept of asthenia in 1869 to the current 'new age diseases', these various metaphors are explored through contemporary patients' verbalisations of their illness.

The written life stories of 136 rehabilitation patients are divided into sub-groups according to whether they convey a) an exclusively specific and limited picture of complaints, b) medically unspecific and vague complaints of fatigue, and c) exclusively mental complaints. Through a qualitative analysis, all meaning units in the texts have been identified and categorized.

The results show that especially in the group of unspecific and vague complaints, the patient is marked by dissatisfaction. The cause of this is attributed to professionals who do not understand, do not listen, and do not recognise the patient's situation. Many patients write that it has been a help for them to receive a somatic medical diagnosis and hence be relieved of psychological causes.

However, in none of the life stories does one find any of the cultural metaphors identified in the historical introduction. A critical appraisal of modern society with its increased flow of information, splitting of the family pattern, exposed gender roles, etc., seems thus to exist only among the professionals.

**Keywords:** Chronic fatigue syndrome, Illness belief, Life-stories, Modern society.

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## Introduction

Patients with fatigue not fully explained by a medical condition have been the subject of years' of controversy (e.g. Shorter 1992, 2004). Within humanistic health research, there is a concern with understanding such illnesses that are difficult to categorise in terms of them being cultural constructions (Garro, 1994). The term 'new age diseases' is an example of disease being described as a construction of the 'new', late-modern society with its emphasis on excessive demands on personal integrity, unmanageable work-load, and physiological contamination (Clarke & James, 2003; Arnetz, 1996).

The purpose of this article is firstly to analyse how these descriptions of so-called 'new age diseases' come into existence, and secondly to identify essential verbalisations in the rehabilitation patients with medically unexplained complaints. Thirdly, the article investigates whether the rhetoric of 'new age diseases' affects the patients' illness perceptions.

Considerable research has been done into various aspects of the experience of unexplained diseases (Clements et al. 1997; Bury, 1991; Corbin & Strauss, 1988; Conrad, 1987; Strauss, 1975), but few have focused on the patients' biographies (Bury, 1982) or life stories (Frank, 1993; Williams, 1994). This study is based on life stories written by rehabilitation patients presenting medically unexplained complaints of fatigue. The method is one of qualitative analysis focusing on how fatigue is cast in the patients' struggle for recognition.

## 1. The History of Fatigue

### Causes of fatigue

In 1733, Cheyne recorded certain conditions of fatigue as diseases and characterised the symptoms as 'lowness in spirits', 'heaviness and dislike to action', 'impatience', and 'abnormal delicacy and sensibility of the nervous system' (Birket-Smith, 1960). Already in the first half of the 19th century, the pathogenic basis for 'weak nerves' was ascribed to living in large, over-populated cities and to psychological traumas, overtaxing, and addiction to medicine. But although there were periods in the 19th century when it was claimed that one could demonstrate an anatomical, physiological cause – such as 'spinal irritation' (Hirsch,



1843, quoted in Birket-Smith 1960: 14), most people noted a lack of anatomical substrate. The condition was characterised as functional and hardly pathological in itself.

The diagnosis of neurasthenia was introduced by Beard in 1869 and was based on a review of 30 cases of fatigue that resulted in difficulties of treatment. Beard counted more than 75 signs of the disease and came to the conclusion that “each case of neurasthenia was a study of its own” (Abbey & Garfinkel, 1991:1639). He found the main reason to be the restructuring of society and ascribed as the reason for it the changed working patterns that industrialisation had introduced along with the rapid exchange of information that telephone and telegraphy had brought about. “The neurasthenic produced his symptoms of fatigue as a justification to be ill and to give up work.” (Beard, 1869, quoted in Abbey & Garfinkel 1991; 1643).

Historians such as Shorter (1992) point out that the symptoms of fatigue were particularly prevalent in the 1860s. Neurasthenia became so widespread that Pontoppidan in 1886 warned against it becoming a “storage space for a conglomeration of various conditions”. Towards the end of the 19th century, neurasthenia dissolved as a symptomatic unit, and in professional journals attention shifted to pathogenic speculations regarding the conditions associated with fatigue such as irritability, anxiety, imbalance of mood, depression, hypersensitivity to noise, etc.

In the beginning of the 20th century, the first exclusively psychological hypotheses began to appear. In 1903, as one of the first, Janet gave to the expression “decreased nervous power” a thorough psychological description which he termed “tension psychologique”. Freud, in his earliest works, distinguished anxiety neurosis from neurasthenia, and he gathered neurasthenia, anxiety neurosis and hypochondria under the heading of “Aktualneurosen”, which was distinguished from the “psychoneuroses”. He thus laid the basis for ascribing to symptoms the symbolic significance that became the starting point of psychoanalysis and of psycho-dynamic thinking.

Kafft-Ebing admitted neurasthenia into neuropsychiatry in 1895 and spoke of neurasthenia as a condition of weakness, having as its basis a lack of correlation between production and consumption of nervous energy, thereby making a direct link between the sharp increase in the occurrence of nervousness and the socio-economic conditions of that time. He described almost every defining socio-economic feature of the social developments in the 1800s as being pathogenic: international economic competition, mass production, demographic changes from country to city, breakdown of families with the adults being too preoccupied with work and hardly seeing their children (quoted in Køppe, 2004: 280).

During World War I, neurasthenia was described as one of most frequent war neuroses. But since the survivors of the war were almost all affected by extreme fatigue, the diagnosis of neurasthenia was rejected on the grounds that there were no detectable somatic or psychiatric diseases. This development was repeated and formed the background for the introduction of the PTSD diagnosis as a reaction to the non-specific psychological symptoms among all the returning Vietnam soldiers (Hackings, 1995; Young, 1995).

In the 1920s, the vague popular perception of fatigue was quashed by way of reference to a distinction between an exogenous “overtaxing” neurasthenia and an endogenous neurasthenic condition in the sense of a psychologically constitutional anomaly. Schneider introduced the term “asthenic psychopathy” within the notion of psychopathy (Schneider, 1923, quoted in Birket-Smith, 1960: 81), which has to some degree been retained today within the personality disorders under anti-social personality (Millon & Davis, 1996).

Although there have thus, in the course of history, been many attempts to describe cultural causes for fatigue, it is notable that there is a constant probing of somatic causes. Birket-Smith (1960) provides an overview of how different physical hypotheses arise as a reaction to primitive psychologisation. Thus poor blood circulation is given as a cause of the so-called “neuro-circulatory fatigue”. During World War I, fatigue was

re-written as heart conditions such as “irritable heart” and “soldier’s heart”, and later on hypotheses arose concerning abnormalities in the carbohydrate metabolism such as the “functional hypoglycaemia” or as “relative adrenal cortex insufficiency”. Shorter provides similar historical examples of how the professional has always sought for physical explanations of fatigue, but that also large proportions of the general population have been on the search for an organic diagnosis for their fatigue in an attempt to avoid an expanding psychologisation (Shorter 1992).

#### **Bulletin for Danish Doctors, 1886**

*“One is probably right in describing as one of the greatest curses of modern society the increasingly prevalent nervousness. Not only does it bear witness to itself through the growing frequency of madness and suicide, but overall it contributes substantially to stamp our time with its peculiar marks. The greater haste that nowadays has entered our existence, the unrest and hurry that mark all relations, are an expression of an intensified cerebral activity; but the greater the demands on the nervous system, the more easily are its powers exhausted, and the quicker its resistance will fail. The greater the efforts civilisation in our century has cost, and the greater the ferocity of working towards the progress and well-being of our generations, the more our nervous constitution has been weakened. Herein we must surely also seek one of the reasons that we, despite all our triumphs in the areas of science and practical inventions, are far from having reached any golden age of health, happiness, or satisfaction. Much more is the physiognomy of our age marked by so much bother and bitter pessimism that we are constantly tempted to wish ourselves back to the good old days with their harmonic rest and cosiness...”*

*Pontoppidan 1886. p 3 – p 4.*

#### **Fatigue as a disease of civilisations**

To a number of 19th century intellectuals, fatigue was identified as a symptom of modernity. The dissolution of the old working conditions, the uncertainty connected to the ferocious development of the means of production, and the expanding industrialisation and consumerism all caused many to become preoccupied with the pathology of social life. Great demands were imposed on the individual performances in modern society, so that the individual could only respond with symptoms that placed him in a position where lesser demands would be imposed on him. Fatigue became an understandable refuge, and the intellectuals conferred on it the prestige of science, not only within medicine, but also in literature and philosophy.

Before Beard introduced neurasthenia as a diagnosis in 1864, there was not within official American medical science any recorded study of fatigue (U.S. Surgeon General Index, Rabinbach, 1992:20). But by the year 1900, more than one hundred studies of “nervous exhaustion”, “brain exhaustion”, “asthenia”, and “spinal exhaustion” had appeared. Fatigue as a medical symptom was not only ascribed to physical overtaxing, but also to constitutional physical and psychological pathologies. Fatigue in mental life was inscribed by an increasing number of doctors and physiologists within a series of social dysfunctions such as crime, alcoholism, and sexual perversions. In the course of the 18th century, an almost manic scientific fascination arose with fatigue as an expression of the anxiety connected with dissolution, fall, social disintegration, and even cosmic death (Rabinbach, 1992: 21).

With fatigue being the cardinal symptom, the ground was prepared for the description of a series of new pathologies. Alcohol abuse, insufficient education, loss of social status, unemployment, crime, dissolution of the family, meaningless jobs; they all produced a psychological state to be distinguished from psychological pathologies. Degeneration, decay, and the cultural decadence of the fin-de-siècle gave rise to new sciences with new focus areas as counterpoints; moral regeneration as a counterpoint to degeneration, preoccupation with social equality and welfare instead of inequality and class divergence, and not least the scientific interest in physical and mental health instead of illness. Fatigue assumed different expressions in France and England,

respectively. With the military defeat of 1870, France was thrown into another kind of cultural decay with an increasing anxiety regarding decadence and dissolution. A new science arose concerning social hygiene being based on a theoretical and almost moral foundation with an obsessive preoccupation with fatigue. Philippe Tissié pronounced in 1887 that the “new generation is born tired and is a product of the decay of the century” (Quoted in Rabinbach, 1992: 22). As a counterweight, he founded the so-called rational gymnastics, which incidentally quickly moved up to Scandinavia.

England however had greater luck with its industrial development and with its transformation of the traditional agrarian society. Here fatigue was not necessarily seen as a negative sign of the decay of society, but rather as the natural resistance of the body against the demands for productivity. Fatigue represented a legitimate boundary for physiological and mental capability of the individual in a society which had to be controlled in order not to develop into a lawless and destructive force. Fatigue became a concept through the help of which the industrial human being could be understood and governed. A body without fatigue became the ideal for the industrial bourgeoisie, and various empirical measurements for fatigue and productivity were developed. As a result of this, social medicine arose with a declared purpose of understanding the relationship between the social and industrial conditions for physical and mental health. Overtime, overtaxing, and fatigue became the new taxonomies of a different view on work-related diseases. In 1875, the first scientific medical article was published in the *Lancet*, attempting to provide some objective distinctions and measurements regarding fatigue.

In the 19th century, work was at the centre of attention. Social modernity, the attempt to transcend the class conflicts, as well as social restructuring took place on the basis of a cosmology including the possibility of rationalising the human body, ‘the human motor’. The body was the productive power that could transform natural forms of energy into mechanical labour and integrate the human organism into a highly specialised and technological working process. Marx’ image of modernity was the indefatigable transformation of human labour into capital. Taylor’s utopia was that the body would enter into a harmonic relation between nature and capital. This cosmology consisted in the factory and labour being extensions of the ‘human motor’; and hence arose the subsequent preoccupation with fatigue and exhaustion. During that period, Schopenhauer, Nietzsche and Ribot wrote fatigue into literature with references to modernity and its restructurings.

In 1888 Nietzsche asked, “Where does our modern world belong – to exhaustion or ascent?” (Quoted in Rabinbach, 1992: 19). The statement is characteristic of the situation in which civilisation found itself. The metaphor of fatigue had become symptomatic of the extensive fear among the middle class that society had been drained of its accumulated energy. The industrialised society had become so fast with such a demanding process of production and with so many social changes that fatigue had become a necessary counter-precaution. Exhaustion became the nemesis of the idea of overwhelming progress.

State and individual subject were mutually dependent, and the survival of the state depended on the performance of the individual and hence on fatigue. Fatigue became a means of the state, and if the individual persons were to become producers and conscripts for the state, then they were of little use if complaining about fatigue. At the same time, the state could not abuse the individual, and in order to indicate boundaries, the citizen would give vent to fatigue in contexts of stress.

Today the work-centred society has gradually lost its original interest in the ‘human motor’, and the body and fatigue have been inscribed within new paradigms. With the restructuring of the welfare society, the human machine has been inscribed within many more contexts than just the place of work, and fatigue has become an issue pertaining to much more than being burnt out, overtaxed, and stressed.

A whole series of thinkers including Giddens, Habermas and Gorz have described as the most significant change in postmodern society the cessation of the work-centred society. Today many people like Rabinbach

(1992: 298) note how manual labour has now assumed a more cerebral character and has been dressed in cognitive and semiotic codes. Thereby the body and fatigue have also assumed new forms.

We see this in Denmark as the rehabilitation clinics change form. They are no longer primarily preoccupied with occupational re-training for new jobs, but emphasise the mental development of new forms of working for the unemployed.

### New age diseases

Many of the descriptions stemming from a popular critique of civilisation are close to being identical with what is today known as stress, which is again very similar to the modern fatigue syndrome (Clements et al. 1997; Abbey & Gardinkel, 1991; Wessely et al., 1998; Arnetz 1996). A lot of the explanations are the same in principle, only the nervous system has been replaced with for instance the immune system which is weak, easily affected, reduced, etc.

Today one is faced with the same diagnostic difficulties as in the case of the homeless fatigue patients at the time of Beard. The popular illness experiences are too vague, shifting and fluctuating for the logical and rule-governed professional disease system. Shorter has, in a historical review of the psychosomatic diseases, described how patients are today in search for an organic diagnosis, and he accounts for how certain vague symptoms such as fatigue become ingredients of trendy diseases. Especially patients with chronic fatigue react strongly against being given a psychiatric diagnosis, more strongly than what is seen with patients suffering from common somatic diseases. "Needless to say, psychiatrists are unwelcome in the subculture of chronic fatigue" (1992: 317). These subcultures would rather have unspecific organic diseases such as food allergies, hypoglycaemia; so-called "diseases of pathoplasticity and environmental hypersensitivity". The patients extract particular elements from the cultural pool of symptoms pertaining to trend-related illness models, amplify them, and turn them into their own personal perception of what is going on inside their bodies.

Many of the patients have become incapable of understanding their fatigue in social isolation and join patients' associations or seek alternative treatment. Some doctors accompany them into a subculture that has lost its faith in the dominating medical system, and instead of addressing the popular experience, they dress up in symptoms that they acquire from sources including media reports on the various trendy diseases mentioned (Shorter, 1992: 323).

### The YDUN case

In its general aims of 1998, the Danish clinic for pre-rehabilitation, YDUN, stated that its purpose was "to strengthen the ability for self-governance and increase the life competencies of the person in rehabilitation". The target group consisted of "persons with poor, unstable, or no attachment to the labour market – persons who, in addition to physical, mental, or social problems suffered from a subsequent social labour market impairment". Some of the rehabilitation clients had some of the 'new' diseases such as fibromyalgia with associated fatigue symptoms. YDUN offered activities such as courses and dialogue groups on 'human development', 'crisis and mourning', 'our defence mechanisms', etc. Some of the staff had received psychotherapeutic training and set up therapy groups.

The majority of the rehabilitation clients have been satisfied with the rehabilitation stay. But there are clients who found the psychological work to transgress their boundaries and who made contact with the media:

*"In my opinion, it is terrible what goes on. We arrive to get some clarification as to our future working capacities and should end up full of self-confidence when we are finished, but what's happening? Some feel that it would be easier, if you weren't around any more; some get extra tranquilisers. Many are really scared about what the future holds. Many feel that they have been abused beyond all limits"*

*(Vest Kysten. July 17 1998).*

*“Save the sick people any further humiliation and measurements of control. Rather spend the money on providing them with a tolerable existence” (Vest Kysten, July 9 1998).*

*“I have never had mental problems before I entered rehabilitation” (Vest Kysten, March 18 1998).*

*“As course participants, we had to sign a contract stating that we are mentally ill and intellectually subnormal” (Vest Kysten. March 18 1998).*

## 2. A Contemporary Analysis of Life Stories of Fatigue

### The Material

In the period 1998- 2002, 628 patients completed a rehabilitation course at a Danish rehabilitation center (YDUN Rehabilitation Center, Department of Social Medicine, Aalborg Hospital. The clients were referred with a broad spectrum of medical and psychiatric diagnoses. During a three month rehabilitation course, participants were requested to write down their life-stories as one of various course activities, and each Monday throughout the course, time was set aside for writing these stories. The participants were free to develop the form and content of the stories, as they wished.

In 2003 the Social-Medical Unit at Aalborg Hospital contacted 610 participants and asked if they were willing to anonymously make their life-stories accessible for our research project. 230 participants were willing to do this and sent their stories.

10 stories were discarded due to missing pages and lack of basic information, such as gender and age. To make the data comparable and suitable for a quantitative analysis, 84 stories were discarded as stories of less than 2000 words, as were stories containing less than 250 words under the main items of childhood or adulthood.

136 life-stories fulfilled the criteria, and were considered suitable for the analysis. Of these 136 stories, 58 were written by men, and 78 by women. The average age was 40, and the age-range was from 21 to 61 years old. The average story was of 5022 words, the shortest being 2550 words and the longest 23,750 words.

The life-stories have been divided into groups according to whether they convey 1. an exclusively specific and limited picture of complaints, 2. medically unspecific and vague complaints, 3. exclusively mental complaints. The groups with medically unspecific complaints contain patients who state that they have been diagnosed with the so-called new age diseases or environmental illnesses such as multiple chemical sensitivity, fibromyalgia, chronic fatigue syndrome.

The group of 58 patients with unspecified complaints form the basis of the qualitative analysis.

### Qualitative analysis

In 30 randomly chosen life-stories, units of meaning in the text have been identified and categorized guided by our interest in 1. general level of stress in childhood and adulthood, 2. specific work-related stresses, 3. self perception and causal understanding of symptoms, 4. user satisfaction and requirement of retirement for pension. A scoring manual was developed on the basis of these data-driven categories. A further 30 life-stories were scored with the manual, following which the manual was corrected and completed. All 136 life-stories were then coded by the authors RM and MHT according to the final scoring manual, containing 105 individual categories. Disagreements between scoring were solved at weekly meetings and discussed with the research group.

The quantitative analysis of the material is presented in Elsass et al. (2006). In the qualitative analysis presented here, the meaning units are arranged in order to qualify the patients' struggle for recognition by identifying opposition between the categories of patient, helpers and opponents, respectively.

## Results

All the life-stories in the three groups were marked by the complexity of psychological, social, and medical factors, but none of the stories contained the rhetoric of new age diseases. In the following, the variation within each category is shown with focus on the opposition between the patient's helpers and opponents.

### The subject

The situation of the subject is characterised by many complaints which are described as confusing, unclear, without cause, and which create chaos within him. The unspecific picture of complaints can hence not be understood within the specific disease categories like pain and headache. The complaints are described as causing mental strain.

#### Confusion, chaos and meaninglessness

*"Very troubled, with lots of pain in all kinds of places. Increased consumption of pain-relieving medicines. Mental confusion due to anxiety regarding the future." (Case 18, p.5)*

*"This illness has created chaos in my life." (Case 58, p.8)*

*"At the moment, I experience everything around my illness as being unclear. It stresses me a lot in my everyday life, that I have not succeeded in finding a cause of my disease, that something new crops up all the time." (Case 25, p.7)*

*"The rest of the day and evening are not a life in my view, but survival. It is meaningless." (Case 63, p.12)*

*"The last eight years have been very much up and down, and the fact that I have not had a name put on my disease makes me feel powerless. I cannot accept that my illness has no name. That is the same as saying: There is nothing wrong with her!" (Case 76, p.11)*

Most people describe overtaxing as the cause of their illness and often characterise themselves as dutiful persons who have not been able to set limits for themselves. The recurrent theme is the story of a busy working life and far too many stress factors that the patient has not been able to cope with, even if there has been the wish to do so.

#### Worn out, never free, the body says stop, can take it no more

*"I have been slogging and slaving, and now I am worn out." (Case 67, p.11)*

*"My working day started at seven in the morning finishing at one in night, that's how I went on without any days off. Then I could no longer go on, neither financially nor mentally." (Case 8, p.3)*

*"I have actually been through quite a few things, and that has worn me out, both physically and mentally. The flag has reached the bottom of the pole." (Case 48, p.7)*

*"I have always been the nice one and will probably continue to be so." (Case 64, p.2)*

*"I got a prize for diligence in 7th and 10th grade" (Case 64, p.2)*

*"This damned illness makes everything very difficult, because I still want to do it all in my head, but my body says, 'No!'" (Case 90, p.12)*

The patients position themselves as victims and describe themselves in terms of 'common sense' psychology regarding 'not letting themselves be governed by others' and 'choosing themselves'. There are no examples of speaking of the illness from positive angles such as it being a gain that provides free-space from the demands of the surroundings.

Not setting limits, lacking self-confidence, thinking of satisfying others, letting others decide.

*"Whether I get better will to a large degree also depend on whether I get more self-confidence." (Case 47, p.10)*

*"I have been afraid of being inadequate, and I spent a lot of time satisfying everybody in the family and at work." (Case 49, p. 2)*

*"Strangely enough, I never called in sick. I was much too conscientious, and then that was probably a way of forgetting myself and my own misery. The more I worked, the more was I able to avoid feeling myself." (Case 117, p.15)*

*"It is better to try to pretend being happy and satisfied. Just think if someone got angry with you. That would really hurt. I have always lived my life like that. Lately I have become better at setting limits and taking care of myself. (Case 130, p.16)*

## The opponent

The patient is marked by dissatisfaction. The cause is placed with the opponent who does not understand, does not listen, and does not recognise the patient's situation. The dissatisfaction is expressed in general terms and vaguely. Only a few real examples are given.

Humiliations and experiences of not being of value, running your head against a wall of indifference, being talked down to.

*"The local council became too harsh. Never again shall I allow it to knock me out that hard. I have never experienced anything like it before in my life. It almost finished me off." (Case 39, p.10)*

*"Every time I have approached my social worker, I felt like running against a wall, and that I was met with suspicion, and also they did not feel any obligation towards me." (Case 156, p.8)*

*"I have been treated by the council as though I were a hypochondriac who did not want to work." Case 67, p.8)*

*"It's as if you are just treated like a number in the 'system'". (Case 106, p.8)*

*"I felt that the doors were locked everywhere." (Case 98, p.2)*

*"I have the sense that the doctor has no idea what it is like to be a patient with an invisible complaint – although he claimed the opposite. There is simply nobody who knows how you feel, how you are, even though they have had a lot to do with it" (Case 108, p.7)*

## The helper

It has been a help for the patients to be understood, both by professionals, family, and friends. The helper has in some cases been in the form of getting an organic diagnosis and be relieved of psychological causes.

Meeting people like yourself, an understanding spouse, and a professional who listens and gives an explanation that can be understood

*"I was probably quite relieved after the consultation, as I really felt he believed in me." [Concerning YDUN's medical consultant] (Case 54, p.9)*

*"Had I not had my husband, it would probably have been even worse for me. He has always been prepared to help." (Case 106, p.4)*

*"The others on my course are all like me. We actually have almost the same problems or tasks to deal with. That was really something, like an enriching peace." (Case 110, p.8)*

*"It was nice that there was someone who would sit down and explain what it was all about." [Concerning YDUN's medical consultant] (Case 125, p.9)*

*"The work place found a sheltered job." (Case 70, p.8)*

## The weapons of the subject

The patients enter this struggle for recognition with some resources that in most cases are tied to certain personal qualities like self-confidence and 'drive'.

Self-confidence, an interesting job, self-governance and autonomy

*"Fortunately, I have always had self-confidence - otherwise I would have collapsed long ago." (Case 39, p.11)*

*"I basically know that I am good enough (...) my greatest desire is to live." (Case 75, p.7)*

*"I have always been interested in my job and have had a lot of joy out of it." (Case 76, p. 9)*

*"I you want to make progress in the world, then push ahead!" (Case 97, p.11)*

*"Every morning when I wake up, I say to myself: 'Today is going to be a good day!' Many things have changed, but the problems are there to be solved. 'You aren't better, just because you're in good health'." Case 207, p.3)*

## The struggle for recognition

The encounter between subject and opponent may be characterised as a struggle for recognition. The struggle is carried out in two areas: Which name (diagnosis) is the illness supposed to have, and does it have psychological causes?

No name for the illness, mental suffering, the invisible handicap

*"The last eight years have been very much up and down, and the fact that I have not had a name put on my illness makes me feel powerless. I cannot accept that my illness has no name. That is the same as saying, 'There is nothing wrong with her'" (Case 76, p.11)*

*"It can be difficult to convince the system that your body is worn out, when you don't even understand it yourself." (Case 141, p. 13)*



*"I am afraid of being labelled with something that I know I'm not, such as mentally ill. There may be something wrong with my head, but mentally ill I'm not" (Case 168, p.5)*

*"There is no purpose in bringing up a lot from your past if it is not transformed and worked through, which takes time." (Case 175, p.5)*

*"How easy life would be, if you had lost an arm or a leg. Then the disability would be visible. A handicap like mine is obviously just lies and bogus. (...) Do you have to be admitted to the closed ward before the system is satisfied?" (Case 200, p.12)*

The patients are often losers in this struggle and express a loss of hope and dignity.

### **Uncertain future, hopelessness and anger**

*"I have difficulty coming up with any wishes for the future. (...) I still have a fear and uncertainty about the future." (Case 29, p.9)*

*"It is very easy to fall into the trap of going to the pub every day, and a lot of times you get frustrated about not having anything to get up to." (Case 65, p.8)*

*"Realistic wishes for the future – I don't know... bag lady, criminal, or refugee..." (Case 67, p.2)*

*"I feel a hopelessness and anger about not having got any further with my life, and that for so many years I have accepted being 'pissed on'!" (Case 175, p. 17)*

*"I cannot relate to the future at all. What is going to happen? I probably have to admit that I am afraid of the future." (Case 205, p.6)*

## **Discussion**

All the life-stories are marked by the complexity of psychological, social, and medical factors that have historically characterised patients with unspecific complaints since the 1800s. Overall, the life-stories convey a high amount of stress in both childhood and adulthood. The patients were marked by dissatisfaction, and the cause was placed with the medical system that does not understand, does not listen, and does not recognise the patient's situation. It has been a help for the patients to be understood, both by professionals, family, and friends. The help has in many cases been one of being given an organic diagnosis and hence be relieved of psychological causes.

There are a number of limitations to this paper. First, the sample selected was small and non-random. The study took place within one institutional setting, and although the life-stories are written for the patients themselves, they did have the option of having them discussed with the professionals at the centre.

With these reservations the life-stories can be viewed as a struggle for recognition concerned with the right to achieve an organic diagnosis and hence avoid a psychological aetiology. The meaning units in the texts have been arranged in order to qualify the patients' struggle for recognition by identifying opposition between the categories of patient, helpers and opponents, respectively. Within this organisation, one finds that the disease is given solely negative attributes. The disease is the unconditional opponent, whereas the professional helpers such as the doctor and the social worker are given various positive and negative attributes and may serve as both helpers and opponents.

Although the life-stories are permeated with different expressions of strains and burdens, in no stories does

one however find a critique of post-modern society formulated in metaphors such as the increased flow of information, the splitting of the family pattern, the exposed gender role, as we saw it in the debates about new age diseases.

The life-stories show how patients suffering from fatigue as a medically unexplained symptom must often work hard and search for a long time to find a medical definition of their reality. A diagnosis provides a legitimacy that is awarded to those who are easily medicalised. Similar Ware (1992) found that some of the suffering experienced by the people in her sample of about 150 with chronic fatigue syndrome was due to "delegitimization" or to the experience of having one's perception and definition of illness systematically rejected.

An important aim of the clinician is to create consistency and coherence in the patient's illness perception. The healing lies in exploring under which circumstances the coherence of one person becomes the relief of the other (Kirmayer 2000: 175). Our hypothesis is that this may not be accomplished by paying attention to metaphors of modernity as e.g. information overload, splitting of the family and the self, lack of tradition and historical sense. Although this rhetoric is on the side of humanistic health research, it is not a part of the patient's illness perception and may therefore create an additional delegitimization of the patient.

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