

# *International Journal of Psychosocial Rehabilitation*

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PRACTITIONERS, CONSUMERS & APPLIED RESEARCHERS***

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

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*July 2008 - June 2009*

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## **Journal Information**

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Articles on psychosocial interventions, psychopharmacotherapy, mental health primary care, institutional and community care innovations, decentralization, policy changes, community & regionally based systems, and program evaluation are given particular attention. However, all articles that relate to psychosocial rehabilitation will be considered.

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# Acceptance Rates Research and Program Evaluation

Nicole A Jones

East Carolina University

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*International Journal of Psychosocial Rehabilitation*. 13(1), 5-9

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## Abstract

This paper is about Acceptance rates research for minorities specifically African Americans and the possible need to re-evaluate the eligibility component of the vocational rehabilitation program. Acceptance rates research is discussed and linked to the process of program evaluation. Program evaluation is a continual and necessary process for human service organizations. Program evaluation allows human service organizations to examine all aspects of programming to address areas of possible improvement.

**Key words:** acceptance rates, program evaluation, vocational rehabilitation, and eligibility component

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## Introduction

The purpose of this paper is to present a literature review of acceptance rates research of minorities in vocational rehabilitation to support reevaluation of the eligibility component of the Vocational Rehabilitation System. Program evaluation is a necessary and continuous process to measure the effectiveness of a program. Multiple acceptance rate research studies have been conducted and they indicate that African Americans are accepted at lower rates than their European American counterparts (Atkins & Wright, 1980; Wilson, 2002; Rosenthal, Wilson, Ferrin & Frain, 2005). This literature review can be used as an instrument to reevaluate the eligibility process of minorities seeking entrance into the vocational rehabilitation system.

Program evaluation is defined by Rossi, Lipsey and Freeman (2004) as “the use of social research procedures to systematically investigate the effectiveness of social intervention programs that is adapted to their political and organizational environments and designed to inform social action in ways that improve social conditions” (p.16). The vocational rehabilitation program is a social intervention program. The examination of acceptance rates as social research can be utilized to re-evaluate the vocational rehabilitation program. Lewis, Packard and Lewis (2007) conclude that evaluation can be used to aid in administrative decision making, improve currently operating programs, provides for accountability, build increased support for effective programs, and add to the knowledge base of the human services. Based on the literature review one could possibly conclude that minorities are underrepresented and underserved in the vocational rehabilitation system (Wilson, 2000). To this end, utilizing program evaluation as a tool to re-evaluate the eligibility component in the vocational rehabilitation system would provide feedback to increase minority acceptance.

## Literature Review

Acceptance rates have been examined by the rehabilitation community and legislation in great depth. The American Disabilities Amendments of 1992 stated that:

“Patterns of inequitable treatment of minorities have been documented in all major junctures of the vocational rehabilitation process. As compared to European Americans, a larger percentage of African Americans applicants to the vocational rehabilitation system is denied acceptance. Of applicants for service, a larger percentage of African – American cases are closed without being rehabilitated. Minorities are provided less training than their European American counterparts.” (Rehabilitation Act Amendments of 1992, Pub No. 102-569, 106 Stat. 4344-4488, 1992).

Atkins and Wright’s seminal study of 1980 examined the acceptance rate of minorities in vocational rehabilitation (VR). They documented that acceptance rates for African American applicants were proportionally lower (about 5.5%) than European American applicants in vocational rehabilitation programs. Several studies have been conducted utilizing the Rehabilitation Services Administration-911 data and concluded that there are significant differences in acceptance rates for minorities (Chan, Wong, Rosenthal, Kundu & Dutta, 2005; Wilson, Harley & Alston, 2001; Olney & Kennedy, 2002). Evaluation of human service programming is essential to provide information that helps the agency gain political support and continued community involvement (Lewis et al., 2007). Moreover, evaluation can also enhance an agency’s position by providing the means for demonstrating or even publicizing an agency’s effectiveness. The eligibility component of the VR system in six landmark studies stated that acceptance rates for minorities are more likely to be found ineligible for VR services (Herbert & Martinez, 1992; Dzeikan & Okocha, 1993; Feist-Price, 1995; Peterson, 1996; Wilson, 2000; Wilson, Harley, and Alston, in press).

By examining the rate of acceptance for minorities in the vocational rehabilitation system, administrators in the field may gain insight to further evaluate the differences in acceptance rate and discuss avenues for increasing minority acceptance rates.

Historically minorities have been noted in VR for being underrepresented and underserved. Schorr (1997) stated that:

“The moral underpinnings for social action, especially by the government, are not powerful enough in the cynical closing years of the twentieth century to sustain what needs to be done on the scale that it needs to be done. In this era of pervasive doubt, public investment of the needed magnitude will be forthcoming only on evidence of achieving its purpose and contributing to long-term goals that are widely shared.” (p. 136)

The measure of how effective a program is can be determined by the outcomes achieved. Schorr (1997) continued that in the past, outcomes accountability and evaluation were separate activities. Now, however, the accountability world is moving from the monitoring processes to monitoring results. Lewis, et al., (2007) additionally found that the dissemination of evaluative reports describing the agency’s accountability is paramount. People concerned with agency performance can gain knowledge about the results of services, and this information undoubtedly increases community members’ influence on policies and programs. By reviewing the literature of acceptance rates for minorities, a basis for reevaluation is discussed.

Bolton and Cooper (1980) questioned the fact of whether Atkins and Wright’s (1980) study was sufficient to support the conclusion that African Americans and European Americans receive unequal treatment in VR. They replicated the Atkins and Wright (1980) study. Bolton and Cooper were not able to determine the discrepancies of eligibility determination and this concern remains to be highly debated since 1980. Herbert and Martinez (1992) investigated whether ethnicity was statistically significant. They confirmed that minorities specifically African Americans were less likely to be accepted for VR services than their majority counterparts. Dzeikan and Okocha (1993) explored the accessibility of VR services for minority groups: African American, Hispanics, Native Americans and Asian Americans. They agreed with the earlier research done by Atkins and Wright (1980) and Herbert and Martinez (1992) that African Americans were more likely to be found ineligible for VR services. In 1995, Feist -Price

concluded with the same outcome. Hence, the results of these studies investigating VR acceptance and ethnicity between 1980 and 1995 strongly suggest that ethnicity may be an influencing fact in VR acceptance (Wilson, 2002).

## Opposing Research

In contrast to the earlier studies, Wheaton (1995)'s work concluded that the proportions of European Americans and African Americans found eligible for VR services are not statistically different. However, Wheaton (1995) employed different hypotheses and sampling procedures. Although he found no statistical significance he still reported that European Americans (52.7%) had a higher acceptance rate than did African Americans (47.3%). Peterson (1996) concluded that VR acceptance rates among African Americans, Europeans Americans, Native Americans, Eskimos or Aleuts, Asian/Pacific Islanders, Hispanics and "others" were not statistically significant. Wilson (1999) also reported no differences between European Americans and African Americans in VR acceptance rates in his study. Wilson, Harley and Alston (in press) replicated Wilson's (1999) study and the results were similar to those reported by Atkins and Wright 1980. The Wilson et al., (in press) study challenged the findings of Wheaton (1995); Wilson (1999); and Peterson (1996) that ethnicity and VR acceptance were independent. Acceptance rates research continues to be debated.

## Discussion

There are various possible reasons as to why African Americans are less likely to be accepted into VR services than their majority counterparts. Herbert and Martinez (1992), Wilson (2000) and Wilson et al., (2001) noted that one must address the issue of possible discrimination. The current United States VR demographics indicate that about 93% of the VR counselors and 92% of the VR administrators classify themselves as Europeans American (Whitney-Thomas, Timmons, Gilmore, & Thomas, 1999). How one is perceived when seeking VR services has been and still remains an issue in the state/federal system. Further, Rosenthal, and Kosciulek (1996); Sue, Arrendondo, and Mc Davis (1992); and Middleton, et al.,(2000) reported that the stereotypes can lead practitioners to hasty conclusions and unsound postulations about customers. Devine and Elliott (1995) concluded that the stereotypes of African Americans tend to be extremely negative, and Dzeikan et al., (1993) reported that the counselor's perception of the customer's level of involvement may produce an inaccurate determination of the customer's ability to benefit from VR services. Wilson, 2002; Rosenthal and Berven (1999); and Boski (1988) agree that VR counselors, like other health-care professionals, bring their biases and prejudices with them when they are assisting customers. Moreover, Wilson (2002) concludes that VR counselors and counselors in training are like to prejudge people of color based on prior negative stereotypes, when they receive information contradicting these stereotypes; they tend to resist changing their preconceived stereotypes. Consequently, these negative perceptions of African Americans (and others) may or may not be intentional; one can logically contend that some eligibility decisions are based on impressions of a person's ethnic or racial group status in the United States ( Wilson, 2002).

Rosenthal (2004) examined the counselor bias and its effects of consumer's race on the clinical judgment of practicing European American vocational rehabilitation counselors in a web based environment. He specifically investigated whether participants demonstrated bias in their general evaluation, perceptions of psychopathology, and estimates of the educational and vocational potential of African American consumers. Rosenthal, et al. (1999) stated that stereotypes are activated under conditions of uncertainty when limited information is given. Stereotyping provides short cuts to process information on prototypical characteristics. The danger with stereotypes is that initial impressions are resistant to change, even when the advent of contradictory evidence (Eddy, 1990; Elstein, Shulman & Sprafka, 1978). The findings of this study stated that African American consumers were judged more negatively than European American consumers, and these differences persisted after reviewing subsequent information. Middleton, et al. (2000) stated that "professional multicultural rehabilitation competencies and standards are necessary if persons with disabilities from diverse ethnic backgrounds are to be well served" (p. 220). Rosenthal, et al. (1999) stated that negative perceptions of VR counselors unfairly judge African Americans seeking VR services.

Based on this study Rosenthal et al., (1999) concluded that European American VR counselors find some African American consumers ineligible for VR services, having based their decisions on stereotypes and biases.

Alston, Russo, and Miles, 1994; Fujiura, 2000; Jones, 2000; NOD/Harris; 1998 concluded in their studies that despite nearly half a century of civil rights reform and three decades of disability rights legislation, people of color and people with disabilities continue to experience social, economic, educational and vocational disadvantages. Hanna and Rogovosky (1992) stated that persons with disabilities who are also from racial and ethnic minority groups face dual disadvantages within the disabilities services system. A growing body of research has documented important racial differences in all stages of the VR process (Olney et al., 2002) such as the process from application, acceptance, service provision, case closure and current employment status.

Brown (1993) and Wheaton et al., (1996) suggested that the type and amount of VR services provided differ by racial or ethnic group. Wheaton's (1997) research indicated that European Americans were more likely to receive services in the form of college, business school, vocational training, and on the job training than were African Americans. To this end, it is imperative to re-evaluate our VR programming eligibility determination component to identify areas of improvement as it relates to more inclusiveness of minorities in rates of acceptance.

## Conclusion

Although some research shows statistically insignificant differences in acceptance rates across racial lines, the overall evidence shows a significant difference, in favor of European Americans. This unequal outcome is especially true for African Americans, and merits focused attention, at the state and national levels to close the gap.

### Future Research

Vocational rehabilitation as a social intervention program for consumers would be well served if opportunities for improvement are examined. The vocational rehabilitation system based on this literature review is currently serving the majority population. Re-evaluating the eligibility component of vocational rehabilitation by examining counselor bias, providing multicultural trainings to staff, as well as attempting to eliminate subjectivity in the determination process and recruiting more diverse staff into the vocational rehabilitation system may prove to be effective in increasing minority representation the VR system.

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# Celebrex and Potential Heart Disease and Liver Disease: A Personal Account

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## Abstract

The author took Celebrex for seven years, only to find out that it could be associated with heart disease, which I now have, and other possible diseases, too. This article discusses some of my experiences and the possible link between Celebrex and heart disease and other illnesses. It is apparent that while I was helped in various ways, I did not always receive complete, excellent medical advice.

**Keywords:** Celebrex, heart disease, liver disease, Vioxx, Cox 2 inhibitors, lumbar spinal stenosis.

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## Introduction

Several studies or scientific reviews have been performed in the area of COX 2 inhibitors and heart disease, including some preventive qualities of aspirin (1-11). There is some evidence that Celebrex and Vioxx increase the risk of heart disease. (12).

I took Celecoxib (Celebrex) for seven years for the pain of lumbar spinal stenosis. That disease causes back and leg pain. Celebrex seemed to help a lot, causing me to suffer less pain. But, as a COX-2 inhibitor it may have put me at risk for heart disease. Indeed, six years ago I was diagnosed with 90% clogging in two coronary arteries and 70-80% clogging in two other coronary arteries. I do not know if this is coincidental or if the coronary arteries being clogged was somehow caused by my taking Celebrex.

I finally decided to stop taking celecoxib (Celebrex) after all the negative publicity about Vioxx (also a COX-2 inhibitor) ensued. I called the nurse of my cardiologist (I do not get to speak to the cardiologist directly, as most people probably find if they try to communicate with their doctor). I got the answering machine and I asked about the wisdom of continuing vs. discontinuing Celebrex. She never returned my call. I called the nurse (or whoever it was who worked in the doctor's office; it might not have been a nurse) of my regular doctor, and this "nurse" incorrectly informed me that Celebrex was taken off the

market and I should stop taking it immediately. I informed her that she was thinking of Vioxx which had just been taken off the market, but she wrongly insisted that she was correct.

### SEEKING ADDITIONAL HELP

Unable to find out locally what I should do, I sought advice from my brother, a Yale University Ph.D. in medical sociology, who works for a large HMO (Health Maintenance Organization) in another state. He asked some doctors there and one said I should not take Celebrex for more than a year, due to possible liver damage. I had already taken it for seven years. I quit immediately. For two weeks I felt more pain than I should, but after that my pain went away. I still get back and leg pain, especially if I walk to any great extent or bend over. But, after initially helping a lot, Celebrex was apparently no longer doing much for me in everyday matters, and things seemed to work out well when I stopped taking it.

### CONCERNS ABOUT VIOXX AND CELEBREX

An excellent summary of information regarding concerns about Celebrex and related drugs can be found in Bennett et al. (13). Bennett et al. said

“Recent clinical trial data have raised questions about the degree to which patients and their physicians should consider an increased risk of cardiovascular or cerebrovascular events when selecting medications for pain relief. In September 2004, Merck announced a voluntary worldwide withdrawal of Vioxx (rofecoxib) because of an increased risk of heart attack and stroke. In early December 2004, the US Food and Drug Administration (FDA) announced a "black box" warning for Bextra (valdecoxib), stating that its use in patients undergoing coronary artery bypass grafting is contraindicated. A week later, the National Institutes of Health suspended the use of Celebrex (celecoxib) in the APC (Adenoma Prevention with Celecoxib) clinical trial because of increased cardiovascular events. The drug was not removed from the market, but the FDA advised physicians to consider alternate therapy or to use the smallest effective dose of Celebrex. Three days later, the National Institutes of Health announced that the ADAPT (Alzheimer’s Disease Anti-inflammatory Prevention Trial) showed an increase in the risk of cardiovascular events in patients given naproxen but not in those given celecoxib; the trial was halted. At the end of 2004, the FDA issued a Public Health Advisory summarizing the agency’s recent recommendations concerning the use of the nonsteroidal anti-inflammatory drug products (NSAIDs) Vioxx, Bextra, Celebrex, and naproxen.” (13, p. 1713).

Thus, Celebrex was never removed from the market (contrary to what the “nurse” told me) but the federal government did temporarily suspend its use in a clinical trial, because of concern about possible increased risk of heart attack.

Presented below is information from the U.S. Food and Drug Administration regarding Celebrex (14), which raised questions about using the drug.

### THE U. S. FOOD AND DRUG ADMINISTRATION ALERT ON CELEBREX

#### Patient Information Sheet

Celecoxib (marketed as Celebrex)

This is a summary of the most important information about Celebrex. For details, talk to your healthcare provider.

---

[FDA ALERT-\[4/7/2005\]: Celebrex has been linked to an increased risk of serious cardiovascular \(CV\) events \(such as heart attack or stroke\) which appears to be a risk shared by all medicines called non-steroidal anti-inflammatory drugs \(NSAIDs\) \(excluding aspirin\).](#)

[FDA has requested that the package insert \(labeling\) for all NSAIDs, including Celebrex, be revised to include a “boxed” or serious warning to highlight the potential increased risk of CV events, and the well known risk of serious, and potentially life-threatening, stomach bleeding. FDA has also requested that the package insert for all NSAIDs be revised to state that patients who have just had heart surgery should not take these medicines.](#)

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### What is Celebrex?

Celebrex is used to:

relieve symptoms of osteoarthritis (the arthritis caused by age-related “wear and tear” on bones and joints)

relieve symptoms of rheumatoid arthritis in adults

manage acute pain in adults (like the short term pain you can get after a dental or surgical operation)

treat painful menstrual cycles

reduce the number of colon and rectum growths (colorectal polyps) in patients with a disease called Familial Adenomatous Polyposis (FAP). FAP is an inherited disease in which the rectum and colon are covered with many polyps. Celebrex is used along with the usual care for FAP patients such as surgery and exams of the rectum and colon.

### Who Should Not Take Celebrex?

Do not take Celebrex if you:

have had an allergic-type reaction to sulfa medicines.

have had asthma, hives or allergic-type reactions after taking aspirin or other NSAID (nonsteroidal anti-inflammatory drugs) medicines. If you have asthma, you may have aspirin-sensitive asthma. If an aspirin-sensitive asthmatic takes aspirin it can cause severe narrowing of the airway (bronchospasm), and even death. Since this type of reaction also has occurred after taking NSAIDs Celebrex should not be given to aspirin-sensitive patients.

Some examples of NSAIDs are ibuprofen (Motrin, Advil), naproxen (Naprosyn, Aleve), diclofenac (Voltaren, Cataflam), and ketoprofen (Orudis). You can ask your doctor or pharmacist for a complete list of these medications.

are pregnant, especially during your last 3 months

### What are The Risks?

Celebrex and other NSAID medicines can cause serious problems such as:

Stomach ulcers that bleed. The chance of this serious problem increases the longer you take Celebrex, but it can also happen suddenly. Stop taking Celebrex and call your healthcare professional right away if you get a burning stomach pain, black bowel movements that look like tar, or vomit that looks like blood or coffee grounds.

Liver damage. Some of the warning signs of liver damage are nausea, vomiting, tiredness, loss of appetite, itching, yellow coloring of skin or eyes, “flu-like” symptoms and dark urine. If this happens, stop taking Celebrex and call your healthcare professional right away.

Kidney problems that include sudden kidney failure or worsening of kidney problems that you already have.

Fluid retention (holding of water in your body) and swelling. Fluid retention can be a serious problem if you have high blood pressure or heart failure.

In addition to the serious side effects listed above, some common, but less serious side effects with

Celebrex may include:

headache  
indigestion  
upper respiratory tract infection (a "cold")  
diarrhea  
sinus inflammation  
stomach pain  
nausea

### What Should I Tell My Healthcare Professional?

Tell your healthcare professional if you:

have heart problems or high blood pressure  
have liver or kidney problems  
have or had stomach ulcers or stomach bleeding  
have asthma  
are allergic to aspirin or other NSAID medicines  
are trying to become pregnant, are already pregnant, or are breast-feeding

### Are There Any Interactions With Drugs or Foods?

Tell your healthcare professional about all the medicines you take, including prescription and non-prescription medicines, vitamins, and herbal supplements. Some medicines may affect how Celebrex works or Celebrex may affect how your other medicines work. Your healthcare professional may have to adjust your dose or watch you closely if you take any of the following medications:

certain blood pressure medicines called ACE inhibitors  
furosemide  
fluconazole or ketoconazole  
phenytoin  
warfarin  
aspirin

Celebrex FDA Approved 1998

Patient Information Sheet Revised 04/2005

Patient Information Sheet - Questions? Call Drug Information 301-827-4570

Date created: April 7, 2005

## Conclusion

In conclusion, there is no way to know for sure if Celebrex led to my coronary artery disease or my current liver problems (see below), but I should have received warnings from doctors about that possibility and I should have been warned about not using Celebrex for more than one year due to possible liver damage. As a patient, I may have been put at risk unnecessarily, for heart disease and for liver damage. More information from doctors and nurses would have been appropriate and perhaps very beneficial.

I have lumbar spinal stenosis, which involves a wearing away of the protective covering of the spinal cord. Spinal cord problems can be associated with psychological problems, as well, as recently shown by Craig, Tran, Lovas, and Middleton (15). And pain can lead to loss of intimacy, as shown by Bral, Shaughnessy and Eisenman (16). Initially, Celebrex helped ease some of the pain associated with lumbar spinal stenosis. But, the threat of heart disease made me give it up, after seven years usage.

I also have heart disease (specifically, coronary artery disease) although the blockage is now less than when originally diagnosed. However, the medical tests done on me in recent years do not allow my

cardiologist to say exactly how much less blockage there is. Probably, quite a bit of blockage remains. Heart disease can also lead to psychological problems, as well as the obvious medical ones. Thus, I have suffered from physical and, likely, psychological problems due to limitations on what I can do, imposed by my conditions. And, some of my problems may have been caused by medicine intended to help me. In fact, I just recently had a Hida Scan to evaluate my liver, and it is barely functioning. My family doctor suggested that I either have my liver taken out or avoid dairy, fatty, and greasy foods. I am opting for the latter.

I previously wrote of some my experiences with physical disability (17). This current article takes the discussion of illness further, to consider other diseases and to consider if Celebrex is potentially harmful. Not all treatment will be ideal, and often patients will receive less help than should be the case (18).

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# A Qualitative and Quantitative Review of Equine Facilitated Psychotherapy (EFP) With Children and Adolescents

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## Abstract

This paper presents a comprehensive review of the literature on Equine Facilitated Psychotherapy (EFP) with children and adolescents. Methods used in EFP, including traditional mounted, vaulting, husbandry, and unmounted activities are described. The theory and background of EFP is summarized with references to various psychotherapeutic perspectives, such as Freudian, Jungian, cognitive, behaviorist, and psychodynamic models. The status of the research is discussed, and available empirical studies and reports on this topic are summarized. Possible applications to patients with eating disorders, anxiety, trauma history, attention-deficit hyperactivity disorder, oppositional defiant disorder, and delinquency are described. Recommendations are made regarding the direction of future research on EFP.

**Keywords:** Equine facilitated psychotherapy, youth, review

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## Introduction

In the fifth century B.C. horseback riding was used for rehabilitating wounded soldiers (Gamache, 2004). In 1860 Florence Nightingale suggested, “[an] animal is often an excellent companion for the sick” (p. 103). For many years, animals have been used for the therapeutic benefit of humans in a variety of settings. For example, domestic animals are used to help medically ill children in hospitals and the elderly in nursing homes. But it was not until the 1960s that horses were used in the United States for therapeutic purposes (Engel, 1984).

There are many different names to describe therapeutic interactions between humans and animals. The examples listed above describe animal assisted activities (AAA; Brooks, 2006). In contrast, animal assisted therapy (AAT) is more targeted; it is defined by the Delta Society as a “goal-directed intervention in which an animal that meets specific criteria is an integral part of the treatment process” (Brooks, 1996, p. 197). In AAT the therapist should have a good idea of how working with animals in therapy can be different from traditional psychotherapy. The therapist and the client should have a clear understanding of the therapeutic goals so the client does not confuse it with a social outing. An example of AAT would be a psychotherapy session with a child in which an animal is included in the treatment. For example, Dr. Boris Levinson, the individual often credited as the founder of animal assisted therapy (Lacoff, 2000), was a child psychologist who began using this method by using his dog “Jingles” to facilitate psychotherapy with children.

By the above definition, Equine Facilitated Psychotherapy (EFP) is a type of AAT. Specifically, EFP is a planned treatment using the horse as an integral part of the psychotherapy process (Nilson, 2004). In addition to the name Equine Facilitated Psychotherapy, also encountered in the literature were the titles Equine-assisted psychotherapy (EAP), equine-assisted experiential therapy (EAET), Equine-facilitated therapy (EFT), Equine-assisted learning (EAL), Equine-facilitated learning (EFL), therapeutic riding, psychotherapeutic riding, and hippotherapy (more frequently used to describe physical rehabilitation/therapy; Gasalberti, 2006).

In EFP, therapists work with horses with different styles and using various theories. Esbjorn (2006) reviewed the construct and found that there was a wide variety in the way therapists conceptualized EFP. Not only do the concepts, theories, and names surrounding EFP vary, but also the methods are quite different. Some therapists use un-mounted activities such as herding and leading. Some use non-traditional mounted instruction such as vaulting. Others provide traditional riding instruction. Some focus on care of the animal (husbandry). Some work in groups, others work individually. Many therapists use various combinations of these techniques.

Despite these differences, there is typically agreement in why horses are ideal for psychotherapeutic work: specific equine qualities (such as having a calming effect while requiring total attention to the moment), prospects for metaphor, and relational features (Esjborn, 2006). The horse is a prey animal and is also distinctly social. Fight or flight instincts govern the horse's behavior. Naturally living in herds, the horse is accustomed to social experiences. For these reasons, the horse pays great attention to detail. Accordingly, the horse may respond to things that go unnoticed by humans. It is largely because the horse is social and has great attention for detail that it has been domesticated and trained by humans for thousands of years. During the past century, horses have been used in programs aiding persons with physical disabilities. Riders benefit from the gentle rocking motion that may help to relax muscles and improve balance.

The horse's large size is another factor that may contribute to therapeutic benefit; the horse weighs easily a thousand or more pounds. Some theorists contend that the horse's power and size provide opportunities for riders to explore issues related to vulnerability, power, and control. Lastly, the straightforward nature of the horse's interactions also may lead to therapeutic gains. The horse is not duplicitous in behavioral interactions, and communication between horse and rider is typically clear and unencumbered (Taylor, 2001). Consequently, horses may be instrumental in retraining humans in direct, honest communication.

## Method

This paper will attempt to quantify how well EFP works, and illustrate the way it works by examining the articles, chapters, and books written on the subject of animals and therapy. PsycINFO and MEDLINE were searched using the terms, "equine facilitated psychotherapy" and "animal assisted psychotherapy." Search limits were not restricted. Because few articles were found with this method, a Google internet search was done to access more material. Due to the paucity of results, papers with adults were included, as it was deemed that general findings may be applicable to work with children and adolescents. Search limits were restricted to papers/studies addressing subject matter similar in subject to those found on research databases.

## Results

### Qualitative Review

## Theory

To get a basic understanding of EFP, first some conceptual models and examples will be discussed. Brooks (2006) described two conceptual models. The first is a triangle of patient, animal, and therapist in which the therapist observes the behavior of the animal and patient. The behavior of the animal is interpreted to the patient. The effects of the patient's behavior on the animal are reflected to the patient, and the patient is encouraged to reflect on his/her own behavior and affect. The second is the diamond of patient, animal, therapist, and animal handler. The handler has the responsibility to observe and state how the other two are affecting the animal. These methods emphasize the fact that horses in particular (of animals) will be affected by discrepancies between stated intent and observed behavior.

Brooks (2006) described a 13 year-old with swearing and rude behavior. This patient's violent and desperate behaviors stemming from fear of rejection did not serve to bring people close to him, but rather pushed people away. The author notes that "animals can teach children about energy, boundaries, how we move our bodies, and the intensity of purpose we bring to others... because they

are very sensitive to our energy and how we move around them. If we move too fast or want to touch [them], they often move away from the intensity of the energy we convey... [they] are generally careful about maintaining personal space. However, they are also very curious and will usually approach a human who remains calm and unaggressive” (p. 208-209). The case demonstrates how youths can learn to respect the boundaries of the animal and still have positive interaction with the animal.

Brooks also describes a six year-old who was witness to violence and had problems with behavioral acting out. The animal was used to illustrate healthy touch and an analogy was made to Winnicott’s holding environment. This is a safe space, both physical and psychological, which is created by the mother unbeknownst to the infant.

Another study compared a “zoo-group” of children with a control group (Voelker, 1995). Both groups were diagnosed with attention-deficit hyperactivity disorder (ADHD) and conduct disorder. The zoo-group had responsibility for and interaction with a variety of animals for about four hours per week. In three months, the children in the zoo program had a decline of one standard deviation in symptomatology (aggression). During this period the control group had 35 episodes of very aggressive behavior, while the zoo-group had zero. Efficacy reportedly lasted for four years or more.

Work with horses also may be used to break through a client’s defensive barriers and require them to develop fresh insights and perspectives for dealing with their old patterns and problems in a way that conventional office therapy does not (Tyler, 1994). In EFP, clients who are behaving in ways that were inconsistent with feelings or thoughts are required to become behaviorally consistent and cooperatively affective in order to work with the horse. While a therapist in office work might not be aware of the dissonance, the horse may display unsettled behavior until the client was internally consistent.

There are a variety of theories as to how and why EFP works. These range from the more physical concepts such as relaxation training taught on horseback, to more intangible ideas like self-awareness, to abstract schemas of unconscious. Roberts (2004), for example, describes the horse as a living, breathing biofeedback machine because it externally reveals internal processes in real time. She discussed how nursing students benefited from EFP while learning how the program worked for their child clients. The students had an opportunity to participate in a one day learning experience in horse therapy. According to Roberts, “EFP is not just pet therapy. Horses are unique in their response to humans because they are prey animals, not predators, and their survival demands that they be extremely sensitive to the environment... Horses respond to the internal state of the person, no matter how much the person tries to disguise it” (p. 33). Nursing students were able to take different perspectives on disease and think more creatively about how to help their patients after the program.

Patients with eating disorders describe another treatment population. Christian (2005) detailed work with a patient with anorexia who benefited from equine-assisted therapy. In one session, the patient participated in un-mounted activities using problem solving with two therapists, an equine specialist, and three horses simultaneously. Post-session, practical applications to life outside treatment were discussed. In another session, the patient was mounted and had other challenges to solve. Therapists reflected behavior and drew analogies to the patient’s life choices. The patient learned to ask for help and be specific in her requests. In addition her attitude improved and she became more optimistic about recovery. Cumella (2007) described multiple benefits experienced by clients, including improved self-confidence, self-efficacy, communication, trust, perspective, assertiveness, and boundaries. Another group that may benefit from EFP is clients with problems relating to physical contact or closeness. For example, Bates (2002) noted that “being carried” by a horse may have positive associations for women who have shunned physical closeness by humans.

Vidrine (2002) discusses different ways that therapeutic riding may be beneficial. One way is teaching humans to send congruent messages with spoken and body language. Horses communicate almost entirely through body language and are not capable of “double-bind” communication. A horse can be perceived as a very large mirror to promote conscious attention to our specific behaviors. This encourages authentic communication and awareness of our secret intentions. An article by Colclasure (2004) provides a quote from the director of the Remuda Ranch equine program, “[Horses] are relational animals that have the natural ability to mirror what our body language is saying. As a result, [we are] able to gain insight into [our] own nonverbal communication and behavior patterns” (p. 2).

Another conceptualization, based on the theorized importance of rhythm as one the first experiences of a developing child, uses equine therapy to build up “body-identity” and help with correcting pre-verbal dialogue. Because humans can actually ride horses, there is a unique relationship there that is not present with a dog or cat. A literal holding and sustaining dynamic is created when a rider has close skin contact with a big and supporting living being. A noted point is that the ratio between the body weight of a horse and rider is not unlike the body weight ratio between a mother and infant. The horse may interact with the individual in an appropriate and physical way that would not be possible for the therapist.

The uninhibited nature and unconditional response of the horse also may be of importance. Quoting Vidrine, “Horses are, by and large, naked and unashamed. They get dirty and eat off the ground; they are hairy and at times, sweaty, and breathing hard. They relieve themselves when they need to, their genitals are visible, yet clients can safely physically interact with them on a fairly intimate basis... [and] at a pace they can control... Horses are also not judgmental... and don’t know if you are small for your age, or have crooked teeth” (2002, p. 595). These qualities may contribute to greater connectedness and self-acceptance on the part of the rider.

Vidrine (2002) also discusses the importance of archetypes as emphasized by Carl Jung. Some old archetypes are the Pegasus and the unicorn. Some modern archetypes are embodied in the stories of *The Black Stallion* and *Misty of Chincoteague*. Some particular aspects of horse archetype are: worker, bolter, helper, victim, vital, destructive, sensitive, and panicked. The horse provides a whole new object that may be projected upon with various transferences. Children may imagine horses as magical, powerful, beautiful, brave and strong. These perceptions may contribute to the therapeutic benefits of EFP for children. Vidrine describes her work with children and vaulting and describes some of the noted benefits. Children were very motivated to attend sessions. EFP taught structure, responsibility, routine, care for another (the horse), empathy, safe mistake-making, the value of practice and mastery, discipline, problem-solving, body awareness, visual learning, patience, respect for others choices, creativity, self-esteem, relaxation, the value of completing necessary but unpleasant tasks, self-reflection, and nurturing. In addition, the fact that the EFP was done as a group activity widened the children’s “circle of trust” and promoted interpersonal interaction.

Bates (2002) uses an analogy comparing the id, ego, and superego to the horse, patient, and therapist, respectively. The horse also may be represented as the object of transference. The rider’s repressed id can be associated to horse’s impulsivity and vitality. The therapist acts as superego, limiting the rider and horse to safe behavior. Scheidhacker stated, “the therapist’s job (superego) [is] to show the patient (ego) how to control the horse (id) without losing the horse’s vitality” (1997, p33). Therapeutic benefits are achieved in part through ego strengthening.

The husbandry and care of an animal can be instrumental in healing. McCormick and McCormick wrote a book called *Horse Sense and the Human Heart* (1997) in which the human-animal bond, including the myth and metaphor of horses are emphasized. The authors promote the Jungian perspective that wild horses represent the instinctual, uncontrollable parts of the unconscious and that

the centaur represented an attempt to integrate these separate parts. The McCormicks had many different ways to use horses therapeutically; they varied from simple observation, to animal husbandry and care, to grooming and riding. They chose to use the Spanish Peruvian horse for these interactions because it was known for a “gentle, consistent, trustworthy disposition” (p. 43).

The McCormicks see holding and touch as instrumental in development. Horses can provide this in an appropriate manner to aid in correction of negative experience. They discuss a specific case in which a 16 year-old was helped with a psychotic break. The use of trance in therapy and the horse as a means to help a rider focus into an alpha meditation state are explored. The natural gaits and regular motion of the horse may promote this rhythm and relaxation.

The authors differentiate between the words “feeling” and “emotion.” “Feel” comes from “felen” (middle English) and concerns sensations and perceptions. “Emotion” comes from “emouvoir” (middle French) and describes movement and behavior (expressed feeling). The horse’s sensitivity may help a person coordinate their emotions with their feelings.

Taylor (2001) detailed how horses may be used in family, cognitive behavioral, play and analytic therapy. She related many possible benefits including decreased therapist burn-out and increased client motivation. Correspondingly, in a comprehensive paper in 2007 on the theory and methods of EFP, Karol expounded on the potential therapeutic benefits of EFP for patients working with professional psychotherapists. She notes that very few EFP programs use professionals at a masters or doctorate level. Within the context of traditional psychotherapy, the therapist may use traditional equitation instruction as a therapeutic tool. She states that the use of EFP can help the therapist explore the world of the client on verbal, non-verbal, and pre-verbal levels. Karol reports, “When an advanced-level clinician works in the EFP setting, the therapeutic work can move from a narrow use of cognitive-behavioral techniques, here-and-now therapies, and limited stages of personality development to a more complete psychotherapeutic experience and involvement” (p. 78). It is noted that while CBT and psychodynamic theory could be widely applied to EFP, this multimodal approach to therapy remains very uncommon. She details her work with children in EFP, and describes how the sessions are developed and what guiding principles are used. She observes that like traditional psychoanalytic work, in EFP the therapist and client are often free to talk without focusing on the facial expressions and reactions of the therapist.

Karol discusses six aspects of psychodynamic work done in sessions: existential experience (including aspects of biofeedback, here-and-now attention, and immediate communications), unique relationship with the horse, therapeutic relationship with the therapist, nonverbal experiences communicating with the horse, preverbal experiences such as comfort, touch and rhythm, and the use of metaphor. She notes that, “When a child is on top of a horse, sometimes for the first time in [that] child’s life, he or she is looking down onto an adult... and can experience power... and an enhanced sense of his/her own body... [furthermore] the horse is also a vulnerable creature and so serves as an apt companion for a child overwhelmed by his or her own sense of vulnerability and imperfections” (p. 81). The relationship with the horse can help develop a child’s self-concept and ethics. Transference can occur in relation to the animal and be used therapeutically, and countertransference may develop, especially if the client takes out his/her frustrations on the animal. Nonverbal experiences communicating with the horse refers to how the client listens for and interprets the nonverbal cues of the horse. This can be expanded into how the client relates to the outside world in human behavior and communication. Preverbal experiences relate to the development of object relations. Karol states she sometimes uses music to augment and encourage the development of an internal consistent rhythm. Metaphor can be developed through the child’s imagination, through problem-solving, or through story-telling. Metaphor can help bridge the inner and outer worlds of the client. Karol describes EFP as a “theater” in which to explore and catalyze change in the child’s universe.

## Effects on the horse

So EFP may be helpful to humans, but what effect does it have on the horse? Kaiser (2006, 2006) published a studies concerning the well-being of the horse in which the question “Does therapy using horses cause the horse too much stress?” was addressed. Stress indicators were behaviors such as ears-pinned, head tossed, etc. The results suggested that equine therapy with at-risk children might stress horses more than simple lessons with recreational riders. This might be due to behaviors that at-risk children sometimes exhibit (e.g., sudden movements, not following safety directions, making loud noises).

Moors (2003) did a biography of a horse used for therapy sessions. He was a 16 year-old palomino Quarter Horse gelding named “Yeller.” Yeller’s disposition was described by a mother of a patient as quiet and calming. He was used as a therapy and lesson horse at the Rancho Vista Equine Center in Fort Collins, Colorado. Previously a 4-H horse, he was described as having a tranquil, steady gait. His owners stated that his toughest challenge was to adjust to many different riders with varying skill levels.

### Treatment populations

Therapists use EFP as treatment for many different patient populations. Bates (2002) reviewed three 1997 studies that showed that once per week riding contact with horses decreased the number of acts of aggression in young people who were “seriously emotionally disturbed.” This author concluded that Equine Facilitated Psychotherapy is recommended for use with patients with anorexia, substance abuse, schizophrenia, borderline personality and abusive behavior. EFP was also considered for use in a therapy program for mothers and children to teach parenting and relating.

Tyler (1994) found equine therapy was effective in treating patients who were fearful, anxious, depressed, angry, or dissociative. However, Tyler asserts that because the therapy is expensive and time consuming it should be limited to clients who are not reached by conventional methods. An example was provided of a post-traumatic eight-year old boy with conversion disorder affecting speech. He started speaking after his third therapeutic riding session. Treatment with horses was also valuable with “counselor-wise” adolescents with a diagnosis of oppositional defiant disorder.

Besides the diagnoses mentioned above, “special needs” is another area where EFP has been used. A few articles have been published in the online magazine of Arizona State University (ASU) on equine therapy by McCann (2005, 2005). She reports on some studies by Crews who is the director of ASU’s Alternative Intervention Research Clinic. For six years Crews studied the effect of sports on children with special needs such as ADHD, emotional disorders, low-income and other at-risk groups. She compared golf, swimming, basketball, horseback riding and many others. She stated, “The most consistently positive intervention [with these groups] was the horse therapy” (p. 2).

As mentioned previously, people with eating disorders are another treatment population that may benefit from EFP. Marx (2003) discussed the use of horses in therapy at Remuda Ranch, a center for the treatment of eating disorders. It appeared due to case reports that this was effective, but he called for empirical studies to evaluate the effectiveness of this method.

Vidrine (2002) summarizes three studies using therapy with horses. One study with children with special education needs showed increased positive behavior among the study participants. Another demonstrated increased social acceptance and self-worth with children with behavioral problems, and a third evidenced improved self-concept among asocial adolescent males. Vidrine suggests that therapy with horses may be particularly effective in treatment of refractory and guarded patients.

Treatment is not limited to mood and childhood disorders. Scheidhacker (1991) found that using horseback riding with patients with severe mental illness facilitated treatment gains. Specifically, he used this method in his German clinic with people diagnosed with schizophrenia, resulting in positive outcomes.

Work with male gang youths is described in detail by McCormick and McCormick (1997). They describe their work with severely emotionally disturbed teenagers and Peruvian Paso horses in Calistoga, California. The boys gained knowledge about discipline and education by watching the family unit of a stallion, mare and foal, and then by learning themselves the care and routines of horses. The authors mention that no client was forced to do anything; all were allowed to proceed at their own pace. They note the case of one gang boy who stated he initially did not like horses but eventually went through their program and left the gang to become a productive member of society, eventually joining Peace Corps. They recommend use of these methods when traditional psychotherapy fails.

#### Quantitative Review

Having described theory and practice, it is now time to turn to efficacy. The quantitative data (Table 1), presents findings from 12 studies representing data from at least 300 participants. Their problems include abuse, behavioral disorders, being “at-risk” or juvenile offenders, “various mental health problems,” post-traumatic stress disorder (PTSD), “in a residential facility,” “psychiatric disability,” and bereavement. Interventions varied from hippotherapy, to therapeutic riding, to EFP (equine facilitated psychotherapy), to EFT (equine-facilitated therapy), to EAET (equine-assisted experiential therapy). Outcomes measured also varied. They included “effective intervention”; qualitative positive results; decreased anger, aggression, depression, and dissociation; increased self-esteem, locus of control, global assessment of functioning, “life-functioning,” self-confidence, self-esteem, attention-span, verbal communication, and “cognitive areas.” One study mentioned some negative effects on the self-esteem of non-clinical adolescent girls. A particularly important noted negative outcome was increased aggression in another study. It was discussed whether attachment to and then loss of the animal could have been a factor leading to this negative finding. Positive outcomes in the above studies included decreases in anger, depression, dissociation, and aggression and increases in self-esteem, self-confidence, attention-span, and social interaction.

Table 1  
Summary of Quantitative Sources

Reference	Type	N	Intervention	Outcome
Bizub et al. (2003)	Study	5 adults with psychiatric disabilities	Therapeutic riding	Improvements in self-efficacy and self-esteem
Bowers, MacDonald (2004)	Study	10 at-risk adolescents	7 equine facilitated psychotherapy sessions of 1.5 hours each	Decreased feelings of depression per self-report
Bradberry (2006)	Presentation	7 women with history of abuse	“participation in Equine Facilitated Psychotherapy”	Taped interviews showing EFP as an “effective intervention”
Ewing (2007)	Article	28 children aged	9 2-hour EFP	No statistically



		10-13 with learning and behavioral disorders	sessions	significant results; qualitative positive reports
Frame (2006)	Paper	15 licensed therapists	“Experienced in EAP/EFP”	Perceived that depressed adolescent clients improved self-esteem and self-efficacy and decreased isolation
Glazer (2004)	Literature review	5 bereaved children aged 4-14	6 week hippotherapy program	Increased self-confidence, trust, self-esteem
Hayden (2005)	Paper	10 at-risk youth	“participation in Equine Facilitated Psychotherapy”	Presence of protective processes of resilience
Hemenway (2007)	Study	10 non-clinical adolescent ♀	“horseback riding”	Improved mood, reduced depressive feelings; positive and negative effects on self-esteem
Kaiser, Smith (2006)	Abstract	17 at-risk children (6 ♂), 14 special education children (7 ♂)	8 sessions of therapeutic riding	Significant decrease in anger in special education boys
Klontz et al. (2007)	Study	31 adults in a residential program	28 hours of equine-assisted experiential therapy (EAET)	Reduction in regret, guilt, resentment, fears for future. Enhancement in self-support and independence.
Lehrman (2001)	Literature review	Case study of 10 year old with multiple impairments, some physical	10 weeks hippotherapy	Increase in verbal communication and attention span
MacDonald (Download 2007)	Paper, review of several programs	13 at-risk 13-16 year olds	14 Equine facilitated therapy (EFT) sessions	Significantly higher scores on self-esteem and Locus of Control measures

MacDonald (Download 2007)	Paper, review of several programs	20 juvenile offenders and at-risk children aged 11-17 years	6 EFT sessions of 2 hours each	Significantly lower scores on aggression
MacDonald (Download 2007)	Paper, review of several programs	10 at-risk 13-17 year-olds	12 EFT sessions of 2 hours each	No statistically significant results
MacDonald (Download 2007)	Paper, review of several programs	33 at-risk 8-16 year olds	10 EFT session of ~2 hours each	Statistically significant increase in aggression (“termination issues”)
MacDonald (Download 2007)	Paper, review of several programs	14 at-risk 8-14 year olds	9 EFT sessions of 1.5 hours each	No statistically significant results
MacKinnon (1995, 1995)	Literature review	11 studies reviewed	Various times of therapeutic horseback riding	Increase in attention span, self-confidence, self-esteem
Schultz (2007)	Study	63 children with experiences of intra-family violence	Average of 19 EAP sessions	Improvements in GAF scores (average 8 point improvement)
Shambo (2006)	Paper	6 women with PTSD	10 EAP sessions	Self report on outcome questionnaire: Significant improvement in depression, dissociation, and life functioning
Splinter-Watkins (1999)	Literature review	12 References reviewed	Therapeutic riding	Improvements in sensorimotor, psychosocial, and cognitive areas

## Discussion

Considering all the varieties of method, style, technique and treatment groups described above, how is a therapist to make a choice about EFP in treatment with children and youths? Overall, the idea of this unconventional therapy is very appealing, especially for difficult to reach groups of patients. Mentioned several times were “therapy-wise” patients, hardened youths, and gangs. Furthermore, abused, eating-disordered, or neglected children who do not respond to the typical office therapy might also benefit. Also compelling was the theory of a holding environment and the related detail concerning similar ratios of horse/human versus mother/infant sizes.

While the described literature is quite fascinating, and possibly convincing on an individual basis, to get a conclusive evidence base on the efficacy of EFP for a particular population, a large multi-center study is needed. It should be standardized, controlled, and longitudinal. Additionally, the terminology, methods, and theories in this field are rather varied. Standardization of the language used to communicate between them would be recommended. The treatment population studied within a given study should be homogeneous and clearly described. Well-established, reliable and valid measures should be used to measure outcomes.

As Taylor (2001) noted, like any developing field, EFP has at this time much more literature on practice than on research and theory and currently therapists fall into two groups: those who are willing to try out an “experimental” therapy and those who are waiting for more studies to come out. Longitudinal studies using biofeedback to measure physiologic heart rate variability, skin conductance level, and even beta vs. alpha brain wave activity, and blood samples measuring neurotransmitter uptake could significantly enhance research efforts.

Biofeedback was referred to in several articles. A noted point was how the natural gaits of a horse might promote relaxation and the alpha meditation state. It would be an especially remarkable study to pair already available software programs (Wild Divine, 2008) that measure physiological biofeedback with equine facilitated psychotherapy. Physiological parameters tracked by these programs, such as previously mentioned skin conductance and heart rate variability, could be used as outcome variables in such research.

Cautionary tales warned that specific goals should be delineated when embarking on this atypical therapy and the patient should have a clear idea that despite the use of an animal. EFP is not a recreational activity. The therapist should also be unambiguous in establishing boundaries with the patient since the treatment is done in a non-conventional setting and therefore limits could possibly be confused or blurred.

Regarding obtaining sound and conclusive evidence for the quality and efficacy of EFP, the following design is recommended: 1) multi-center, 2) standardized types of EFP compared in different treatment arms, vaulting vs. animal care vs. riding vs. non-riding, 3) longitudinal (pre-treatment, and at least 2 years post-treatment), 4) controlled (using a treatment-as-usual control group), 5) outcomes of four types: cognitive, emotional, behavioral, and objective physiological variables.

For more information on using horses in psychotherapy and various biofeedback sites see the following:

[www.bearspotfoundation.org](http://www.bearspotfoundation.org)

[www.catr-therapeuticriding.org](http://www.catr-therapeuticriding.org)

[www.eagala.org](http://www.eagala.org)

[www.heartmath.org](http://www.heartmath.org)

[www.horsesenseotc.com](http://www.horsesenseotc.com)

[www.narha.org](http://www.narha.org)

[www.serenityfarm.org](http://www.serenityfarm.org)

[www.takeflightfarms.org](http://www.takeflightfarms.org)

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# Evaluation of the rehabilitation process in Greek Community Residential homes: resettlement from Greek Psychiatric Hospitals

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## **Abstract**

**Objective** The aim of the study is to evaluate the impact of transfer of care from the psychiatric hospital to community residential homes on the patients' level of social functioning, one year after discharge. **Method** A repeated measures design was employed in order to compare 73 patient's level of functioning one week before the transfer to the psychiatric hospital and one year later in community residential homes. A Personal data and psychiatric history form was used as well as the Scale of Rehabilitation Evaluation of Baker and Hall (1984). Descriptive statistics and One-Way ANOVA were used to analyze the data. **Results** A statistically significant improvement was noted in the rehabilitation and social functioning status of the patients ( $p < 0.01$ ). **Conclusions** Specific interventions developed in the community residential homes seems to have positive impact in many domains of social function of chronic psychiatric patients.

**Keywords** psychosocial rehabilitation, social functioning, Greek psychiatric reform, community residential homes

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## Introduction

Until the beginning of the psychiatric reform, the mental health system in Greece was highly centralized, lacking primary care and rehabilitation facilities. The operation of the psychiatric hospitals was anachronistic and failed to serve the needs of the population. Psychiatric care was provided mainly in 9 state psychiatric hospitals (some were commonly called “warehouses of chronic psychiatric patients”) and 40 private hospitals. The Greek psychiatric reform began in 1983 with the introduction of the National Health System and the membership of Greece in European Community. A five year plan was then constructed aiming at developing sectorization, deinstitutionalization of chronic psychiatric patients, implementation of psychiatric clinics in General Hospitals, development of community mental health facilities within the sectors and programs of prevocational and vocational rehabilitation. The implementation of the plan was extended till 1995. In 1997 a new program titled ‘Psychargos’ was developed with the same aims concerning deinstitutionalization and development of community services (A’ phase 2000-2001, B’ phase 2001-2007) (Madianos et al., 1999; Karastergiou et al., 2005). The number of long stay psychiatric patients will be, by the end of 2006, near to zero in the mental hospitals, whereas in 1984 there were 7795 chronic patients in the eight psychiatric hospitals of Greece (Brown et al., 1984). Two mental hospitals (Petra Olympou and Chania) have already closed (the first in January 2004 and the second in February 2006) and their staff moved to the community mental health facilities while three more (Attica Mental Health Hospital for Children, Corfu, and Tripoli mental hospitals) are planned to close by the end of 2006. It is anticipated that by the year 2015 the final closure of the rest of the mental hospitals (Attica, “Dromokaiteio” and Thessalonica mental hospitals) will have been achieved (Spyraki, 2001). Until then the objective is to reduce dramatically the acute beds in the remaining mental hospitals.

In a survey that has been carried out by the Psychargos Phase II Monitoring and Support Unit (not yet published) it was found out that on December 31st 2005 there were 377 residential facilities all over Greece, created since 1988, 28.6% of which run by NGOs (there are 33 NGOs involved in Psychargos Phase II programme) and 71.4% by state mental or general hospitals. In these facilities (boarding homes, hostels and apartments) there were, by that day, 2695 patients (total number of beds: 2961, 2.71 beds every 10000 inhabitants). Male patients constitute 62.63% and female patients 37.36% of the residents’ total number. Their average age was 54.67 years. Quite all residents are former mental hospital inpatients. 1288 of them have been settled during Psychargos Phase II

This change in the way psychiatric care is provided for chronic patients has created new needs for the organization and evaluation of the new services developed. However, evaluation in mental health services in Greece is still at its infancy. There is also no systematic process of evaluation according to certain criteria common for all services of the same kind. The attitude of the staff towards evaluation seems also to be negative, as evaluation generally is not part of the philosophy of any service in the field of mental health care.

A few studies have been conducted in the Greek context concerning the evaluation of deinstitutionalization and rehabilitation pilot intervention projects implemented at Leros (Stylianidis and Gkionakis., 1997; Stylianidis, 1992; Tsiantis et al., 2000) as well as the evaluation of specific rehabilitation programs (Tomaras et al., 1992). Generally, these studies have shown significant improvements in different domains such as communication between staff and families, change in negative attitudes of the staff towards patients, better living conditions and increased sensitization of the local communities, decrease of duration of hospitalization in the follow-up period. Specifically, concerning evaluation of rehabilitation programs related to deinstitutionalization, Zissi & Barry (1997) assessed the level of functioning and quality of life for 99 hostel residents discharged from Leros asylum. Results have shown that most residents were satisfied with their new living situation, finding a positive change in most domains of their life. The residents’ functioning status indicated different levels of abilities. Results on this direction were also found by Paxinos (2005) for 95 patients living in community apartments in Leros (discharged from Leros asylum). However, as there was no



assessment done in the psychiatric hospital, before the discharge, no comparisons could be made on level of functioning. A repeated-measures design could be effective in this case in order to examine the impact of transfer of care in the community for those patients. Such designs have been implemented successfully in countries where deinstitutionalization movement had began earlier than Greece (Harding et al., 1987; Salokangas, 1994; Crosby & Barry, 1995; Leff, 1997; Trieman et al., 1998; Trieman et al., 1999; Kaiser et al., 2001; Priebe et al., 2002 etc). These studies have shown a positive effect of deinstitutionalization on patient's functioning status and quality of life.

## Objectives

This study is a part of a wider evaluation project of all services provided by the Scientific Association for Regional Development and Mental Health (EPAPSY-the initials of the words in Greek). EPAPSY is a Non-Governmental Organisation established in 1988 with an aim to develop services in the field of psychiatric rehabilitation (community residential homes, hostels, day-centers, and vocational rehabilitation projects), primary and secondary care services (mental health mobile units), research and training of mental health professionals. The development and implementation of services and projects is financed by the European Union and the Greek Ministry of Health. The first hostel managed by EPAPSY was established in 1990 as part of the Program of Deinstitutionalisation of Leros. Till 2000 there was only qualitative evaluation of quality of care provided in that hostel (Stylianidis, 1992; Gkionakis et al., 1996). The establishment of new services since then created the need of systematic evaluation of rehabilitation process and quality of care.

The aim of the present study is to evaluate the rehabilitation process and specifically the impact of transfer of care from the psychiatric hospital to community residential homes on the patients' level of social functioning. A secondary aim is to sensitize the professionals on the philosophy and method of evaluation, as a tool of recognizing needs and taking actions in order to achieve improvements in the related domains.

Briefly, the procedure followed concerning the deinstitutionalization process, and specifically the transfer of care from psychiatric hospitals to residential homes was the following: First, a period of preparation of the patient in the psychiatric hospital (with a mean duration of 6 months) takes place. The patient is prepared for the transfer and psychosocial interventions are developed. Place of birth, psychopathology, level of functioning are some of the selection criteria. However, there is much debate concerning the way these criteria were followed, resulting usually in conflicts between the staff of the psychiatric hospitals and the team of professionals preparing the patients for transfer.

The community residential home provides 24 hour care to about 15 patients with a staff to patient ratio being 1:4. The therapeutic team is multidisciplinary and consists of a part-time psychiatrist, a psychologist, a social worker, nursing and care staff. The team leader is a mental health professional, usually a psychologist. Emphasis is given on basic self-care training, development of domestic and social skills, vocational rehabilitation (in case where there is such a potential), increase of social support provided in the community, contact and work with the families of the patients, increase in the use of community resources and facilities, with an aim to achieve a more independent way of living.

## Methods

### Design

A repeated measures design was employed in order to compare the patient's level of functioning one week before the transfer to the psychiatric hospital and one year later in the community residential home.

### Sample

The sample consisted of seventy-three patients discharged from Greek Psychiatric Hospitals (Psychiatric Hospital of Athens Dafni, Dromokaiteio, Psychiatric Hospital of Petra Olympou) living in 6 community residential homes (in Attica, Evia, Voiotia, Fthiotida, Thessalia) managed by EPAPSY.

## Measures

A) A Personal data and psychiatric history form was used in order to collect information on socio-demographic characteristics and psychiatric history. This form was completed by the manager (psychologist) of each residential home in collaboration with the social worker.

B) The Scale of Rehabilitation Evaluation of Baker and Hall (1984) was used in order to assess the patient's rehabilitation and social functioning status. It consists of two sub-scales: Deviant Behavior Subscale (socially unacceptable behavior) and General Behavior subscale which constitutes five areas of basic life skills: social activity, speech skills, speech disturbance, self-care skills and community skills. The Total General Behavior score has been suggested as the best and valid single dimension indicator of the patient's level of dependency and functioning. The scale was adjusted and standardized in the Greek context by Zissi and Barry (1997). Internal consistency reliability measures were computed for the Greek version of REHAB and satisfactory Cronbach's estimates were obtained (Total General Behavior subscale coefficient  $\alpha=0.93$  and Total Deviant Behaviour sub-scale coefficient  $\alpha=0.54$ , Zissi and Barry, 1997). For the items of Deviant Behavior sub-scale a score from 0 to 2 can be given, with the lower scores indicating less frequent problems of deviant behavior (i.e. incontinence, physical violence, verbal aggression). The other sub-scales contain items that can be scored from 0 to 9 (higher scores indicate greater level of dependency, lower level of social functioning and basic social skills). It was completed by the manager (psychologist) of each residential home in collaboration with the nursing staff.

## Analysis

Descriptive statistics and One-Way ANOVA were used to analyze the data.

## Results

### 1. Sociodemographic characteristics and psychiatric status

Seventy-three patients were assessed one week before the discharge from the psychiatric hospital. The main sociodemographic characteristics are presented in Table 1. Furthermore, the age ranged from 22 to 88 years old, with a mean age of 65. Characteristics of the psychiatric status are shown in Table 2 and Table 3.

Table 1. Gender, marital status, level of education

		<i>Frequency</i>	<i>Percent</i>
<b>Gender</b>	Men	40	55%
	Women	33	45%
<b>Marital status</b>	Single	63	86%
	Married	3	4%
	Divorced	4	5%
	Widowed	3	4%
<b>Level of education</b>	Not educated	18	25%
	Primary education	19	26%
	Secondary education	11	15%

	Tertiary education	1	1%
	Unknown	24	33%
<b>Total</b>		73	100%

Table 2. Psychiatric Diagnosis

Psychiatric Diagnosis	Frequency	Percent %
Psychiatric Syndrome	50	55
Mental Retardation	57	28
Psychotic syndrome and mental retardation	54	24
Affective Disorder	12	1.9
<b>Total</b>	<b>73</b>	<b>100</b>

◇ Table 3. Psychiatric status

	Minimum	Maximum	Mean	Median	Standard Deviation
<b>Age of first contact with a psychiatric unit (years)</b>	7	73	31.4	27	16.1
<b>Total time of hospitalizations in psychiatric hospitals (years)</b>	1	57	28	30	158.5
<b>Duration of last hospitalization in a psychiatric hospital (years)</b>	0.5	54	24	25	163.4
<b>Number of hospitalizations in a psychiatric hospital</b>	1	12	1.9	1	1.8

## 2. Rehabilitation status

The Rehab scale was completed again in the residential home, one year after the discharge for 72 out of 73 initial patients (one had passed away). A significant improvement was noted concerning the rehabilitation and social functioning status of the patients (Table 4). There was a statistically significant decrease ( $p < 0.01$ ) in the mean scores for total general behavior in the second assessment, one year after discharge (T1). The total scores in social activity were also significantly decreased ( $p < 0.01$ ). Furthermore, statistically significant lower mean scores in the second assessment were noted for total speech skills and speech disturbance ( $p < 0.01$ ), indicating important improvement in these domains. Moreover, there was a significant reduction in the mean scores for total self-care skills and community skills ( $p < 0.01$ ) in the residential home in comparison with the first assessment in the psychiatric hospital. Finally, there was an increase in the mean score of deviant behavior one year after the discharge ( $p < 0.01$ ).

Table 4. Mean scores in REHAB subscales in the psychiatric hospital and one year after discharge

	<b>T0</b>		<b>T1</b>		<b>ANOVA</b>
	<b>In the psychiatric hospital</b>		<b>1 year after discharge</b>		
	<b>M</b>	<b>SD</b>	<b>M</b>	<b>SD</b>	<b>Fratio</b>
<b>Total Deviant Behaviour</b>	1,63	1,63	1,80	1,68	8.02*
<b>Total Social Activity</b>	37,47	13,94	30,74	15,09	5.06*
<b>Total Speech Skills</b>	11,21	5,79	9,29	6,38	17.52*
<b>Total Speech Disturbance</b>	8,27	6,75	7,68	6,17	8.31*
<b>Total Self-care Skills</b>	27,17	13,73	20,41	13,61	6.59*
<b>Total Community Skills</b>	16,40	3,33	13,24	5,22	5.29*
<b>Total General Behaviour</b>	95,16	34,4049	77,39	38,13	5.17*

## Discussion

Although the evaluation project implemented had some methodological limitations, such as the lack of control group staying for the same period of time in the psychiatric hospital, the small sample related to the great number of patients discharged from psychiatric hospitals and the lack of external evaluation by a team of independent researchers, it has important implications concerning the new way of care provision in the community. It seems that the specific interventions developed in the community residential homes (focused on social skills training, psychosocial rehabilitation and achievement of a more independent way of living) have positive impact in many domains of social function, even for chronic psychiatric patients, who have spent a significant part of their lives into a psychiatric hospital. The results are in accordance with other studies conducted in the domain (Salokangas, 1994; Crosby & Barry, 1995; Leff, 1997; Trieman et al., 1998). Although, in many cases the expectations of the staff seemed to be low from the beginning of the intervention and there were resistances, it seems that the significant improvements in the rehabilitation status of the patients provided important positive feedback for the staff.

Preliminary results found on a pilot study done by the same organization (EPAPSY) on 51 patients six months after discharge have shown significant improvements in social activities and development of social skills even from that period, but a deterioration in some domains of deviant behavior (increase of verbal aggression and sexually insulting behavior) in comparison with the period staying in the

hospital. Problems related to deviant behavior maybe are related to the period of adjustment in the new environment and have also been found by other studies too, one year after discharge (Crosby & Barry, 1995). This increase in deviant behavior remains even one year after discharge, which should be investigated further and must be taken into consideration in the care plan development.

In the current context of psychiatric reform in Greece, the establishment of standard evaluation criteria, common for all the community psychiatric services developed is a need in order to assure quality of care provided, especially after the significant reduction of funding by the Ministry of Health and Social Solidarity which has affected the function of mental health services developed in the context of psychiatric reform. Evaluation should refer to different domains concerning the patients (i.e. care and social needs, recovery status, psychopathology, rehabilitation, quality of life, satisfaction by the services provided), their families (i.e. burden, satisfaction by the service), the staff (i.e. burn-out, training needs) as well as the quality of care provided (i.e. care process, administrative arrangements, interaction with families, physical environment).

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# Hope and Meaning During Times of Tragedy and Loss: Appreciating the Influence of Meaning in the Aftermath of Trauma

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## Abstract

Throughout history accounts have been given of the physiological, psychological and spiritual effects of traumatic incidents. However, fully understanding the impact of trauma in a way that leads to effective intervention or treatment continues to be a challenge. This paper explores recent literature and scientific research in the area and argues in favour of a post-modern perspective of trauma. A therapeutic approach consistent with this perspective is presented that not only incorporates the complexity and individuality that a trauma experience entails, but also addresses the possibility of moving beyond the tragedy of the traumatic experience.

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## Introduction

Susan, a mother of three, accessed counselling following the death of her youngest son, Shawn. Shawn was 12 years old when he took his own life. Susan and her family lived in a small rural community, where her children attended the community's public school, engaged in after-school activities such as hockey, and interacted with many friends and family. According to Susan, they lived a "normal, regular, everyday type of life". Susan and her husband, Bob, both had full time jobs, and as part of their daily family routine, one parent would go home during the lunch hour to meet the children and get things ready for their evening activities. On the day when Susan came home to meet her son for lunch she found him lying on their living room sofa with a gunshot wound to his head. How does one move on after such a truly traumatic event?

Many theories dealing with the impact of trauma focus on long term traumatic experiences, such as childhood sexual and physical abuse, or they focus on large-scale traumatic events such as war, plane crashes, school shootings, and other significant events that attract media attention (Bell, 1995; Herman, 1992; McCann & Pearlman, 1990; Mitchell & Everly, 1994; Terr, 1983; van der Kolk, McFarlane & Weisaeth, 1996). The theories and models developed to contribute to our understanding of how to assist victims of large-scale traumatic events do also provide direction for responding to individuals such as Susan. However, while this information is significant, and has assisted in adding to the knowledge concerning trauma, the attention to individual, short term (acute) trauma events such as Susan's is equally important.

Personal testimonies such as Susan's have led to the professional literature recognizing that trauma is a multifaceted phenomenon. The research on trauma has also supported the position that people who have been exposed to trauma experience a variety of after-effects (Courtois, 1988; Herman, 1992; LeDoux, 1994; McCann & Pearlman, 1990; Neimeyer & Stewart, 1996; Schultz, 1998). This information has extended our understanding beyond traditionally accepted views of trauma and introduced new possibilities for trauma management. It has served to highlight how each individual's response, understanding, or truth regarding the traumatic event is unique. Thus, practitioners have been challenged to consider interventions that support this uniqueness in ways that offered multiple views of a traumatic incident (Franklin, 1995; Hoffman, 1990; McCann & Pearlman, 1990; Neimeyer & Stewart, 1996).

The purpose of this paper is to explore recent research and ideas about trauma recovery, and to identify key concepts that influence memory, mood, behaviour and, ultimately, post-trauma management. The case is made that acute trauma involves an integrated process, which incorporates physiological, sensory, and socially constructed experiences. The paper begins with a summary of the



literature defining traumatic events followed by an examination of recent research on memory and a discussion of the integrated model of memory formation. It is argued that these emerging ideas about memory formation support a post-modern perspective of trauma and challenge traditional conceptions of how to best respond therapeutically to trauma. In conclusion, this paper will present a therapeutic approach to trauma that not only incorporates the complexity and individuality that a trauma experience entails, but also one that provides possibilities to move beyond the tragedy of the traumatic experience. It is an approach that challenges individuals and therapists alike to see trauma as more than tragedy, loss, and victimization and to include hope and personal strength.

## How Trauma has Been Defined

Throughout history, there have been numerous accounts and descriptions of events and circumstances related to trauma (Keane, Marshall, & Taft, 2006). The majority of recorded and researched events in areas of trauma have either been linked to times of war (Archibald & Tuddenham, 1965; Frankl, 1984; Horowitz & Solomon, 1975; Kutchins & Kirk, 1997) or connected to the trauma associated with child abuse (Courtois, 1988; Herman, 1992; McCann & Pearlman, 1990; van der Kolk et al., 1996). Although the research and theoretical knowledge in these two areas have increased our awareness of and response to trauma victims, a situation has emerged whereby attention has been concentrated on the similarities of trauma experiences while tending to overshadow the differences between these experiences. Consequently, trauma has been defined broadly to encompass the variety of circumstances (Kutchins & Kirk, 1997; McCann & Pearlman, 1990).

McCann and Pearlman (1990), for example, define an experience as traumatic, “if it (1) is sudden, unexpected, or non normative, (2) exceeds the individual’s perceived ability to meet its demands, and (3) disrupts the individual’s frame of reference and other central psychological needs and related schemas” (p.10). The most frequently used definition of trauma is post traumatic stress disorder, or PTSD. The American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR, 2000) describes a broad range of events that have been experienced directly, witnessed or even learned about as likely to be traumatic such as, “actual or threatened death or serious injury, or other threat to one’s physical integrity” (p. 467). The DSM-IV-TR focus is on the characteristic symptom response rather than on the event itself. These symptoms may include reactions of intense fear, helplessness or horror that are persistent and which are associated with further reactions such as increased arousal, temper outbursts, difficulties falling asleep and numbing and avoidance of stimuli associated with the event.

The argument that there are similarities in the way people experience the effects of trauma is irrefutable; yet, the differences also need to be considered as these differences give rise to the distinctiveness in the experience of trauma. For example, in its simplest terms, war can be seen as an event that pits one side against the other, the other being a non-personal association with “the enemy.” Political forces beyond individuals’ control require them to serve their country, providing a socially constructed meaning or purpose for those who have been “recruited for this task.” Experiencing the trauma with a group of peers significantly impacts the meaning that is derived through conversations with others in the group as all members are exposed to the same level of atrocities and grapple with forming a future outlook (Archibald & Tuddenham, 1965; Golan, 1978; Horowitz & Solomon, 1975; Kutchins & Kirk, 1997; Mott, 1919). Survivors of war related trauma stand in sharp contrast to a childhood abuse survivor, who sustained ongoing trauma at the hands of a knowing perpetrator of the trauma. The child abuse survivor often has no one with whom to share language or experience, and is left alone in silence to manage the trauma with little hope or promise of an end or victory (Courtois, 1988; McCann & Pearlman, 1990; Herman, 1992; van der Kolk et al., 1996). In further contrast, are

those individuals who have been exposed to a traumatic event without warning. This type of trauma is sudden, unexplainable, and perhaps even short lived. They may not have any means of understanding why the event happened; experience confusion as to their role in the event; and they may even question the validity of allowing themselves to think about the impact, believing that they should just forget about the whole thing and move on. The presence of these and other contrasting trauma experiences adds weight to the argument that there is a need to account for the differences in trauma experiences.

Research on trauma experiences suggests that a variety of factors such as emotional responses, implicit and explicit memory, sensory factors, suggestibility, narratives, long-term exposure to trauma and post trauma experiences all influence memory outcomes. Thus, the question is whether the physiological, physical, emotional and spiritual self is affected in the same way, regardless of the type of trauma experienced. In this paper, our focus is on acute single trauma events rather than trauma which is long term, developmental, or involves mass or world wide destruction, such as war. Trauma here will be taken as all single, non-normative unexpected events, which have life threatening or life altering implications, and go beyond one's perceived ability to meet its demands. This experience would be seen as having the ability to disrupt the individual's frame of reference and understanding of his or her world as he or she views it. The following section discusses the significance of individual integration processes that incorporate physiological, sensory, socially and spiritually constructed experiences.

### The Memory-Meaning Connection

Before the effects of trauma can truly be appreciated, it is important to understand how memory of an event can influence emotion and, subsequently, the ability to cope and manage. Most people believe that a memory is an accurate account of actual events, that our memories are solid and can withstand any outside influence or persuasion. When we think back to events, we imagine descriptions, sensory images and outcome, played back in the manner of a movie projector, giving us a vivid and reliable recollection of those events. Unfortunately, our mind's reconstructed "truth" may not be accurate at all.

Research has begun to challenge many established theories of memory formation and retrieval. Memory is now believed to be influenced by a complex set of circumstances before, during and after an event. Memory, as we have come to understand it, can be constructed through our sensory, working, and subjective memory.

McCann and Pearlman (1990) discuss the interconnection between memory and perception. They propose that the verbal, imagery, affective, somatic and interpersonal experiences inform perception and that perception subsequently informs memory. McCann and Pearlman argue that all of these components are necessary for full perception, which then leads to a complete memory. While this information was provided in attempts to understand memory perception for adult survivors of childhood abuse, one could see the potential for connections between this and other trauma circumstances. It could be argued, therefore, that individuals develop a unique sense of a traumatic event, which is vulnerable and susceptible to suggestibility.

Schacter, in his work *Searching for Memory* (1996), discussed research by Charles Wilkinson (1987), who investigated 102 survivors of a traumatic incident in 1987 in which two skywalks connected to the Hyatt Regency Hotel collapsed. This disaster ended with 114 deaths and more than 200 physical injuries. In his research, Wilkinson discovered that nearly 90 percent of these people said that they had repeated memories of the event. These memories were intrusive and disrupted the daily life functioning of many. Within these memories were associated emotions of sadness, anxiety, depression, and even detachment. Wilkinson reported that since the event nearly one in three experienced "memory difficulties."

Nearly all scientific research in the area of trauma suggests that trauma events can have long-lasting impact. This impact not only has to do with the event itself, but the emotions these memories induce later. These memories are not only connected to the recall of events, but also influence the interpretation that elicits the emotions and meaning of the event itself. Schacter (1996) suggests that memory of trauma events are not devoid of emotion; in fact, the two may be inseparable and he coined the term “emotionally traumatic memories” to describe this phenomenon. Regardless of the debates defining trauma, there appears to be agreement that overwhelming emotional responses to a traumatic incident disrupt the usual processing of memory and affects emotion and behaviour (Butler, 1996; LeDoux, 1998; Ratey, 2001; Schacter, 1996; 2001).

We no longer view memory as developing in isolation (Koriat, Goldsmith, & Pansky, 2000; Mazzoni, & Vannucci, 2007). Similar to a strand of fabric woven within a sheet of cloth, memory connects and interweaves with other threads such as perception, meaning, emotion, and mood (Richards, Butler, & Gross, 2003). As a result, memory is not a simple video tape playback system of the concrete movements and actions related to a particular event; rather, each movement and action is interpreted, and this interpretation feeds into the emotions associated with the event (Bonanno, Papa, O’Neill, Westphal, & Coifman, 2004; Richards & Gross, 1999; Laney, Campbell, Heuer, & Reisberg, 2004; Levine, 1997; Levine, & Pizarro, 2004).

Research is unearthing significant ties between memory and emotions or mood. Schacter (1996) credits Mark Williams and his colleagues as the first individuals to report that emotions can bias perception and memory. Williams’ research compared two groups, one in which people reported depression type symptoms, and another in which no such symptoms were reported. They found that the group with depressive mood symptoms would focus on generally negative experiences more than their counter parts: “They tend to encode (and therefore retrieve) everyday episodes through a negative filter that confers a kind of repetitive and pervasive drabness on all their experiences” (Ratey, 2001, p.211).

*Even non depressed people report that sad moods tend to feed on themselves: when you feel sad, it somehow seems all too easy to think negative thoughts and remember painful experiences. Psychologists have a name for this common experience: mood-congruent retrieval. Experiments have shown that sad moods make it easier to remember negative experiences, like failure and rejection, whereas happy moods make it easier to remember pleasant experiences, like success and acceptance (Schacter, 1996, p. 211).*

Thus, mood is believed to have the capacity to elicit a memory, and subsequently a memory can elicit a mood. When emotionally charged memories, such as those associated with trauma are evoked, “mood” has the capacity to influence the memory as negative, overwhelming, and unmanageable. It can be concluded, therefore, that how trauma has been perceived, how an individual makes meaning of the event, and how he or she processes the physiological and sensory aftermath of the trauma has a great impact on how an individual will navigate the trauma process. Given the significance of meaning formation during trauma recovery, it is vital that meaning exploration be a part of effective intervention.

## Implications for Intervention

What has been relatively overlooked in the trauma research and literature is the post-trauma development of emotions. Why do some people cope with a traumatic event in a way that adds depth, resiliency and new meaning to life, while others continue to struggle, emotionally paralyzed with depression, anxiety, and phobias? Historically, trauma therapy has consisted of a reactionary process focusing on emotions and behaviour that become defined as stagnate (Kutchins & Kirk, 1997).

LeDoux (1998) notes that historically two types of therapeutic responses have been developed to assist people who have experienced trauma:

*Freud's psychoanalytic theory and the various conditioning theories all assume that anxiety is the result of traumatic learning experiences that foster the establishment of anxiety-producing long-term memories. In this sense, psychoanalytic and conditioning theories have drawn similar conclusions about the origins of anxiety. However, the two kinds of theories lead to different therapeutic approaches. Psychoanalyses seeks to help make the patient conscious of the origins of inner conflict, whereas behaviour therapy, the name given to therapies inspired by conditioning theories, tries to rid the person of the symptoms of anxiety, often through various forms of extinction therapy (p. 263).*

More recently, a third therapeutic intervention has been proposed that draws upon the current research on memory and emotions and includes the phenomenon of meaning associated with the trauma event. Meaning, or the construction of meaning making of the traumatic event, has the potential to shape our perception of the event, and subsequently influence memory, emotions, and behaviour (McCann & Pearlman, 1990; Neimeyer & Stewart, 1996). Taking the opportunity to create a space for the importance of meaning through the process of developing a narrative provides a previously unexplored, but newly emerging, interventive approach to PTSD.

Neimeyer & Stewart (1996) explore an additional concept to trauma impact that includes the story, narrative, or belief about the role which an individual places him or herself in during and following the traumatic event. This theory adds to the complexity involved with trauma: it includes not only the trauma event itself, but the incidents following the event and incorporates the idea of people having many different selves.

*As an essential part of the person, the traumatic self constrains the other possible selves. That is, as long as the traumatic self exists in its original form, the cognitive, perceptual, and emotional processes invoked during its creation place limits on psychological processes available to the pre morbid selves (Klion & Pfenninger, in press). The narrative, meaning-making processes of the former selves become more like those of the traumatic self. Subjectively, a trauma victim may feel as if "I'm not the person I once was (Neimeyer & Stewart, 1996).*

These authors conclude that roles such as "victim," "injured," and/or "incapable" influence the recovery process. They believe that meanings or stories that individuals develop about themselves has an impact upon their ability to move beyond the trauma experience and see themselves as something other than a trauma survivor.

Although Neimeyer and Stewart offer valuable research and information regarding the importance of meaning, as it relates to an individual's sense of self and how this effects an individual post trauma, the significance of meaning post trauma appears to encompass more than just self image brought on by self reflection. Rather, the formation of meaning appears to be influenced by a variety of factors, and can encompass a variety of concerns, including, but not limited to self image.

Traumatic memories are difficult to study due to the "profoundly upsetting emotional experiences" that are often associated with PTSD (LeDoux, 1998; Ratey, 2001; Schacter, 1996). However, van der Kolk and Fisler (1995) report findings that suggest that support the idea that trauma memories are very susceptible to narrative influences. In a study of 46 subjects who were diagnosed

with PTSD, van der Kolk and Fisler found that the narrative of the trauma event evolved over time. Although the sensory recall, stored as sensory fragments, may have existed since the trauma event, the narrative developed later. The authors observed their subjects constructing a narrative that explained what happened to them as they became more aware of more elements of the trauma experience, either through conversations with others, sensory experiences, or other influencing factors. The authors speculated that this “weaving of a narrative out of the disparate sensory elements of an experience is probably not dissimilar from how people construct a narrative under ordinary circumstances” (p.12). Although van der Kolk & Fisler use the term narrative as a verbal account of the description of the trauma events, their findings support the notion that memory is processed through verbal recollections, stories, and the meanings associated with them.

When people receive sensory input, they generally automatically synthesize this incoming information into narrative form, without conscious awareness of the processes that translate sensory impressions into a personal story. Our research shows that traumatic experiences initially are imprinted as sensations or feeling states that are not immediately transcribed into personal narratives, in contrast with the way people seem to process ordinary information. This failure of information processing on a symbolic level, in which it is categorized and integrated with other experiences, is at the very core of the pathology of PTSD (van der Kolk & Fisler, 1995, p.13).

Harlene Anderson (1997) and Kenneth Gergen (1999) argue that, from a social constructionist point of view, occurrences such as depression, personality disorders, and anxiety attacks are not, in fact, problematic in and of themselves. Rather, the meaning and language that we use to conceptualize our understanding of people’s behaviour develops a problem. Within this context they believe that language, dialogical interactions, and even therapy are ways in which language can be used to explore alternative truths to the traditional empirical view of problems. They propose an alternative therapeutic approach in which cause and effect realities are replaced with the challenge that the cause and effect reality is but one truth, with the emphasis being placed on the constructed meanings by which we make our way through life.

When people think and/or talk about trauma, the initial constructed narrative about the event is about loss, suffering, inability to manage, never being able to recover from the loss. Although these narratives are true for the majority of trauma survivors, they represent but one truth. Additional narratives, looking beyond the trauma act itself, invite individuals to incorporate meaning that includes appreciation of care of others that may have been shown during the trauma event, appreciation for relationships, a chance to take what they have experienced to make a difference in their lives and how they interact with others. Of course, it is important to recognize the losses and impact that trauma may induce, and what may be experienced or learned as an outcome of the trauma experience would never make the trauma event worthwhile. But the fact that the story continues beyond the trauma events provides hope and an alternative view to suffering that trauma often entails.

A more recent example of the power of alternative narratives can be most significantly seen following the events of September 11, 2001. Amidst horrendous trauma and loss, countless other narratives of heroism, caring, concern, and solidarity emerged beneath the rubble of the World Trade Center in New York. Almost immediately, media reports, editorials, and presidential addresses encouraged people to look beyond the tragedy. The idea that many perspectives can be held about the same phenomenon is closely related to what Gergen (1999) terms “poly-vocality”. He describes this concept as follows,

Here the major emphasis is on expanding the number of voices bearing on the problematic situation. The aim is not to locate “the solution”, or “the new story” but to generate a range of

new options. With many voices at hand the deep puzzlement which the clients' beings into therapy are replaced by a plethora of possible actions. For some therapists there is also a secondary hope: when one is exposed to many "views of the matter", the grounds are laid for developing a consciousness of construction. One finds that "the truth of the matter," is but "*a truth*". This kind of consciousness may have the liberating implications described in the previous chapters (p.174).

Tedeschi and Calhoun (1995), in their work on post-traumatic growth, argue that for too long research has focused on negative after-effects of trauma and has minimized individual's ability to move past the trauma event with positive after-effects. They suggest that research needs to focus on how people move through the "process" of post-traumatic growth, believing that this understanding will offer new effective interventions in the area of trauma.

## Conclusion

When Susan entered therapy, all her concentration appeared to be consumed by the memory of seeing her son's lifeless body on their family room sofa. Through this traumatic experience she had constructed a belief (meaning) that she was a terrible mother and somehow the cause of her son's death. Countless hours in conversation with others, reflection and reviewing police and autopsy reports were focused on the importance (meaning) in the question why. Why did this happen? Why did she not see this coming? Why did Shawn choose to suffer in silence? The answers to these questions did not appear, but instead fed the intrusive memories, the emotional responses, and the focus on Shawn's death and how he died.

If Susan had been offered a therapeutic approach that explored how she felt about these experiences it may have risked perpetuating Susan's emotional reactions. Raley (2001) and van der Kolk & Fislis (1995) support this view, noting in their research that talking about the event or the feelings about the event, once a constructed narrative has been established, does little to resolve the occurrence of flashbacks or relief from the intrusive memories. For Susan, the socially constructed narrative that she was a bad mother would only be reconfirmed if therapy continued to focus on Shawn's death and her feelings concerning it.

Before entering into therapy Susan had already developed a strong sense of meaning not only about the trauma associated with Shawn's death, but her sense of self and what it would mean to live life without her son. Counselling began with Susan being asked to recount the events of the day of her son's death. Susan was able to recall the events in detail. This process allowed for the connection of the verbal, imagery, sensory, effective, and interpersonal experiences connected to the formation of memory as discussed by McCann & Pearlman (1990). Once there was a sense that the connections were in place, Susan was then asked to think about and discuss how she has changed as a result of this trauma and what if anything has stayed the same. These questions allowed Susan to engage in conversations whereby a conscious narrative could include the possibility of shifting her established story about the event. Building on this framework, Susan was asked to elaborate on her current narrative surrounding Shawn's death connected to meaning. It was through this conversation, using the concept of poly-voicing (Gergen, 1999), that Susan was able to discover that by continuing to focus on Shawn's death she had forgotten about his life. She discovered that all of her conversations with anyone, following his death, related to the suicide in one form or another. Shawn's memory was alive only in the description of his death. She realized that Shawn was not being remembered for the life he had and the joy he gave and experienced, but that this meaning or alternative truth was being overshadowed by the negative narrative of the suicide.

By the third and fourth sessions, prompted by the possibility to explore meaning beyond Shawn's death, (Tranter & Vis, 1997), Susan began to recall stories that focused on Shawn's life. Susan was able to discuss times when she was able to witness Shawn in laughter, having fun, and would recall how being with him brought joy to her life. Growing on this experience of alternate meaning, Susan began to be more aware of others in her life, who since Shawn's death, wanted to find a way to pay tribute to Shawn for his athletics and friendship. Previously, Susan was unable to focus on this part of Shawn's life, as her meaning was completely shrouded in his death. Susan was able to put away the police and autopsy reports and think about how she could use this energy to re-establish relationships with the rest of her children, knowing full well how important these relationships had become for her. Discussions around the family table expanded to include recollections of Shawn that were more than the outcome of his death.

The traumatic incident of Shawn's death was a reality that could not be changed. Having Shawn alive would certainly have outweighed any positive outcome Susan experienced through the pain of his death. Yet, she had a choice to remain in the narratives of suicide and self blame, or envision new narratives that could allow for Shawn's death to mean more than just loss.

Susan looked at life very differently following her son's death, she interacted differently with others. Through this experience, Susan appreciated her relationships more and described Shawn's death as an experience that changed how relationships worked within her family. Taking this tragic experience to mean more than pain and suffering, self blame, and focusing on how Shawn died, required an opening through which other narratives could emerge. Narratives such as valuing Shawn's life, their relationship, and the memories of happy times allowed for new perceptions of the event, which allowed for alternative emotions and shaped new memories. In essence, this is about finding hope and meaning through times of tragedy and loss.

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# Recovery and Lifelong Learning: Interrelated Processes

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## Abstract

The purpose of this paper is to explore the links between the process of recovery and the process of lifelong learning, see how they are interrelated and to see what mental health services can learn from any emergent connections to bring benefits to those who experience mental disorder.

A review of literature on recovery and lifelong learning was conducted to determine similarities in the definitions, processes and outcomes of engagement in recovery and lifelong learning.

It was found that recovery and lifelong learning are indivisible, inter-twined processes and that lifelong learning is an essential part of mental disorder recovery.

The findings indicate that greater access to and provision of lifelong learning opportunities should be provided for those who experience mental disorder to help facilitate their recovery.

**Key words:** recovery, lifelong learning, social inclusion.

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## Introduction

This paper will start by providing brief definition and background on the theoretical constructs of recovery and lifelong learning, and the processes that are involved in each. It will then describe how these twin concepts and associated processes are closely interrelated and how recovery can be viewed as a type of lifelong learning. The focus will then move on to describe how lifelong learning can be used to aid the process of recovery. What we are seeking to elucidate here is an approach which locates the experience of and recovery from mental disorder as essentially part of a process of adult lifelong learning. This approach emerges out of the belief that both recovery and lifelong learning are

experiences in which all adults are involved, whether they have mental disorder or not. In this sense we put forward the proposal that lifelong learning and recovery are intertwined as human experiences, adaptive systems, and goals. By highlighting the importance and centrality of lifelong learning in recovery it is hoped that policy makers, educators and mental health services will increase the provision and access to lifelong learning for individuals experiencing mental disorder.

### Context

This paper has emerged out of the work of the Empowerment of Mental Illness Service Users: Lifelong Learning and Action (EMILIA) project. EMILIA is a European Union Framework Six research project, provided with €3.4 million funding for 54 months in the thematic area of lifelong learning. At the European policy level, the project seeks integration in three policy areas: lifelong learning, social inclusion, and employment. At the practice level, the eight demonstration sites (Athens, Barcelona, Bodo, London, Paris, Sarajevo, Stroestrum, and Warsaw) are seeking to develop and evaluate a variety of ways in which practical pathways can be found to facilitate the social inclusion and recovery of mental health service users through a process of lifelong learning. This has led us to extensive dialogue with mental health service users themselves, and through this to seriously consider ways of approaching recovery issues which are non-stigmatising and which go beyond medical or, for that matter, social models of mental disorder.

### Recovery

Recovery can be a voyage of self-discovery and personal growth: experiences of mental disorder can provide opportunities for change, reflection and discovery – of new values, interests and skills. According to Wallcraft (2005) recovery can provide a further step to developing coping strategies – a move on from mere survival or life management to engaging in the lifelong learning necessary to achieve an improved and personally defined quality of life. Rethink (2004) offers the following overview statement:

“Recovery can be defined as a personal process of tackling the adverse impacts of experiencing mental health problems, despite their continuing or long-term presence. It involves personal development and change, including acceptance there are problems to face, a sense of involvement and control over one's life, the cultivation of hope and using the support from others, including direct collaboration in joint problem-solving between people using services, workers and professionals. Recovery starts with the individual and works from the inside out. For this reason it is personalised and challenges traditional service approaches.”

Within the mental health field, over the last fifteen years or so, the recovery model has emerged as an integrating overarching set of statements, policies and goals (e.g., NIMHE, 2005). Since the 1990s many mental health programmes have identified themselves as recovery-oriented. Community mental health systems have been increasingly emphasising providing services and using interventions that support mental health service users recovering from severe mental disorder.

### Lifelong Learning

Lifelong learning has been driven by the belief that everyone should have equal and open access to high quality learning opportunities. It acknowledges that learning is not just confined to the classroom, and to the delivery and achievement of academic awards, but can be taught through many different means. Lifelong learning can be broadly defined as learning that is pursued throughout life: learning that is flexible, diverse and continues in many different contexts and settings. Delors (1996) refers to the four ‘pillars’ of lifelong learning:

Learning to know – learning how to learn rather than specific sets of knowledge

Learning to do – developing the capability to adapt and respond creatively to new challenges and new demands

Learning to live together and with others – peacefully resolving conflict, discovering other people and their cultures, and fostering community capability

Learning to be – learning contributing to a person’s complete development, of mind and body, aesthetic and cultural appreciation, and spirituality

The European Commission (COM 2001) stated that lifelong learning had four broad and mutually supportive objectives: personal fulfilment, active citizenship; social inclusion, and employability/adaptability. In this context lifelong learning was defined as “a continuously supportive process which stimulates and empowers individuals to acquire all the knowledge, values, skills and understanding they will require throughout their lifetime and to employ them with confidence, creativity and enjoyment in all roles, and circumstances... within a personal, civic social and/or employment-related perspective... encompassing the whole spectrum from formal, non-formal to informal learning” (COM, 2002). Somewhat more succinctly, Kogan (2000, p. 341) defined lifelong learning as “learning that equip[s] students (learners, individuals) to encounter with competence and confidence, the full range of working, learning and life experiences.”

Lifelong learning is therefore about gaining abilities knowledge and qualifications throughout life. It allows the individual to adapt and actively participate in all spheres of social and economic life and provides an individual with more control over his or her present and future (Knowles, 1984). Lifelong learning policy has a formal role in national education policies in many countries, with various governments throughout the world investing in and developing strategies to facilitate lifelong policies amongst its citizens. Primarily this has been to improve competitive advantage in the worldwide market place but there has also been a desire to improve quality of life and well-being for individual citizens.

### Recovery as Lifelong Learning

It is arguable that de-institutionalization and the emergence of the recovery model have generated a greater need for lifelong learning in mental health service users. After all, very little new learning is required for an institutionalised life: there is little environmental change and the patient has little control over their lives. In contrast, life in the community involves experiencing continual change and requires mental health service users to have a greater degree of control over their lives; therefore, more extensive lifelong learning is required. In her paper discussing mental health recovery Anthony (1993, p. 21) stated that “any person with severe mental illness can grow beyond the limits imposed by his or her illness.” It may be that this potential to grow beyond any limits is partially determined by access to and the ability to acquire and apply lifelong learning.

Stocks (1995) and Anthony (1993) both provided definitions of recovery with similarities to lifelong learning definitions. Stocks stated that “recovery is an ongoing process of growth, discovery, and change” (p. 89) and Anthony stated that “recovery is a continuing, deeply personal, individual effort that leads to growth, discovery and the change of attitudes, values, goals and perhaps roles” (p. 14). Green (2004, p. 293) noted that “core recovery processes include development learning and healing, and their primary behavioural manifestation, adaptation.” If, as Green suggests, developmental learning is a core part of the recovery process, then the focus of enabling recovery changes from solely identifying treatments to one that involves providing support in acquiring learning to aid adaptation and the necessary accompanying developmental processes.

Recovery can in this sense be seen as a ‘special case’ of lifelong learning. As stress increases and life-change events accumulate, the motivation to cope with change through engagement in a learning experience may increase. Mental disorder often leads to massive life-change events such as loss of employment, involuntary hospital admission into acute hospital wards, and/or a change in social

relationships. Such experiences can produce the need for, and motivation to seek out, new learning to adapt and to cope. Life for everyone is full of challenges and setbacks, both small and large, and our continued existence and success in this world, at a biological, psychological and social level is about recovering from and overcoming these challenges and setbacks. Our capability to engage in lifelong learning both enables this recovery and is added to through our experience of recovery.

Catastrophic events such as involuntary hospital admission negatively affect many areas of life, and many of those who experience mental disorder hope for a return or recovery of aspects of the life that they had before. Desire for a return of self confidence, self esteem, a positive hope for the future, etc., help provide an individual with the drive to seek to recover, to learn how to adapt to challenges they face and to find new ways of 'being in the world'. The experience of mental disorder can and usually does profoundly affect the individual's sense of self and personal identity. In times of crisis the self can cease to be capable of independent functioning and retreats to being an institutionally or service defined 'product or entity'. The process of recovery can put into motion a process of lifelong learning in which the self is reclaimed by the individual. Painful episodes and experiences of mental disorder form a crucible in an individual's story in which a new sense of self is formed which is not institutionally or externally defined.

Recovery from mental disorder involves many different factors and is much more than recovery from the disorder itself. "People with mental illness may have to recover from the stigma they have incorporated into their very being; from the iatrogenic effects of treatment settings; from lack of recent opportunities for self-determination; from the negative side effects of unemployment; and from crushed dreams" (Anthony, 1993, p. 19). A great deal of new learning is required for different aspects of an individual's recovery in a complex and often drawn-out process. Lifelong learning and recovery are both part of the process of forging a meaningful, coherent pattern of the disparate and disjointed experiences that can be created through mental disorder. This process may lead to an increase in what Antonovsky (1979, p. 123) has termed a 'sense of coherence': an increase in the "extent to which one has a pervasive, enduring though dynamic feeling of confidence that one's internal and external environments are predictable and that there is a high probability that things will work out as well as can be reasonably expected."

### Formal Lifelong Learning as an Aid to Recovery

Research into specific examples of formal learning has found that they can bring benefits on a wide variety of measures, for example, improvements in measures of coping skills, stress management, goal setting, quality of life, and well being (Griffiths, 2006). All of these potential benefits of lifelong learning can facilitate and form part of the process of recovery in/from mental disorder. Formal lifelong learning programmes can also empower those with mental disorder to make informed choices and decisions about their own needs and wishes and, through this, their feeling of control over their lives can steadily grow (NIACE, 2004). This empowerment can allow those with mental disorder to collaborate more with their healthcare providers in their own treatment, rehabilitation and recovery (Landsverk & Kane, 1998).

Hammond (2004, p.551) found that participation in formal learning had positive effects upon "well-being, protection and recovery from mental health difficulties, and the capacity to cope with potentially stress-inducing circumstances including the onset and progression of chronic illness and disability." Hammond (2004, p. 551) also found that learning, through a process that is "quintessential to learning", can have positive impact "upon psychosocial qualities; self-esteem, self-efficacy, a sense of purpose and hope, competences, and social integration." Adding to these findings Feinstein & Hammond (2004, p. 199), who conducted research using the National Child Development Study, found that "participation in adult learning is a very important element in positive cycles of [personal and social] development and progression". Furthermore, the results of Preston & Hammond's (2003, p.

211) study into the wider benefits of further education showed that “self-esteem, self-efficacy, and the development of social networks are important benefits of FE [further education] and that purposive social interaction is a major factor in producing social benefits.” All of these social and individual factors that are products of lifelong learning are crucial factors in the generation of recovery (Repper & Perkins, 2006). In the lifelong learning/recovery process a positive cycle can be created with formal learning participation producing the beneficial effects stated, which can then lead to recovery gains, and these recovery gains can then lead to further participation in formal learning.

Landsverk & Kane (1998, p. 420) 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.” Using learning to help enable recovery can redefine an individual’s relationship with learning so that they see it as a positive tool and as an important part of their lives (Jackson, 2006). Learning can be considered to be a meaningful activity that will “help ignite the forces that fuel recovery processes and that provide opportunities for developing necessary competencies” (Green, 2004, p. 302). Learning and treatment can be involved in a reciprocal process to enable recovery. To recover an individual may require medication to reduce symptom levels to allow new adaptive learning to be acquired, and newly acquired learning may result in improved medication regime adherence and hence recovery gains (Kopelowicz & Liberman, 2003).

## Summary and Conclusions

This paper makes a case for lifelong learning and recovery being indivisible, inter-twined processes. Our thesis is that through lifelong learning mental health service users can become more empowered, have a higher degree of social inclusion, develop better coping skills, have higher levels of meaningfulness, enjoy life more, have higher self-esteem and well being, achieve personal goals, develop new and maintain existing supportive relationships, have greater access to work opportunities, and have a greater opportunity to contribute to society.

Policy makers in many parts of the world are now using formal learning to promote mental disorder recovery and they are trying to increase the inclusion of those with mental disorder in state funded formal lifelong learning provision. In addition, mental health services are increasingly offering learning programmes specifically targeted at aiding the recovery of those with mental disorder. In summary, the aims of these formal lifelong learning provisions are two fold: to increase the numbers of people with mental disorder who take part in formal lifelong learning and for that formal lifelong learning to aid recovery.

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# What Would a Recovery-Oriented Program Look Like?

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## Abstract

Research and practice-based knowledge has grown over the past 30 years concerning what is helpful to recovery and what is not. This information comes from a variety of sources including research, professional practice, family experience, and the recovery experience of people with mental illnesses. Through these complementary perspectives the author describes the conditions under which people with psychiatric disabilities change, and, how positive or negative internal and external factors influence these changes.

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## Introduction

As a result of the newness of the shift toward recovery-based practice, mental health professionals, family members, people with mental illnesses, and people in the community are at different levels of understanding and implementing the recovery paradigm. The current transition is leaving some people very confused and frustrated. A critical first step, however, is to understand what recovery is and what a recovery-oriented program would look like.

Recovery has been defined in numerous ways. The definition the author proposes has been developed, in part, by a consensus-building process involving professionals, family members, and people with mental illnesses in Connecticut (Davidson, Tondora, & O'Connell, 2007). They describe recovery as being connected to your community in meaningful ways; having an identity separate from one's condition; and having a life that is satisfying, fulfilling, and contributing to others despite of or within the limitations imposed by that condition.

A recovery-oriented program is one that provides the knowledge, skills, support, and resources to facilitate the achievement of each individual's recovery. Giving a program a new recovery title or adding a new recovery policy statement will not work unless there is a clear understanding and implementation of the current research, professional practice, family experience, and consumer experienced-based components of a recovery-oriented

program. This paper will pull this varied information together and present it in terms of guidelines for what constitutes a recovery-oriented program with examples of program policy statements supporting the components. And of course, it will be necessary to periodically review and update these guidelines as our knowledge grows. Not all components need to be in the same program, but they need to be an active part of the local helping community and readily accessible to all members of the “recovery community.”

## Recovery Program Components

### Strongly Affirm Recovery in the Mission Statement

Programs need to affirm President Bush’s New Freedom Commission on Mental Health Report (2003) and the state Departments of Mental Health State Plan statements on family- and consumer-directed care and the new vision of recovery. The President’s New Freedom Commission on Mental Health report is being widely adopted by individual state Departments of Mental Health and mental health programs across the country. Local, state, and community program adaptations should be developed collaboratively between organizations, family members, people with mental illnesses, and community representatives. It is important that the Mission Statement derived from this consensus-building process focus on the recovery vision rather than the essential components, policy changes, or practice guidelines. The recovery vision refers to outcome—and the components, policy changes, and practice guidelines are the means to achieve the recovery outcome. An organization needs to be clear about its vision first and only then can it adequately focus on the means required to achieve that vision.

### A Climate of Hope

Hope is essential to building a life for anyone. The accumulation of traumatizing, devaluing experiences can wear people down over time, and lead to the giving up of hope. Hopelessness, apathy, and indifference are best seen not as problems people have but as learned solutions to shattered lives. They are strategies that desperate people adopt in order to stay alive (Deegan, 1996) and to manage their sense of powerlessness (Mack, 1994). Without hope, it is hard to cope. People just barely survive—they don’t feel alive or a part of life. Their personal vitality is broken and numbed. We also certainly know of many examples where hope has been taken away—where someone has said there is no hope. This is especially devastating to people with psychiatric disabilities. And, if these words come from a mental health professional, it is doubly disabling.

Hope is a combination of empathy with respect to the person’s present life (i.e., what is) and also with respect to the person’s capacity (i.e., what can be). Both of these aspects of hope need to be communicated to the person and can be parallel processes. If the helper focuses solely on capacity, the person may experience him or her as a “cheer leader” who can not adequately acknowledge his or her full experience. The present, or “what is,” is often painful and sometimes terrorizing because of the illness, symptoms, past history, prejudice, or discrimination. These experiences need to be validated and integrated in order for the person to rebuild his or her life. Helping a person focus on their aspirations and goals represents respect for the person’s capacity, and gives the person hope. It is a way of saying “I assume you have aspirations and goals and I expect you to be able to achieve them.”

Mutuality means that each person brings something important to the interaction. Hope, for example is often described as something the provider holds for the person with the mental illness. While this may be initially true, the bearer of the hope can shift. There are many instances where the provider may feel frustrated or even hopeless concerning the person they are helping and then the person they are helping may do or say something which shifts the provider back to a hopeful place. Relationships that are mutual are respectful. Each person is open to giving to and learning from the other. A mutual relationship can generate many wonderful surprises for each person (Eldridge, Surrey, Rosen, Baker Miller, 2003).

Policy example: Providers will empathize with the person’s situation in life and help each person to identify aspirations and goals and provide the knowledge, skills, support, and resources to achieve them.

### Affirm Key Recovery Values

The explicit affirmation of key recovery values is an important component of a recovery-oriented program. These recovery values need to be articulated in the policies of the program; providers should be trained in the theory and implementation of the values, and should receive ongoing supervision to develop their own expertise in implementing the values. These key recovery values include:

**Participation:** People need to be involved in all aspects of their treatment and recovery processes. The 2003 President's New Freedom Commission on Mental Health report stated that: "Nearly every consumer of mental health services... expressed the need to fully participate in his or her plan for recovery" It must be assumed that people are able to participate even when it doesn't look like they can. Encouraging participation may take persistence and patience on the part of the helper. Participation can grow over time as people develop confidence in their ability to act in their own interest.

**Self-determination/choice:** People have the right to be in the center of decisions that affect their lives. Choice empowers people because it gives them some control over their lives. Choice, even when it involves failure, builds a sense of possibility rather than a sense of impossibility. In the Report of the 2004 Consumer Direction Initiative Summit, *Transforming Behavioral Health Care to Self-Direction* (SAMHSA, 2004), the term "self-directed care" was defined as a system that is "intended to allow informed consumers to assess their own needs . . . determine how and by whom these needs should be met, and monitor the quality of services they receive" (Dougherty, 2003). A general principle is that self-determination is essential to everyone's mental health and well being and is often regarded as a basic human right (Adams, Grieder, Nerney, 2005).

**Empowerment:** Empowerment means the person is able to say "I can" rather than "I can't." Empowerment is built through achieving success in life's many tasks, even small ones. As successful experiences accumulate, peoples' sense of empowerment gradually grows. Loss of power is a loss of one's ability to act in one's own interest—this is a loss of belief in oneself. Loss of power is also the loss of one's sense of agency and vitality—the inability to experience oneself as an active and vital agent. People with psychiatric disabilities often experience themselves as having no power, no real choices. Power is further lost through the severing of our connections. When our connections are broken, we feel powerless and despairing (Lifton, 1996). There are a variety of forms of power. The power that is healing, that is more than oneself, that can move another person, is acquired through our relationships. It is power with people not over people. It is a power acquired through reconnecting with oneself, others, our environments, and meanings in life. It is a power acquired through a deepening of our capacity to experience life fully and directly without being overwhelmed or intimidated. It is a power acquired by coming alive (Mack, 1994).

**Growth potential:** It is important to see people's growth potential regardless of current difficulties or disabilities. Their growth potential may appear small at any given moment but it needs to be seen as an important opportunity for developing confidence and empowerment. Getting hope from others and having others show confidence in you is reported by many people with mental illnesses as an important turning point in their lives. Hope can be contagious and can plant a seed of promise, a new potential perspective, in a person who is distraught and despairing (Deegan, 1995).

**Community focus:** Providers need to facilitate integration into community life by providing opportunities for the development of multiple roles to discover and create an identity that is separate from and greater than the illness such as a student, worker, volunteer, neighbor, friend, and one who can enjoy life. The identity of "patient" is very debilitating and needs to be actively countered by providing opportunities for new identities through acquiring the ordinary roles in life.

**Whole person/family centered:** People need to be treated as whole human beings, with natural responses to a profound trauma, and with a deeply felt connection to their family regardless of their current relationship. People with mental illnesses and their family members are not to be diminished or dehumanized in any way by their need for help.

**Recovery as an expectation:** It is clear from the research and many personal accounts by people with mental illnesses that most people with serious mental illnesses recover. By recover we mean that people can work, have a social life, have an intimate relationship, live in housing of their choice, have an identity separate from the illness, and contribute to their community. We also know that there are many factors that enhance the recovery process—and some that inhibit it (Davidson, Harding, & Spaniol, 2006; Davidson, Harding, & Spaniol, 2005; Whitty, 2008). We can not promise people that they will recover but we can say that most people have recovered and that with assistance they have a good chance of having a life that is satisfying, fulfilling, and contributing. Because we currently have no way of accurately predicting who will recover it is important to assume that the person we are helping has the potential for recovery.

Policy example: Providers will affirm in their practice the above recovery values essential to a recovery-oriented program.

### **Provide Acute and Ongoing Psychiatric Care**

There are a variety of interventions and resources that have been shown to be helpful in a person's recovery process. These include crises intervention which is necessary to care for someone with an acute onset of a mental illness or for periodic crises that arise in the recovery process. Inpatient/outpatient treatment is required to help stabilize a person in a crisis and to assist with the re-entry into his or her community. Assertive community treatment involves actively reaching out to people in need of special assistance in coping with the debilitating and persistent nature of mental illnesses and co-occurring disorders. Respite facilities provide an opportunity for people to resolve crises without hospitalization. Transitional and supported housing provides residential options as people are released from hospitals. Case management helps people to maintain themselves in the community and to rebuild their lives. A Hot-line provides a regular opportunity where people in crises can talk to another human being about their current concerns or worries. A Warm-line helps people who are lonely or isolated to connect with a compassionate listener.

Policy example: The program will make available, assist in developing, or connect to in the community, the above essential elements of acute and ongoing psychiatric care.

### **Availability of Primary Health Care**

Consumers of mental health services die an average of 25 years earlier than the general public (Everett, Mahler, Biblin, Ganguli, & Mauer, 2007). Unfortunately, many medical problems of people with mental illnesses go undetected or untreated (Druss, et al., 2008). And their health is further complicated by lack of attention, ignorance, poverty, and neglect. As Lauren Spiro Director of Public Policy, National Coalition of Mental Health Consumer/Survivor Organizations has said in a recent presentation at the 2007 National Wellness Summit for People with Mental Illness (Spiro, 2007):

Each individual's life depends on the society they live in and the services and supports that are available to them. To frame the co-morbidity and early mortality rate as simply a medical issue is not only inaccurate but an injustice to everyone. The problem of co-morbidity and early mortality is an indicator of a broken system within a broken society. The coalition was formed because the survival of our brothers and sisters is being threatened by the oppressive policies, services and attitudes of the system and of society. We die young because we have no hope. We die young because our dreams have been crushed. We die young because our voice is neither heard nor understood. We die young because many of us live in poverty, and some of us live on the streets. We die young because our physical health needs are routinely ignored, often because any problems we have are attributed to our mental illnesses.

Clearly, attention to basic health needs is critical in a recovery-oriented program as well as attention to other aspects of the person's life that threaten their health and wellness.

Policy example: The program will make available, assist in developing, or connect to in the community, the above essential elements of acute and ongoing medical care.

### **Interventions for the Psychosocial Impacts Prior To, During, and After the Acute Onset of the Illness**

The onset of a mental illness is a trauma for the whole family, including the person with the illness. And with trauma comes shock, disorientation, panic, denial, and shattered lives. In addition there are the reoccurring traumas of living with a mental illness in our society. For example:

People have to live with the daily impact of prejudice and discrimination.

They often live with hopelessness and despair. People live with the perceived impossibility of recovery.

They quickly lose faith in the mental health system.

They are believed and come to believe that they are unable to have normal roles such as student or worker,

There is often a long-period of recuperation that may last several years.

People experience plateaus with the appearance of no progress followed by periods of integration and consolidation.

Their normal developmental phases are interrupted.

Thus, many of the distresses people feel do not come from the illnesses but from the reoccurring traumas of living with a mental illness in our society. Interventions such as peer support groups, therapy, education, skill building, goal setting, and patience on the part of providers and families are required that support and understand the often extreme emotional responses to living with a significant and potentially long-term illness.

Policy example: Practitioners will be responsive to the ongoing psychosocial impact of the illness on the person and the person's family members.

### Respect People and Their Unique Process

Each person is unique and individual. No path is the same. Learn from the experiences of people with psychiatric disabilities. Assume people can learn how to lead their own lives. Given the information, skills, and support people can make life decisions. "Taking charge" is an important turning point in the recovery process. This is clearly evident in many research studies and from the recovery literature.

People, in their recovery process, tend to experience some variability in growth within the various developmental dimensions i.e., vocational, social, educational, physical, and emotional. People will show variability from others and within themselves over time. This variability can be a function of barriers or facilitators to growth such as quality of personal contact, opportunities, treatment interventions, resources, personal drive, resilience, personal successes, and other factors. It is interesting to note that level of achievement on the various developmental dimensions is not solely or simply related to level of symptoms but also involves successfully engaging a wide variety of barriers and facilitators to recovery. People can have symptoms that they are managing or struggling to manage successfully and still be growing in their recovery.

Policy example: Practitioners will be responsive to the developmental needs, priorities, and choices made by their clients.

### Value the Importance of Relationships and Connectedness

Personal stories of people with mental illnesses reveal a pervasive loss of interpersonal connectedness, loneliness, and isolation, yet a profound longing to be connected in meaningful ways to others (Davidson & Stayner, 1997). Yet people become so shocked by the illness, prejudice, and discrimination that they feel they cannot act on their own desires for contact (Magliano, et al., 2008). Providers, families, and peers can find opportunities for people to interact. Connecting can be very healing to the body and to the mind. Providers need to teach interpersonal skills for selecting, building, maintaining, and repairing relationships. Examples of rebuilding connections are:

Oneself: Provide opportunities for building confidence/self-esteem through meaningful roles. Loss of "roles" devastates a person's sense of value and meaning.

Others: Provide interpersonal skills and opportunities for developing sustaining friendships and intimacy.

Loneliness is a major problem for people with mental illnesses. Foster an atmosphere of a recovery community.

Broader environment: Provides opportunities for social programs, volunteering, and work that help people feel a part of the community and connected to others.

Meaning and purpose: While developing larger meaning and purpose is helpful (e.g., spirituality), people also need to identify their own personal purpose in life. A personal purpose often involves activities or relationships which make people feel useful and valued.

Policy example: Practitioners will be responsive to the connectedness needs of their clients.

### Value Involvement

Listen to what people say they need and want. Encourage people to be involved in all the decisions that affect their lives. They are their lives to live. Assume that people can participate in decisions that affect their lives, even

when it does not appear that they can. Listening can seem to be a fairly simple skill. Yet our projections of what we think people need often get in the way of hearing what we are being told. To be listened to is to be respected.

Policy example: Practitioners will encourage clients to be involved in all decisions that affect their lives.

### **Include Rehabilitation and Skill Building**

Education and skill building are critical interventions. Focus on strengths. Help people to build a life. The tendency historically has been to focus on pathology. Focus on strengths builds up confidence and self-esteem. It provides an opportunity to be successful. Individualized goal setting provides assistance in setting personal goals and the steps to achieve them. Setting and working toward goals is an important part of the recovery process. Without ongoing goal setting programs are at risk of becoming sheltered workshops or social clubs and people are at risk of languishing in hopelessness. Rehabilitation provides skills and opportunities for developing job skills, finding work, maintaining work, developing a career, and continuing one's education (Corrigan, Barr, Driscoll, & Boyle, 2008). People with psychiatric disabilities have been found to be working at all levels of employment (Rusinova, Wewiorski, Lyass, & Rogers, 2003).

Policy example: Practitioners will encourage clients to set goals and provide the knowledge, skills, and supports to achieve those goals.

### **Involvement of Family Members**

Providers need to value family involvement and understand its importance in order to assertively reach out to family members. Programs can establish policy for family involvement, develop guidelines, train staff, and supervise staff in implementation (Bogart & Solomon, 1999). Program can encourage a collaborative alliance among all parties. Providers need to involve families in the planning, implementation, and monitoring of all interventions. Shared decision making can reduce the isolation and tension the various participants often feel. Decisions that are made are more likely to meet the needs, aspirations, strengths, and limitations of those involved. And, crises are more likely to be avoided or interrupted. Providers need to believe that families do not cause mental illnesses and that there is a substantial research supporting family involvement as useful to recovery. When family members are involved, people do better (Fischer, et. al., 2008).

Policy example: Practitioners will educate clients about the value of family involvement and encourage signing of appropriate confidentiality release forms. They will encourage clients to involve family members as part of their treatment and rehabilitation team.

### **The Active Presence of Recovered People at All Levels of the Treatment and Rehabilitation Process**

People need models and mentors, i.e., other people with a psychiatric disability who have succeeded in their lives. The active presence of recovered people is common practice in recovery programs for people with other disabilities. People who are more fully recovered can and do serve at all levels of mental health programs from directors to peer professionals. Programs are also being entirely run by peers. Peer support or modeling can be an important factor in helping people to cope, to feel that they are not alone, and to have hope for their own recovery.

Policy example: Programs will educate staff about the value of peer support and actively and assertively involve peers who are in recovery in working for and volunteering for the program.

### **Provide Opportunity to Resolve Impact of Substance Abuse**

There is a well documented need for the integration of mental health and substance abuse services for people with dual disorders (Doyle-Pita & Spaniol, 2002). Fifty percent or more of people with mental illnesses will experience a co-occurring substance disorder at some point in their lives. For many, this will be an ongoing struggle with the need for an integrated treatment program and a long-term relationship with an assertive community treatment team.

Providers need to understand that untreated substance abuse is a major barrier to recovery and that people in recovery from dual disorders are a very important part of any treatment team. People with dual disorders often need ongoing interventions for substance abuse related symptoms—which usually begin prior to or after the onset of the mental illnesses. Substance abuse often leads to further trauma, particularly from prejudice, discrimination, and violent victimization, which are common among people with severe mental illnesses.

Policy example: The program will provide integrated dual disorder services including regular substance abuse assessments to new clients.

### **Provide Fitness and Wellness Opportunities**

There is a strong connection between wellness and recovery (Hutchinson, Skrinar, & Cross, 1999). Wellness programs such as nutrition, weight management, yoga, meditation, regular exercise, good physical health care, and symptom management, with programs and encouragement for active involvement, are essential elements of a recovery-oriented program. It is also important to provide opportunities for self-determined alternative choices such as Tai Chi, homeopathic medicine, vitamins, massage, and acupuncture.

Providers need to educate people with mental illnesses about intimacy and human sexuality. Help people learn the social skills necessary to find and maintain intimacy. Close personal relationships are important for recovery. Sexually transmitted diseases, especially HIV infection, are a high risk factor for people with mental illnesses.

Providers need to train people with mental illnesses in writing a Relapse Management Plan and an Advanced Directive Plan with a clearly designated surrogate decision maker. The Wellness Recovery Action Plan (WRAP, Mary Ellen Copeland) is an effective course for helping people identify and self-monitor symptoms of the illness and of stress. The WRAP is also effective for developing new beliefs and ways of thinking and challenging self-defeating thoughts. An Advanced Directive Plan gives people choices when they may be unable to make them themselves. The plan identifies how you want to be treated; what place you want to be treated at; who you want to be treated by; what medications you want to receive; and who will be making the decisions for you. The designated surrogate decision maker is the person, identified by the person with the mental illness, who will have final say over all treatment decisions. This is an important role to have someone take when we are unable to make our own decisions. So, the choice should be carefully thought through and put in writing in the plan. Unfortunately, Advanced Directive Plans are not always followed faithfully by psychiatric staff so the designated surrogate decision maker needs to be particularly one who could be actively involved during crises (Srebnik & Russo, 2007).

Policy example: The program will provide comprehensive and ongoing wellness and fitness training and activities to clients.

### **Provide Long-Term Commitment to People**

People with mental illnesses have a right to assistance as long as it is needed and required. This may require a long-term commitment by their program. The program should have a “no fail” policy. “No fail” means that people may need “time outs” but that the program is willing to take them back and continue working with them if they want. The use of force, either obvious or subtle is never a “first option” intervention. People are treated with respect and there is tolerance for multiple personal perspectives on what is helpful or not in their recovery journeys. People are expected to take responsibility for their own recovery. People should not be looked at as “resistant” only as people with another perspective on what is helpful. Understanding another person’s perspective creates intimacy and trust, which are essential to helping people on their recovery journey. Providers and people with mental illnesses will need to “hang in there” through the inevitable emotional upheavals. Both need their own support to manage the normal stresses of the helping and the recovery process, to avoid over-reacting in the moment, and to avoid burn-out.

Policy example: The program will provide a long-term commitment to clients and adopt a no-fail policy.

### **Provide Opportunities to Contribute to Others**

Recovering the capacity to be helpful to others is an important turning point in the recovery process. Many people find that contributing to others with mental illnesses is an important aspect of their recovery. Their contributions can be within programs where those who are further along help those who are less far along, or, by contributing or volunteering in the community.

Policy example: The program will provide ongoing opportunities for clients to contribute within the program and within the community.

### **Ongoing Education and Support for Providers, Family Members, People with Mental Illnesses, and the Community.**

The provider’s role has changed from that of all-knowing, all-doing caretaker to that of coach, facilitator, or

mentor (Adams, Grieder, & Nerney, 2005). The family's role has changed from that of the cause of the illnesses to a resource in the recovery process. The person with the illness's role has changed from hopelessness to an expectation for self-determined recovery. Education and support must reflect these profound changes.

All parties need knowledge about recovery basics, hope, expectation for recovery, choice, listening, whole-person orientation, collaboration, supporting one another, encouraging self-care, knowledge of the illnesses, medications, side effects, and available resources. And, they also need the skills and positive attitudes to support the knowledge.

Policy example: The program will provide ongoing continuing education for providers, family members, people with mental illnesses, and the community.

### **Advocacy**

Advocacy is an essential component of a recovery-oriented program. All parties must share in that advocacy for it to be effective and to achieve its goals. Programs can establish a collaborative process for assessing and understanding the challenges and needs of all parties. This will lead to a comprehensive grasp and consensus of the policy and programmatic implications of these needs and a collaborative strategy for change.

Policy example: The program will provide ongoing advocacy to improve the daily lives of people with mental illnesses, their families, and providers.

## **CHALLENGES TO A CLIMATE OF HOPE AND RECOVERY**

There are many challenges to creating a climate of hope and recovery.

### **Lack of Awareness and Inertia**

NAMI hopes to create more awareness. There is a programmatic and personal inertia that needs attention. Programs and people tend to keep doing what they are doing. Change is difficult and the change to a climate of hope and recovery requires a change in culture, knowledge, skills, attitudes and the supervision to embed the changes into practice. The consensus-building process mentioned above under Advocacy helps to embed the needs cognitively and emotionally in the various audiences. It helps to overcome the "numbing" of people to the needs of people with mental illnesses. **Lack of Support for**

### **Self-Help**

We need to move from a professionally driven system to a client driven system. Self-help is often misunderstood in mental health although it is well established in other disability areas. Helpers need to be chosen for competence as well as for presence of a disability.

### **The One Model Trap**

We need to advocate for a variety of interventions and opportunities. There are many evidence-based practices and they need to be individualized for each person. There are many paths to recovery.

### **Retrenchment**

Retrenchment means continuing to do the same thing rather than change. This occurs when people get overwhelmed by change or are not well prepared, trained, and supported in it.

### **Evidence-Based Practice vs. Process**

Evidence-based practices are very important but we can not lose sight of the human variables in interventions. Hope, positive expectations, and optimism are important adjuncts to evidence-based practices.

### **Funding Neglect**

Mental health has not been a public priority. It is not even on an equal "playing field" with respect to funding for other disability groups. Parity needs to be taken seriously in terms of reimbursement but also in terms of up-front funding for mental health that is at least on a par with funding for other disability groups.



## Conclusions

People with mental illnesses can recover and build a self-determined life for themselves in communities of their choice. If the basic components of a recovery-oriented program are in place, their hopes for a fuller life can be more likely realized. It is hoped that by providing this brief summary of a recovery-oriented program providers, family members, and people with mental illnesses can better evaluate the closeness of their programs to what is now known that works.

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Recovery- and Community-Based Mental Health Services in the Slovak Republic: A Pilot Study on the Implications for Hospitalization and Inpatient Length-of-Stay for Individuals with Severe and Persistent Mental Illness

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## Abstract

**Objective:** This study seeks to assess the impact of community mental health service interventions (i.e., case management, sheltered housing, and psychiatric rehabilitation services) on the probability of hospitalization, 30-day re-hospitalization, and inpatient lengths-of-stay for individuals with severe and persistent mental illness.

**Method:** Using a natural experiment design on a five-year, longitudinal cohort, generalized estimating equation models are used to compare 757 individuals who were hospitalized at the psychiatric hospital in Michalovce in

2001 to 46 individuals who received some type of community mental health service intervention between 2001 and 2005.

**Results:** Although community service interventions did not have a statistically significant effect on the probability of hospitalization, the interventions were associated with significantly decreased probabilities of 30-day re-hospitalization and inpatient lengths-of-stay.

**Conclusion:** Findings support the continuing policy initiative of building deinstitutionalized, community-based mental health systems in Eastern European countries.

**MeSH Keywords:** Slovakia, schizophrenia, community mental health services, deinstitutionalization, hospitalization, length of stay

## Introduction

As Central and Eastern European countries focus on rebuilding governmental infrastructure, much attention has turned to mental health reforms, as evidenced by the 2005 Mental Health Declaration for Europe and the Mental Health Action Plan for Europe (World Health Organization, 2005a, 2005b). In central and Eastern European countries, mental health reform has embraced deinstitutionalization and a greater role for community mental health services (Becker & Kilian, 2006; Becker & Vazquez-Barquero, 2001; Roberts, 2002; Thornicroft & Rose, 2005). Actual reform activities to meet these objectives, however, have varied widely (Becker et al., 2002; Becker & Kilian, 2006; Becker & Vazquez-Barquero, 2001; Kallert et al., 2004), and some evidence suggests that little progress has been made on de-institutionalization. Rittmannsberger et al. (2004) conducted a one-day census of psychiatric patients in five European countries (Austria, Hungary, Romania, Slovakia, and Slovenia) in 1999. Researchers found that patterns of involuntary admissions and inpatient lengths-of-stay had changed insignificantly compared to 1996 data and that little progress had been made in transitioning psychiatric patients to life in the community (Rittmannsberger et al., 2004).

Eastern European countries lag behind their western European counterparts with regard to mental health therapies (Jenkins, 2001; Mossialos et al., 2003). The Soviet legacy has perpetuated a system of care that is heavily institutional with little focus on community services, social work, or multidisciplinary team work. Such legacies include a lack of understanding for the social needs of individuals with severe mental illness that accompanied a lack of research and training in different types of effective community treatments. Also, the fractionalization of psychiatric services separated from physical health services contributed to the stigmatization of mental disorders and the isolation of individuals with severe and chronic mental illness (Mossialos et al., 2003).

Two main challenges exist to the decentralization of health services and the development of community services for individuals with mental disorders. One challenge is the development of trained professionals in community settings. Another challenge is the lack of infrastructure, both in terms of economic and social support, to build and to sustain community service reforms (Mossialos et al., 2003; Rutz, 2001). Strategies for mental health reform have included developing national strategies, supporting system infrastructure, building linkages between systems of care, encouraging client/user participation, and de-stigmatizing mental illness (Jenkins, 2001). Some reforms have focused on the development of collaboratives for sharing and disseminating reform practices. The Network of Reformers in Psychiatry, a convention of mental health professionals, represents an attempt to organize and to share experiences around reform and best practices. Other reforms aimed at service delivery changes and professional changes have also occurred (van Voren & Whiteford, 2000). The following section will describe reforms that have recently been implemented in Slovakia.

## Mental Health Reform in Slovakia

Slovakia, a country of approximately 5.4 million persons, is located in Eastern Europe, surrounded by Poland and the Czech Republic to the north, Hungary to the south, and Austria and the Ukraine to the west and east, respectively. After the pull-out of the Soviet Union, Slovakia became independent in 1993 and joined the European Union in 2004 (Central Intelligence Agency, 2006). The country has approximately 30,000 inpatient beds with 3.6 physicians per 1,000 population (Organisation for Economic Co-operation and Development, 2004).

The Slovak Republic has been actively engaged in mental health de-stigmatization efforts. Government and non-government organizations have collaborated on projects to reduce stigma around mental illness and to develop community services. The “Open the Doors, Open Your Hearts” anti-stigma program has been engaged in an active media campaign allowing individuals with mental illness to document their struggles with mental illness on film and collaborating with local media stations for vocational training of individuals with mental illness (Nawka et al., 2005). The primary focus of the de-stigmatization reforms is to bring together four stakeholders: mental health professionals, consumers, family members, and the community. The “Open the Doors, Open Your Hearts” program in combination with other community-based mental health programs offers the only integrated community-based mental health programs in the country to combat mental illness. In 2002, the government officially initiated the Transformation to an Integrated System of Mental Health Care to create a model region of standard mental health care in Michalovce, a city of approximately 40,000 residents in eastern Slovakia (Nawka et al., 2004; The Government of the Slovak Republic, 2004).

Mental health reforms in Slovakia have embraced four core components: 1) building community service infrastructure through non-governmental organizations; 2) decreasing reliance on inpatient psychiatric hospitals; 3) reducing stigma associated with mental illness; and 4) emphasizing the recovery model. To date, three types of community services-- rehabilitation services, case management, and sheltered housing-- have been developed and are being offered to consumers with severe and persistent mental illness. Rehabilitation services and sheltered housing were offered beginning in 1997, and case management services were offered beginning in 2003. All services are provided under the recovery model. The recovery model is fundamentally different from traditional institution-based care because of its focus on the needs and limitations of the individual (Nawka et al.). Therapies and treatments proceed in accordance with a client’s motivation and possibilities for achieving the highest quality of life. The aim of rehabilitation services is to support client recovery, finding optimal solutions with respect to each client’s current situation and prospects for the future. Case management provides effective health care and social services at home or in the community for clients with mental illness. The nature and needs of each individual client determine the extent of care. Finally, sheltered housing is available year-round for clients with mental disorders capable of leading life independently with help and supervision. Supervision is provided to monitor client behavior and activity during working days, and all observations are documented.

Studies of the utilization of community services in other countries have shown a consistent decrease in the probability of hospitalization, lengths-of-stay, as well as improved quality of life indicators (Balestrieri et al., 1987; Baruch et al., 2005; Hobbs et al., 2000; Rasanen et al., 2000; Ryu et al., 2006). Analysis of psychiatric admission data in Israel after their deinstitutionalization reform showed a significant decrease in inpatient lengths-of-stay over the five year study period (Baruch et al., 2005). Investigation of community-based interventions supplementing deinstitutionalization in Italy have shown similar decreases in hospital lengths-of-stay (Balestrieri et al., 1987). Studies of case management have found that it is associated with decreased days of service utilization (Seltzer et al., 1987).

## Aims of the study

In 2001, Slovakia embarked on a project building community mental health service infrastructure in the town of Michalovce. There, individuals with severe and persistent mental illness could receive recovery-based community mental health services, such as rehabilitative services, case management, or sheltered housing. This study investigates probability of hospitalization and 30-day re-hospitalization, as well as inpatient lengths-of-stay in a longitudinal, five-year sample of individuals with severe and persistent mental illness in Michalovce, Slovakia comparing those who received community services to those who did not receive community services.

## Methods

### Study Design

This study uses a natural experiment design of individuals with severe and persistent mental illness in the Michalovce region (including the adjoining province of Sobrance). The study follows a cohort of severely mentally ill individuals from Michalovce hospitalized in 2001 (n=803) for five years, comparing individuals who received community services to those who did not receive community services on the probability of hospitalization or 30-day re-hospitalization, as well as hospital lengths-of-stay. Following the same persons over time reduces confounding due to possible variation in characteristics of consumers using services at different time periods. By identifying subjects concomitant to the initiation of community-based services, initial differences in treatment patterns could also be assessed and incorporated in the interpretation of community-based service intervention.

### Data Sources

Hospitalization data is taken from administrative data from the Psychiatric Hospital in Michalovce for five years between 2001 and 2005. Community-based services data is taken from the Association for Mental Health Integra in Michalovce.

### Measures

**Dependent variables.** There are three dependent variables included in this study. Hospitalization records begin on January 1st for each year. Hospitalization is defined as any hospitalization that occurred during the calendar year. The variable is coded dichotomously '1' for any hospitalization during the year and '0' for no hospitalization during the year. Thirty-day re-hospitalization is measured as the occurrence of any hospitalization within 30 days of the discharge date of the previous hospitalization. Any single occurrence of a 30-day re-hospitalization is considered a re-hospitalization during the year and is coded as a '1' for the dichotomous variable. Hospital length-of-stay is measured as the total number of days spent in the hospital during the calendar year.

**Explanatory variables.** The community-based services in Michalovce include rehabilitation services, case management, and sheltered housing. The receipt of any one of these services qualifies as receipt of any community service and is coded as a '1' for the dichotomous variable. Those who did not receive any community service are coded as a '0.' Interaction terms between community service and time are also included.

**Other covariates.** Other covariates include gender, marital status, diagnosis, age, and time. Gender and marital status are coded dichotomously. There are three diagnostic groups—schizophrenia, bipolar disorder, and other psychiatric diagnosis—and diagnosis is coded dichotomously where, for example, having a diagnosis of schizophrenia is coded as a '1' and not having schizophrenia is coded as a '0.' Age is centered at the mean. Time is presented as dummy variables for each of the five years between 2001 and 2005.

## Data Analytic Procedures

Generalized estimating equation (GEE) models are used to assess the association of explanatory variables with probability of hospitalization, probability of 30-day re-hospitalization, and hospital lengths-of-stay. Generalized estimating equation modeling is superior to the ordinary least squares (OLS) approach because it accounts for correlated data and corrects for clustering in the standard errors. Analysis of correlated data, due to the longitudinal design of the study, using OLS methods may result in artificially low variance and low p-values (Hanley et al., 2003; Orelie, 2001). Generalized estimating equation models using PROC GENMOD in SAS are especially useful in analyzing clustered data that have a non-normal distribution and result in reasonably accurate standard error measures (Orelie, 2001). The generalized estimating equation models can be used for both dependent variables that are continuous and categorical. We use an autoregressive correlation structure, although estimates have been shown to be consistent even if the correlation structure is incorrectly specified (Johnston & Stokes, 1996). All analyses are conducted using SAS version 9.1 (SAS).

Probability of hospitalization and 30-day re-hospitalization is estimated using generalized estimating equation models of a binary outcome measure. The dependent variable of the regression is a dichotomous variable indicating any hospitalization or any 30-day re-hospitalization during a calendar year. Results of analyses on binary dependent variables are presented as odds ratios. Since the data is derived from hospitalization records, the hospitalization sample is limited to the second through fifth years of data for analyses on the probability of hospitalization. The comparison group for time, therefore, is the second year of the study period rather than the baseline year.

Predicted probabilities are calculated using the formula:  $1/1+e^{-(a+bX_i)}$ . Predicted probabilities are used to graph probabilities of 30-day re-hospitalization for both the community service and no-community service groups found in Figure 1. Predicted probability calculations in Figure 1 for individuals who received community services include estimates for the intercept, mean age, schizophrenia diagnosis, community service, time, and the interaction of time and community service. Predicted probabilities for those who did not receive community services are identical except for the exclusion of the estimates of community service and its interaction term.

## Results

Table 1 presents the demographic characteristics of individuals who received community services and those who did not. There are significant differences between the two groups. Individuals who received community services are younger with a mean age of 39 years (SD=10.5) as compared to individuals who did not receive community services who have a mean age of 53 years (SD=19.3). Also, those who received community services are more likely to be male,  $\chi^2(1, N = 803) = 3.75$ ,  $p < 0.05$ ; unmarried,  $\chi^2(1, N = 803) = 29.34$ ,  $p < 0.01$ ; and have a diagnosis of schizophrenia,  $\chi^2(1, N = 803) = 87.04$ ,  $p < 0.01$ .

Table 1. Demographic Characteristics of Community Services Treatment and Non-Treatment Groups (Baseline)

	Community Service n=46	No Community Service n=757	t or chi- square	p
Mean Age (std)	38.9 (10.5)	52.5 (19.3)	7.98	***
Mean Length-of-Stay (in days) per Year (std)	146.9 (112.6)	47.5 (50.5)	-5.85	***
Sex			3.75	**
Male	69.6%	55.0%		
Marital Status			29.34	***
Married	16.7%	41.9%		
Single	50.0%	23.2%		
Divorced	26.2%	11.6%		
Widowed	7.1%	23.3%		
Diagnoses			87.04	***
Schizophrenia	71.7%	16.1%		
Bipolar Mood Disorder	2.2%	1.5%		
Major Depression/Other	26.1%	82.4%		

\*\*\*  $p \leq 0.01$ ; \*\*  $p \leq 0.05$ ; \*  $p \leq 0.10$ ; two-tailed

Table 2 presents the results for the generalized estimating equation model on the probability of hospitalization. Results show that those who received community services had over five times the odds of hospitalization than those who were not in the community service group (OR=5.52,  $p < 0.01$ ). Individuals with a diagnosis of schizophrenia are more likely to be hospitalized (OR=1.89,  $p < 0.01$ ), while those who are married (OR=0.71,  $p < 0.01$ ) or older (OR=0.99,  $p < 0.01$ ) are less likely. The likelihood of hospitalization decreased significantly over time for all individuals. The likelihood of hospitalization also decreased over time for those who received community services, but differences in the odds of hospitalization were not significant. In summary, both groups experienced parallel decreases in probabilities of hospitalization throughout the study period.



Table 2. Generalized Estimating Equation Model for the Probability of Hospitalization

Variable	Estimate	S.E. <sup>a</sup>	OR	p
Intercept	-0.79	0.13		***
Age (mean-centered)	-0.01	0.00	0.99	***
Schizophrenia	0.64	0.16	1.89	***
Bipolar	0.29	0.49	1.34	
Community Service	1.71	0.46	5.52	***
Married	-0.35	0.13	0.71	***
Male	-0.01	0.13	0.99	
Year 3	-0.50	0.10	0.61	***
Year 4	-0.81	0.11	0.44	***
Year 5	-1.21	0.12	0.30	***
Comm Svc x Year 3	-0.20	0.49	0.82	
Comm Svc x Year 4	-0.69	0.55	0.50	
Comm Svc x Year 5	-0.69	0.58	0.50	
Observations	3212			
df	3199			

\*\*\*  $p \leq 0.01$ ; \*\*  $p \leq 0.05$ ; \*  $p \leq 0.10$ ; two-tailed

Comparison group are individuals with Other diagnoses, non-community service users, unmarried, female, hospitalized in 2002 (Year 2)

NOTE: Year 1 data has been eliminated because all individuals were hospitalized in Year 1.

<sup>a</sup> Standard error is reported for the estimate (not the odds ratio).

Table 3 presents the results for the generalized estimating equation model for hospital lengths-of-stay. Initial lengths-of-stay were longer for individuals in the community service group. Those individuals who had received community services spent, on average, 104 more days in the hospital during a year than those who did not receive community services. Individuals with a diagnosis of schizophrenia had an average of 36 more days in the hospital than individuals with other diagnoses. Those who were married had an average of seven fewer days of hospitalization than those who were not married.

Significant differences in overall and community-services lengths-of-stay appear during the later years of the study period. All individuals showed a significant decrease in hospital lengths-of-stay during the last year of the study period (2005). In the community service group, individuals had a significant reduction in hospital length-of-stay in the fourth year and showed a trend toward a significant difference in hospital length-of-stay in the last year. On average, individuals who did not receive community services experienced hospital lengths-of-stay that ranged from a low average of 71 days in Year 5 to a high average of 86 days in Year 3 with very little fluctuation in between. Individuals in the community service group, however, experienced continuous reductions in hospital lengths-of-stay throughout the study period. Initial average hospital length-of-stay for individuals in the community service group was 185 days, but the average hospital length-of-stay decreased to 109 days by Year 5.

Table 3. Generalized Estimating Equation Model for Hospital Length-of-Stay

Variable	B	S.E.	p
Intercept	43.19	3.10	***
Age (mean-centered)	0.00	0.09	
Schizophrenia	35.81	6.05	***
Bipolar	12.37	9.24	
Community Service	103.90	19.86	***
Married	-6.58	3.19	**
Male	2.46	3.33	
Year 2	2.87	4.18	
Year 3	4.20	5.39	
Year 4	3.94	5.73	
Year 5	-10.79	5.31	**
Comm Svc x Year 2	-38.46	24.66	
Comm Svc x Year 3	-32.51	34.77	
Comm Svc x Year 4	-72.22	28.88	**
Comm Svc x Year 5	-65.78	38.82	*
Observations	1515		
df	1500		

\*\*\*  $p \leq 0.01$ ; \*\*  $p \leq 0.05$ ; \*  $p \leq 0.10$ ; two-tailed

Comparison group are individuals with Other diagnoses, non-community service users, unmarried, female, hospitalized in 2001 (Year 1)

Table 4. Generalized Estimating Equation Model for the Probability of 30-Day Rehospitalization

Variable	Estimate	S.E. <sup>a</sup>	Odds Ratio	p
Intercept	-1.95	0.16		***
Age (mean-centered)	-0.01	0.00	0.99	**
Schizophrenia	0.47	0.17	1.59	***
Bipolar	0.66	0.52	1.93	
Community Service	2.03	0.40	7.63	***
Married	0.18	0.16	1.20	
Male	0.12	0.15	1.13	
Year 2	0.20	0.20	1.22	
Year 3	0.16	0.23	1.17	
Year 4	0.23	0.24	1.26	
Year 5	0.11	0.28	1.12	
Comm Svc x Year 2	-1.06	0.51	0.35	**
Comm Svc x Year 3	-1.20	0.61	0.30	**
Comm Svc x Year 4	-2.47	0.73	0.08	***
Comm Svc x Year 5	-2.61	1.01	0.07	***
Observations	1515			
df	1500			

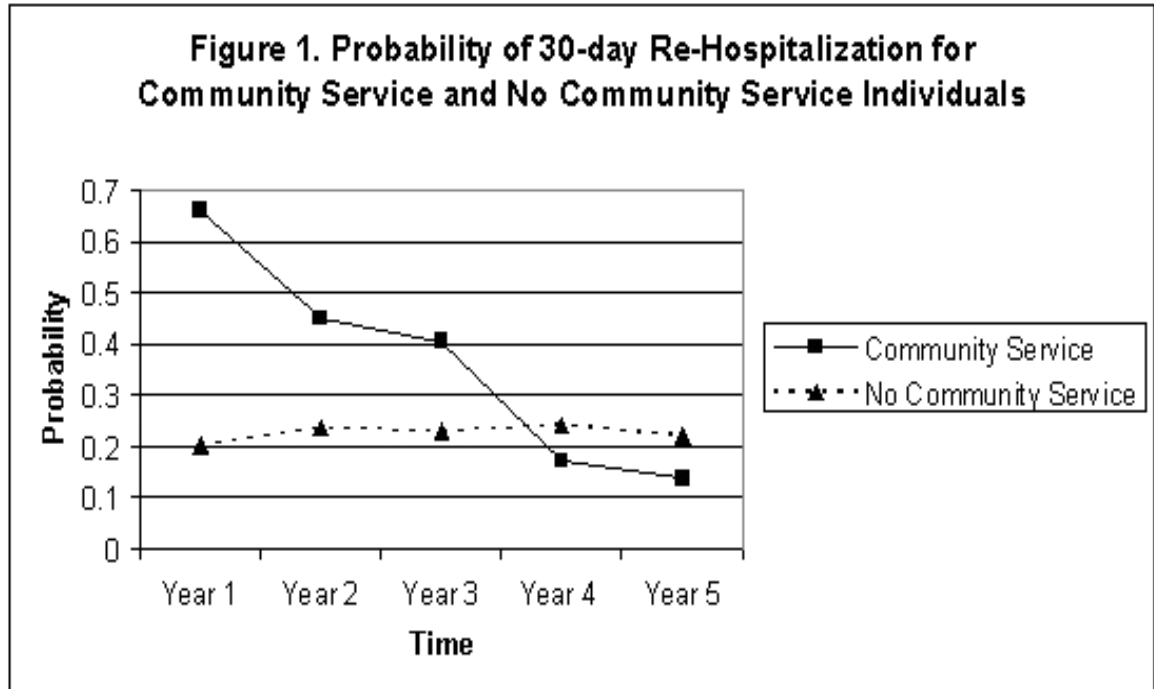
\*\*\*  $p \leq 0.01$ ; \*\*  $p \leq 0.05$ ; \*  $p \leq 0.10$ ; two-tailed

Comparison group are individuals with Other diagnoses, non-community service users, unmarried, female, hospitalized in 2001 (Year 1)

<sup>a</sup> Standard error is reported for the estimate (not the odds ratio).

Table 4 presents the generalized estimating equation model for the probability of 30-day re-hospitalization. Initially, those individuals who had received community services had about eight times the odds of being re-hospitalized within 30 days. After the initial hospitalization in any given year, individuals with a diagnosis of schizophrenia were twice as likely to be re-hospitalized within 30 days than those with other diagnoses. There were no significant changes in the probabilities of 30-day re-hospitalization for those in the no community service group. Individuals who received community services, however, experienced significant reductions in the probability of 30-day re-hospitalization throughout the study period (see Figure 1). For individuals in the community service group, the probabilities of 30-day re-hospitalization during Years 4 and 5 were lower than the probabilities of individuals in the no community service group. The probability of 30-day re-hospitalization for individuals who did not receive community services averaged around 23% with negligible change over time evidenced by its slope of 0.005 probability over time. On the other hand, the probability of 30-day re-hospitalization for those in the community service group averaged about 36% with a high of

66% in Year 1 and decreasing significantly over time evidenced by its slope of -0.13 probability over time.



## Discussion

The results suggest that the community service interventions have been appropriately targeted to individuals who are higher users of hospital services who may have less community support. Generally, those who received community services in Michalovce were young, unmarried, and had a diagnosis of schizophrenia. As the results of the generalized estimating equation models show, there are significant initial differences between the community service and no community service groups. Those who received community services had higher odds of hospitalization and re-hospitalization with concomitant longer lengths-of-stay.

There were time trends that also significantly influenced hospitalization and lengths-of-stay for all mental health consumers. The odds of hospitalization decreased significantly each year. This could be due to general policies and a growing dissatisfaction with institutional care that limited hospitalizations during this time. The decreased probabilities of hospitalization over the study period seem to reflect a treatment paradigm shift away from institutional care.

The community service interventions appear successful in reducing the probability of 30-day re-hospitalizations over time and lengths-of-stay, although the likelihood of hospitalization did not change significantly. There was a significant reduction over time in the odds of re-hospitalization within 30 days for those who received community services. Likewise, there was a significant reduction in lengths-of-stay over time for those who received community services. There were steady reductions in lengths-of-stay after Year 3 and significant reductions in Years 4 and 5. Recall that community

services were implemented gradually with rehabilitation services and sheltered housing offered in Year 1 and case management services offered in Year 3. The full complement of community services, encompassing rehabilitation services, sheltered housing, and community services, was implemented in Years 3 through 5. It is likely that support services in the community were used to prevent acute symptomatic problems that would have necessitated re-hospitalizations or were used as a substitute for institutional care thereby encouraging shorter lengths-of-stay.

This study has a number of limitations. First, the sample of individuals who received community services is small. While significant findings are a testament to the effect that community services had on this small sample of individuals, a larger sample of community service users would improve the robustness and generalizability of findings. A larger sample of community service users would assist in identifying if there were differential effects based on the types of community service interventions or the combination of community services used. Second, lack of randomization in assignment to community services means that unidentified variables may have systematically and significantly influenced results. The study sample was limited to individuals in the Michalovce region in order to control for historical and contextual variables between subjects and to reduce systematic influences of other variables. As the comparison of baseline data shows, however, significant initial differences exist suggesting self-selection into the community services group. Because of limited resources available for mental health reform and interventions in Eastern European countries, however, recipients will most likely continue to be those with the greatest need, i.e., those with severe and persistent mental illness. Therefore, these study findings using the natural experiment design represent a realistic distribution of characteristics found in intervention programs. Finally, we were unable to test the administrative data for reliability. Future studies would benefit from survey designs that collect individual information without relying heavily on administrative data or designs that allow researchers to check the reliability of hospital administrative data.

The findings of this study are encouraging for health systems in Eastern Europe and in other countries that are moving away from institutional care toward recovery- and community-based services. Future studies should investigate the cost-effectiveness of community services, including the optimal combination of community services. Also, future studies should investigate clinical and quality of life outcomes for individuals receiving community services as compared to those who receive only institutional care. Finally, qualitative features of the programs themselves, such as organizational design and recovery-based characteristics, that contribute to the success of the programs should be investigated.

### Implications for Health Care Provision and Policies

The findings from this study support continuing efforts in building community-based mental health infrastructure to support treatment and recovery for individuals with severe and persistent mental illness. Coupled with psychoeducation and anti-stigma campaigns, community-based mental health services can contribute to improved quality of life with decreased reliance on hospital-based treatments. A growing body of literature supports the use of family psychoeducation and caregiver support to address and alleviate alienation in persons with severe mental illness (Biegel et al., 1995; Kopelowicz & Liberman, 2003; Liberman & Liberman, 2003; McFarlane et al., 2003; Miklowitz et al., 2003; Murray-Swank & Dixon, 2004; Perese & Wolf, 2005; Stewart et al., 1999; Vieta et al., 2005). Individuals with schizophrenia whose families participate in mutual support groups show improvements in social functioning, self-maintenance, and community living skills (Chien & Chan, 2004). Individuals with mental illness can be re-introduced into the community with supportive services that help them to thrive and to contribute to the life of their communities. The organization and delivery of community-based mental health services in Michalovce that, as this study finds, contribute to decreased lengths-of-stay in psychiatric hospitals, can serve as an example of one type of

community-based mental health reform instituted by an Eastern European country faced with many governmental, financing, and health personnel challenges.

Finally, an integral element of the community-based mental health services offered in Michalovce is that they are recovery-based services. Recovery-based services focus on individualization of care founded on the philosophy that recovery from mental illness is possible and that the best course of therapy is one that not only draws upon an individual's strengths and weaknesses, but also empowers them to make decisions regarding the course of their treatment (Anthony, 1993). Findings from this study show that recovery-based services are effective in reducing hospital lengths-of-stay and 30-day re-hospitalizations when instituted in a supportive community-based setting. The elements of recovery that contribute to decreased length-of-stay and reduced probability of 30-day re-hospitalizations are unclear, and more research is required to assess the influence of the environment, organization, provider, and individual mental health client in the delivery of recovery-based therapies.

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# Two Bucks for the Bus: Support Enabling Active Recovery for Marginalised Populations

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## Abstract

The Support Enabling Active Recovery (SEAR) model is an innovative service delivery framework designed to engage marginalised populations with support services, to facilitate the attainment of lifestyle and life skill recovery goals and to improve health and quality of life outcomes. SEAR has been developed and implemented by the Homeless Health Outreach Team (HHOT), Royal Brisbane Hospital Division of Mental Health. HHOT provides multidisciplinary specialist mental health, dual diagnosis and drug and alcohol services to the inner city Brisbane homeless population.

The SEAR model enhances clinicians' and agencies' capacities to better meet the needs of individuals who are disengaged from service provision systems by providing key clinicians with multi layered systemic support that optimises the therapeutic alliance and provides enhanced support to clinical interventions. The SEAR approach to service structure also addresses service issues such as continuity of treating clinician, treating team stress management and continuous clinical skill enhancement.

**Keywords:** Homelessness, mental health, case management, service delivery, recovery

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## Introduction

The homeless population not only lack adequate housing, but experience great difficulty engaging with health providers due to negative past health care experiences, financial hardship, limited access to transport and limited knowledge of available health care services (Johansen et al., 1999; Lynch, 2004; Randolph, Blasinaky, Leginski, Parker, & Goldman, 1997; Commonwealth Advisory Committee on Homelessness, 2001). In addition, the prevalence of mental disorders in homeless people is four times higher than that of the general Australian population, 81% of homeless women and 72% of homeless men having at least one mental disorder (Teesson, Hodder, & Buhrich, 2004). This population is also at increased risk of experiencing medical problems, substance abuse and dual diagnosis, each of which can contribute to prolonged periods of homelessness (Chamberlain & Johnson, 2001; Commonwealth Advisory Committee on Homelessness, 2001; Johansen et al., 1999; Lynch, 2004; Randolph et al., 1997). These psychosocial barriers and negative experiences result in a reluctance by homeless people to engage in traditional forms of treatment (Johansen et al., 1999; Morse, 1999). Services for the homeless, who have been described as "markedly mistrustful and suspicious of service providers, and (to) highly value their autonomy" (Morse, 1999), thus need to implement creative and innovative approaches to service provision.

There are a number of mental health service provision models that are relevant to service provision to homeless populations. These include the assertive community treatment model, the recovery approach and the therapeutic alliance model. Each of these approaches is reviewed briefly below.

Assertive community treatment is characterised by the use of multidisciplinary teams that share responsibility for clients (Johansen et al., 1999; Marshall & Lockwood, 2006; Morse, 1999; Rosenheck & Dennis, 2001; Tibbo, Joffe, Chue, Metelitsa, & Wright, 2001). Assertive community treatment teams provide a temporally flexible service that delivers treatment in a direct and assertive manner with the primary treatment goal of reduced psychiatric hospitalisation (Bruce, 2005; Dixon, Krauss, Kernan, Lehman, & De Forge, 1995; Johansen et al., 1999; Marshall & Lockwood, 2006; Morse, 1999; Rapp & Goscha, 2004; Rosenheck & Dennis, 2001; Tibbo et al., 2001). There is an extensive body of research supporting the efficacy of employing this treatment model with homeless clients experiencing severe mental illness (Dixon et al., 1995; Johansen et al., 1999; Marshall & Lockwood, 2006; Morse, 1999; Rapp & Goscha, 2004; Rosenheck & Dennis, 2001; Tibbo et al., 2001). Assertive community treatment clients experience reduced frequency and duration of hospitalisation and reductions in symptom severity (Burns & Santos, 1995; Howgego, Yellowlees, Owen, Meldrum, & Dark, 2003; Johansen et al., 1999; Rosenheck & Dennis, 2001). Additionally, assertive community treatment is associated with higher levels of client engagement, client satisfaction, daily living skills, vocational skills, quality of life, social skills and treatment acceptance (Gerber & Prince, 1999; Herincky, Kinney, Clarke, & Paulson, 1997) and clients are more likely to be employed, living independently and sustaining housing (Marshall & Lockwood, 2006; Rosenheck & Dennis, 2001).

Recovery has been defined as “a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness” (Anthony, 1993). The recovery approach thus focuses on the lived experience of mental illness and the ability to restore life’s hope and meaning (Anthony, 1993; Coodin Schiff, 2004; G. Deegan, 2003; P. E. Deegan, 1988; Jacobson & Curtis, 2000; Young & Ensing, 1999). In a recovery oriented mental health service clinicians are responsible for the facilitation of goal development, symptom reduction, role functioning and self development, advocacy and crisis intervention (Anthony, 2000; Jacobson & Curtis, 2000). When an individual’s functional ability is improved to an extent that impairment, dysfunction or disability is ameliorated, it may be said that the individual has experienced recovery (Anthony, 1993).

A therapeutic alliance is formed when knowledge from lived experience is assimilated with professional knowledge and the combined knowledge base enables the development of a collaborative, recovery oriented treatment relationship where clients are active participants in treatment decisions (Coodin Schiff, 2004; P. E. Deegan, 1988; Glover, 2005; Lester & Gask, 2006; Roberts & Wolfson, 2004). Development of a therapeutic alliance thus supports a recovery focused approach to mental health case management, empowers clients in the therapeutic process and provides a contextual foundation to enable change towards recovery goals.

There are numerous social, psychological, emotional, and environmental factors that influence the development of a therapeutic alliance (Bambling & King, 2001; Bordin, 1979; Chinman, Rosenheck, & Lam, 1999; Coodin Schiff, 2004; Hewitt & Coffey, 2005; Howgego et al., 2003). These include the personal characteristics of the therapist and the client, the therapist’s unique skills, perspectives and competencies and the client’s level of social support and education (Chinman et al., 1999; Hewitt & Coffey, 2005; Howgego et al., 2003). However, factors such as psychotic behaviour and substance abuse may impair a client’s ability to develop a therapeutic alliance (Chinman et al., 1999; Hewitt & Coffey, 2005) due to abnormalities of thought and perception and reduced motivation (Chinman et al., 1999).

Research has shown that an effective therapeutic alliance has the ability to directly influence treatment outcomes for clients with a mental illness (Bambling & King, 2001; Bordin, 1979; Hewitt & Coffey,

2005; Howgego et al., 2003; Martin, Garske, & Davis, 2000). Although the development of a therapeutic alliance is often particularly difficult with long term homeless individuals with a mental illness, once the initial bond is achieved their commitment is often stronger than those who have experienced only short periods of homelessness (Chinman et al., 1999).

### **Mental Health Service Provision for the Homeless: New Directions**

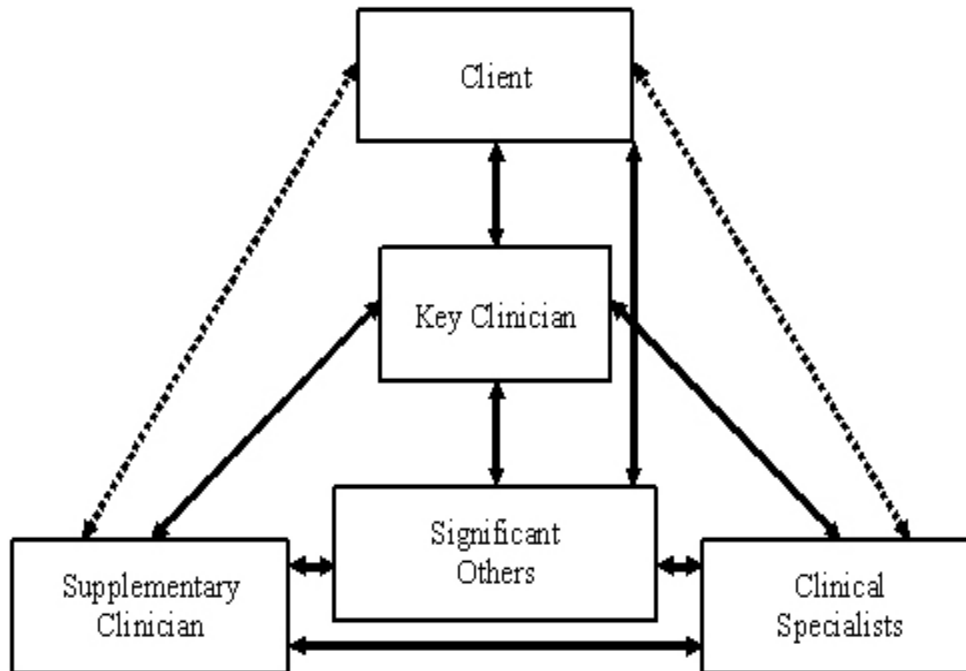
The Homeless Health Outreach Team (HHOT) is part of the Inner North Brisbane Mental Health Service and operates within the Royal Brisbane and Women's Hospital Division of Mental Health. The HHOT incorporates assertive outreach, interagency collaboration and a multidisciplinary team approach to best meet the primary, mental health and dual diagnosis needs of the homeless population it services. Established in 2006, the Team addresses the challenge of developing effective service delivery to the homeless community by providing mental health, drug and alcohol, dual diagnosis and primary health care services to this community in an outreach context.

In order to provide adequate and effective services, the HHOT recognised the need to address the numerous and significant barriers to engagement that exist for homeless people. Identified barriers include the high prevalence of mental illness, trauma, substance abuse, intellectual and physical disability, ethnic minority status, incarceration and institutionalisation experienced by the homeless population. Often these issues present comorbidly and compound the risk of disengagement from support services. It was therefore hypothesised that the intensive, team oriented approach of the assertive community treatment model could provide the structural basis for a service delivery method that would have the development of the therapeutic alliance at its core. Recovery goals previously unattainable due to the aforementioned barriers would thus be enabled via an effective therapeutic alliance providing homeless clients with the opportunity to desensitise and learn skills to minimise the barriers to service access. Fostering and supporting an enduring therapeutic alliance was thus seen as a means to enable access to clinical, therapeutic and welfare services as appropriate to the individual's recovery.

### **Support Enabling Active Recovery (SEAR)**

The Support Enabling Active Recovery (SEAR) model for service delivery was designed by the HHOT to address the above aims and to enable the re-engagement of homeless people previously disengaged from services. The SEAR model incorporates assertive community treatment and employs a multi layered systematic approach that supports clinicians as they support their clients. The critical element of the SEAR model is the supported therapeutic alliance between the client and the key clinician, which is supported by an integrated network of stakeholders as detailed in Figure 1.

Figure 1: Support Enabling Active Recovery (SEAR) Model



A key aspect of disengagement in populations with complex lifestyle issues and co-morbidity is the involvement of multiple service providers, which can be perceived by the client to be superficial and overwhelming. Under the SEAR model, the involvement of the supplementary clinician and clinical specialists is mediated by the key clinician, as illustrated in Figure 1. This strategy streamlines service provision, manages the risk of disengagement and increases the likelihood that the client will remain engaged with the key clinician until recovery goals have been met. The support provided by the supplementary clinician and the clinical specialists is thus employed to facilitate the development of an enduring therapeutic alliance between the client and the key clinician. The SEAR model also provides access to the treating team for the client's significant others, whilst the key clinician is supported by the internal clinical team and by an external structure that may include government and non government service providers.

## Elements of the SEAR Model

The key criterion for implementation of a SEAR based therapeutic intervention is the client's motivation to attain at least one goal, which may or may not be congruent with the goals identified by the therapeutic team, but which allows a central focus for engagement and purpose within the therapeutic context. Exclusion criteria for engagement within a SEAR framework have not yet been defined. However, if the client has difficulty forming bonds the therapeutic team employs a persistent and creative approach to evaluate their potential to engage therapeutically prior to making a final determination of their suitability for a SEAR based intervention.

Initial engagement with the client is through assertive outreach, during which period individual clinicians are introduced to the client as a means of determining which team member should become the key clinician. Clinician suitability for this role is also based on their expertise, interests and individual characteristics (e.g., age, gender and culture) in order to enable the 'best fit' with the client.

If a therapeutic alliance is not successfully developed with one clinician, additional clinicians will be introduced to the client until ‘best fit’ is achieved. Thus, alliance formation between client and clinician determines the role of key clinician. The key clinician does not necessarily have to practice within the lead agency, as lead agency clinicians can assume supplementary and specialist roles whilst coordinating care as appropriate via the key clinician.

The supplementary clinician has graded interaction with the client. Optimally, the supplementary clinician has specific expertise related to the client’s identified goals, therapeutic issues and/or demographic background. The purpose of the supplementary clinician is twofold. Firstly, they undertake the role of key clinician in the key clinician’s absence. This guarantees continuity of care, ensures ongoing engagement with the service and provides optimum management of risk and other complex issues. Secondly, the supplementary clinician provides additional clinical knowledge and perspective, thus providing a venue for informal clinical review and interdisciplinary support.

The role of significant other is allocated to people who provide support or who have significant input into the client’s life. This may include, but is not restricted to, family and friends, paid or unpaid carers, and non specialist agency service providers. Unless therapeutically contraindicated, the role of significant others is viewed as a critical component of the SEAR model. It is specifically recognised that a client’s significant others are likely to continue a sustained relationship with the client well beyond recovery and the cessation of case management. With this goal in mind from the beginning of the supported recovery process, the significant others are provided with support and education by the SEAR treating team to enable them to support the client after case management has ceased.

Specialist clinicians are temporary members of the team recruited to provide goal-specific interventions and support to the client, their significant others, the key clinician and the supplementary clinician. They provide specific skills and resources to enable the key clinician to implement interventions which might normally be initiated by external specialists or by other agencies to which client barriers preclude access. Their input is determined by the client’s specific needs at the time of engagement and may include expertise provided by psychiatrists, drug and alcohol workers, child and youth workers, primary health care specialists, allied health professionals and multicultural health specialists. Specialised support may also be sought from government and non government agencies representing child safety, housing, disability, corrections and social services.

## The SEAR Model in Operation

As selection of the key clinician is based on the quality of the therapeutic relationship rather than clinician or service availability, the issue of individual clinicians being more frequently nominated as key clinicians and thus potentially carrying too high a caseload must be carefully managed. This is achieved by ensuring that staff characteristics and skills are aligned to the demographic characteristics and needs of the serviced community. For example, ensuring the availability of male and female clinicians of varying ages and possessing a broad range of skills, expertise and interests will optimise the chances of individual clients forming effective therapeutic relationships.

Whilst the core treating team consists of all team members relevant to a specific issue at any point in time, the concept of a more broadly based ‘interagency treating team’ is central to the SEAR model. Depending on the specific clinical and quality of life issues being faced by a client, this larger team may include mental health specialist clinicians and representatives of external relevant agencies such as social services, in addition to the client, their significant others and the key and supplementary clinicians.

The core premise in implementing an interagency treating team is that representatives of all agencies servicing a client are part of the team. Whilst this presents a subtle difference in approach when compared to standard practice, the practical implications are significant. Although this coordinated approach may require more interagency communication than standard practice and more clinical time to establish, there are very significant benefits that flow from the development of streamlined and timely access to external agencies. Where the client has been disengaged from services the improved access enables barriers to be broken down and provides opportunities for the client to acquire skills that will enable future independent service utilisation. Cohesive interagency team interventions can also be initiated at the critical time of need rather than being delayed by inefficient interagency processes, thus saving case management time and facilitating efficient outcomes for each agency.

Co-case management is a feasible option to address the needs of the homeless, particularly in light of the inherent risks associated with their physical environment, the complexity of their lifestyle issues and the acuity of their mental and other health concerns. The SEAR model therefore employs co-case management as a strategy to support enduring therapeutic alliances that will facilitate ongoing client engagement and thus improve health and quality of life outcomes. Co-case management ensures continuity of care, provides a forum for multidisciplinary clinical judgement, creativity and perspective, and is an effective risk management strategy. Through co-case management and other strategies the SEAR model provides clinicians with ongoing clinical review and debriefing opportunities, and the opportunity to manage dynamic therapeutic relationship issues and complexities by sharing therapeutic roles. It also provides newer graduate clinicians with opportunities to gain critical skills and experience in complex case and risk management through shared involvement in cases with experienced clinicians. Further, the SEAR model provides a forum, via the supplementary and specialist clinician roles, for clinicians to utilise discipline-specific skill sets that are not often afforded specific roles in generically staffed mental health teams.

The efficient provision of the structure and support required to facilitate co-case management is a core issue in the operationalisation of the SEAR model. The essential doubling of caseloads for individual clinicians is managed by sharing caseloads and responsibilities via daily workload reviews. A daily intake and review meeting at which all significant clinical issues from the preceding day are discussed and daily management plans are allocated involves the entire HHOT team in clinical case review. The team addresses any crises and acute issues requiring immediate intervention and designates clinical duties based on client need. As each clinician is key clinician and supplementary clinician to a number of clients the team operates as a dynamic web of clinical service providers, the form of which changes on a daily basis depending on the clinical needs of the clients. The ongoing communication between team members, coupled with the flexible service delivery approach, facilitates timely and responsive crisis and acute care interventions.

The essence of the SEAR model is the dynamic process by which the therapeutic alliance between the client and the key clinician is employed to facilitate progress towards recovery goals and access to services where barriers previously existed. The trust established by the therapeutic bond enables the key clinician, with the assistance of team members, to intensively support engagement with health services and government and non government support agencies by providing the client with opportunities to desensitise and to acquire skills that minimise past barriers to service access and recovery.

## Conclusions

The purpose of this paper has been to introduce the SEAR model as an alternative recovery based framework for service delivery to marginalised populations. Although formalised inclusion and



exclusion criteria are yet to be formulated and implemented, SEAR has been successfully established within a major government health service provider to the homeless as a framework for service delivery and as a model of assertive community treatment. A formal evaluation of SEAR's effectiveness is now required in order to determine its efficiency, efficacy and sustainability as a practical system of service delivery to marginalised populations. Evaluation of the model's effectiveness for people experiencing significant social disengagement, negative psychotic symptoms, severe depression or unremitting positive psychotic symptoms is required, as is an assessment of the applicability of the SEAR model to other disengaged and/or marginalised groups such as refugee, dual diagnosis, transcultural and mainstream mental health populations. Ultimately, the extent of the SEAR model's applicability and efficacy can only be tested by implementing and evaluating it against current models of service delivery across the range of potential application settings.

The SEAR model offers a distinct alternative to current models of service provision, which accommodates recovery focused service delivery and provides a more holistic therapeutic approach for the homeless population. However, understanding and implementing the SEAR model will require a significant shift in perspective from traditional mental health service delivery models. Debate, discussion and collaboration are therefore to be encouraged.

Enabling recovery can be as simple as providing "two bucks for the bus". Metaphorically, this equates to providing "currency", in the form of stable therapeutic relationships and mediated access to service providers, which in turn facilitate access to the "vehicle", that is, the skills to engage and connect with the wider community, that ultimately "transports" the client towards recovery.

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# Disability in Schizophrenia: Do Short Hospitalizations have a Role?

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## Abstract

Long term hospitalization was considered an important factor in development of disability in patients with schizophrenia. Do short hospitalizations, as is the practice now, also lead to disability, has not been studied. The present study was conducted to compare the disability amongst two groups of patients with schizophrenia, previously hospitalized (PH) and never hospitalized (NH), and to understand the role of hospitalization in causing disability. Sixty patients with DSM-IV diagnosis of schizophrenia (30 each in PH and NH groups) attending follow up in a psychiatric outpatient service in a public funded hospital were assessed for disability, psychopathology and various clinical characteristics. The two groups of patients suffered similar levels of disability in personal and social areas as well as global disability, but the occupational disability was higher in the PH group than in the NH

group. A positive correlation was observed between disability and the number of admissions, total duration of hospitalization, negative symptoms, cognitive deficit and number of exacerbations. The study concludes that short periods of hospitalization do not appear to contribute to disability in personal and social areas, but may affect occupational disability.

**Key words:** Disability, schizophrenia, hospitalization, India.

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## Introduction

Schizophrenia is definitely the most disabling psychiatric disorder. Long-term hospitalization has been recognized as an important factor contributing to the disability associated with schizophrenia (Johnstone et al, 1981). Following deinstitutionalization a number of studies have found decrease in disability associated with the illness and improvement in social functioning (Dickey et al, 1981; Barbato et al, 2004). Disability has been found to be affected by characteristics like age of onset, duration of illness, severity and type of symptoms, duration of untreated psychosis, cognitive deterioration, and intellectual functioning (Alptekin et al, 2005).

With the deinstitutionalization on scene for the last 3-4 decades and more and more emphasis on shorter hospitalizations and community care, long term hospitalizations have become less frequent, though short hospitalizations are still required in a number of patients with schizophrenia. Some patients suffering from schizophrenia may need to be hospitalized a number of times in the course of their illness. The potential of such repeated short hospitalizations as a contributor to disability has not been studied. The present study reports on the effect of short hospitalizations on development of disability in patients of schizophrenia.

## Material and Methods

**Selection of subjects:** The study was carried out in outpatient setting at the Institute of Human Behaviour and Allied Sciences, a public funded neuropsychiatric hospital in the city of Delhi in India. Inclusion criteria were DSM IV diagnosis of schizophrenia, age 18-55 and a minimum duration of illness of one year. Only clinically stable patients were included for the study to control for the effect of acute exacerbations on disability, since the study had a cross sectional design. Clinical stability was empirically defined as the patient requiring no changes in medication and no more than 25% change in the dosage during three months prior to inclusion in the study. Subjects with history of any co-morbid chronic medical illness, axis-II diagnosis, substance abuse (except nicotine), mental retardation and physical handicap were excluded from the study. Sample consisted of two groups; previously hospitalized (PH) and never hospitalized (NH) patients. To be included in the PH group, the last hospitalization should have been at least six months prior to the inclusion in the study. About 200 patients were screened in the outpatient clinic for the study over a period of about 6 months (October 2001 – March 2002) to get a sample of 60 patients with 30 in each group. Sample was of convenience.

**Assessments:** Sociodemographic characteristics and clinical details of the subjects were collected on a semi-structured proforma, designed for the study. Clinical details included age of onset, total duration of illness, duration of untreated psychosis at onset, number of exacerbations or relapses during life time, number of hospitalizations in the past and total duration of hospitalization. Patients and key relatives were interviewed to collect the information.

Psychopathology was assessed on the Positive and Negative Syndrome Scale (PANSS) (Kay & Lindenmayer, 1987). PANSS gives scores on positive symptoms, negative symptoms and general

psychopathology. Psychiatric disability was assessed on the Schedule for Assessment of Psychiatric Disability (SAPD) (Thara et al, 1988), a modification of Disability Assessment Schedule II of WHO. Mini Mental Status Examination – MMSE was used to assess the cognitive functions. Written informed consent was taken from all the subjects or their caregivers, if the subject was not competent to give the consent. The study was approved by the Institute’s Ethics Committee.

**Analysis:** T test and chi-square statistics were used to study the differences between the two groups. Correlations between psychiatric disability and various sociodemographic and clinical characteristics were studied using Pearson’s product moment correlation co-efficient.

## Results

Mean age of patients was  $32.73 \pm 9.44$  and  $36.50 \pm 8.63$  in the PH and NH groups respectively. About 70% patients were in the age range of 20-40. Number of males was higher than the females (63.3% in PH group and 76.7% in NH group). All the patients were living with their families. Around 3/4th of the patients in each group were married. The two groups did not differ significantly on various socio demographic variables.

Total duration of illness varied from 2.5 to 32 years (Mean  $13.27 \pm 8.39$ ) in the PH group and 1.5-18 (Mean  $8.17 \pm 4.95$ ) years in the NH group ( $p .006$ ). Patients in the PH group had been hospitalised on one to 20 occasions (Mean  $2.57 \pm 3.77$ ) for a total period of 7 to 900 days (Mean  $116.7 \pm 176.96$ ). Number of exacerbations suffered during the course of illness varied from 1-20 (Mean  $4.25 \pm 3.76$ ) in the PH group and 1-6 (Mean  $2.83 \pm 1.46$ ) in the NH group. The mean duration of untreated psychosis at the first contact was  $17.36 \pm 31.36$  and  $14.23 \pm 33.48$  months in the PH and NH groups respectively. The two groups did not differ from each other in the number of exacerbations and duration of untreated psychosis.

Patients in the PH group were more severely ill than those in the NH group as indicated by higher scores on positive symptoms ( $p .023$ ). No significant differences were observed in the scores on negative symptoms and general psychopathology subscales of PANSS. The two groups suffered similar levels of disability in personal and social areas as well as global disability, though the PH group got higher scores on occupational disability than the NH group ( $p .007$ ) (Table 1).

Table 1: Scores on PANSS, MMSE and SAPS in previously hospitalized (PH) and never hospitalized (NH) groups (N 60)

Variables	PH (N 30)	Group	NH (N 30)	Group	t value	df	Significance
Positive Score	$12.33 \pm 5.67$		$9.36 \pm 4.02$		-2.34	58	0.023
Negative Score	$12.3 \pm 3.68$		$11.87 \pm 5.46$		-0.36	58	0.72

General Psychopathology Score	25.76 ± 7.31	29.46 ± 8.52	1.80	58	.08
MMSE score	26.80 ± 3.03	26.66 ± 2.32	-0.19	58	0.849
Personal Disability:	0.89 ± 0.18	0.83 ± 0.20	-1.22	58	0.230
Social Disability:	1.08 ± 0.28	1.03 ± 0.26	-0.72	58	0.48
Occupational Disability:	1.26 ± 0.44	1.00 ± 0.26	-2.79	58	0.007
Global Disability:	1.20 ± 0.41	1.03 ± 0.32	-1.79	58	0.079

A positive correlation was seen between disability in various areas, and the number of hospitalizations and total duration of hospitalization. Males showed higher social disability than females. The unmarried patients suffered higher disability in personal area than the married patients. Disability showed a positive correlation with negative symptoms and negative correlation with MMSE score. A positive correlation was seen between disability in occupational area and total number of exacerbations.

## Discussion

Patients in the PH group had been ill for a longer period and had higher scores on positive symptoms as compared to the NH group. But the two groups did not differ on negative symptoms and cognitive functioning, reported to be two important contributors to disability (Klapow et al, 1997). The PH group had been hospitalised for about 4 months on an average during the whole course of their illness with the number of hospitalizations varying from 1 to 20. The two groups suffered similar levels of disability except in the occupational area, in which the PH group had higher scores. The interruptions in the routine functioning due to hospitalisations followed by a latency period to resume work could be the reason. There is also a possibility that occupational disability is more vulnerable and observable indicator of functional deterioration and is easy to recall.

In the past, a number of researchers have reported on the role of long term hospitalisation in causing disability (Klapow et al, 1997; Leffe et al, 1996; Okin et al, 1995). Half of our patients had been hospitalized for different periods in the past. A positive correlation was seen between disability in various areas, and the number of hospitalizations and total duration of hospitalization. This indicates that even frequent short hospitalizations may have some role in causing disability. Higher scores on positive symptoms and longer duration of illness in the PH group were other confounding variables which could have affected disability.

Disability in patients with schizophrenia has been reported to be related to negative syndrome cognitive symptoms (Klapow et al, 1997; Lysaker et al, 1995), and positive symptoms (Alptekine et al, 2005). In the present study also, disability scores showed a positive correlation with scores on negative symptoms, and a negative correlation with MMSE scores (cognitive functioning). However, in case of positive symptoms, significant correlation was present only with the global disability, and not with disability in individual areas. Probably, a small sample size was not able to elicit all the correlations.

The study had a few limitations like a small sample size, absence of longitudinal assessment and lack of randomization. There is also a possibility of recall bias as the patients had been ill for a long duration going up to 20 years.

The findings are difficult to generalize considering a small sample. Prospective studies with larger samples are required to elucidate the role of multiple short hospitalisations in causing disability.

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# How New Zealand Community Mental Health Support Workers Perceive their Role

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## Abstract

As with all fledgling professions the role of the Community-based Mental Health Support Work is forging its own identity in New Zealand's health care sector, with support workers struggling to fashion their own scope of practice. Through the uses of qualitative research methods support workers have been provided with the opportunity to share their perception of their role in community mental health and residential support services.

**Keywords:** Mental Health Support Work, Residential Support Services, Role Perception, New Zealand

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## Introduction

Continual discussions with community support workers have provided the catalyst for the present research, with a focus on offering support workers with a sense of their own identity within mental health services. Currently community mental health workers are primarily defined by the support worker competencies identified by the Mental Health Commission (2001). The competencies guide support worker requirements such as attitudes, skills, knowledge and behaviour (Mental Health Commission, 2001, p. 3). The competence development process included reviews of international mental health recovery literature, a review of the training standards and requirements for support workers as well as other professional mental health bodies, and focus group consultations with services

users, families, Maori (indigenous people) and other pre-dominant cultural groups. More recently the Ministry of Health (2007) has been giving further consideration to competences guiding best practice, focusing on what ‘real’ skills mental health support workers require. Additionally, recent funding developments in New Zealand have seen the inclusion of Addiction Services within the scope of mental health service provision. Additional support and training needs to be provided to mental health workers, as covered in the Ministry of Health (2007) documentation. Definitions given through employment and associated contacts and the self perception of mental health support workers are not necessarily in alignment. The Ministerial documents discussed thus far offer guidance for behavioural conduct and the expectation regarding knowledge, attitudes and skills, but they do not define how support workers view themselves and their position within mental health service provision.

Two recent research papers (Barlow, 2006; Ryan, Garlick & Happell, 2006) have examined the role of community mental health nurses and their associated perception regarding their role within mental health service. Ryan *et al.* (2006) examined the role of mental health nursing with community based geriatric psychiatric services. Data analysis revealed two major themes, the role of the mental health nurse, and the specific function they carry out. Of particular interest to this paper is the role of the mental health nurse. Ryan offered discussion drawing on the narrative provided by the research participants. Central to the mental health nurses was their perceived practical “hands on” approach and their identified need to be a “Jack of all trades” (p. 97). Barlow (2006) conducted a similar small-scale study to examine the perceived role of community mental health nurses and other members of multidisciplinary team for the elderly. The aim of the current paper is to determine the perceived role of the mental health support worker by those who are currently employed in such roles.

## Methodology

A qualitative approach was used to conduct this research. The use of a qualitative methodology appeared particularly appropriate based on similar previous research (Ryan *et al.*, 2006). Individual semi-structured interviews were conducted with mental health support workers from a variety of community based mental health services. All the services were located in the Waikato region of New Zealand’s North Island.

Semi-structured interviews are viewed as appropriate for the exploration of individuals’ perceptions, attitudes, values and beliefs (Richardson *et al.* 1965, Smith, 1975). This approach provides extensive, rich narratives and offers the opportunity for the researcher to clarify responses and follow-up with additional questions (Barriball & While, 1994). The interview consisted of twelve open-ended questions to guide the research participants. The interview duration varied from 30 to 45 minutes depending on the responses given. Detailed interview notes were taken with some of the sessions being recorded with the approval of participants.

### *Participants*

The research group consisted of 14 participants currently working as Mental Health Support Workers, and 1 participant currently employed as a mental health service manager with a support role built in. The research sample produced a mean age 49 ( $M = 49$ ) and a gender spread of 4:1 (Female: Male). The mean time for employment as a mental health support worker was 2 years and 8 months ( $M = 2.8$ ) with a range of 5 months to 6 years and 8 months (range = 6.3). Thirteen of the participants work directly with service users and two with the service user’s family. All participants worked for non-government mental health service providers.

### *Data Analysis*

Major themes were identified through content analysis (Hsieh & Shannon, 2005; Berrios & Lucca,



2006) of the narrative notes and transcripts after multiple viewing. The first viewing was to gain a sense of familiarity with the information (Ryan, Garlick, & Happell, 2006). The interview notes and transcripts were then analysed for the identification and subsequent coding of major themes. A final reading of the information was made to test the accuracy of the coding in line with the identified themes.

#### *Research Validity Measure*

A focus group was formed to offer validation of the findings produced from semi-structured interviews. The focus group consisted of 4 participants who had been involved in the semi structured interviews. The mean time for employment as a mental health support worker was 4 years and 4 months ( $M = 4.4$ , range = 5.7). The focus group was directed to provide feedback on the researcher's analysis of the narratives collected during the original interviews.

## Results

The analysis of the data revealed the following themes as the perceived functions of a community based mental health support worker.

1. Developing and maintaining a therapeutic relationship
2. Working alongside the service users
3. Skill development and training
4. Community reintegration
5. Administration

Each function is described and illustrated with participants' quotes where appropriate.

### *1. Developing and maintaining a therapeutic relationship*

The development and subsequent maintenance of the therapeutic relationship with consumers was identified by all participants as the single most important feature of their role. The therapeutic relationship was viewed as the overarching construct on which their role was created, being referred to as the philosophy behind their current practice. However, indirect references were made to strength based practice but not enough to suggest a theoretical underpinning.

Frequent references were made to the development and maintaining high levels of trust with their client group. Several statements indicating this level of trust required of the support worker in order to make it a meaningful relationship.

"There is huge importance around gaining and maintaining trust. Without it the relationship is worthless." [SW5]

"I think that a large part of the role is about the relationships you have with your clients. Without having that relationship you would not be able to work with them... help them on their journey... the road to a normal life." [SW1]

### *2. Working alongside the service users*

The concept of working alongside the service users featured frequently through the interviews, with a strong sense of partnership and collaborative practice. The general consensus across the participants was that in their role they were happy to support, encourage and engage in shared activities.

"It is really about working with our clients, providing the human connection in support of them and to be a partner

in recovery ... Encouraging them to find their own answers” [SW11]

“I guess... for me... it’s about working with consumers and supporting them towards a better quality of life. That is our real job.” [SW1]

However, a strong sense of opposition was depicted around doing things *for* the service user. This particular concern was voice most clearly around cleaning duties.

“I was not employed as a cleaner. I have no problem helping or working with a client, but I’m not doing all the cleaning for them. Cleaning flats is not in my job description. I mean, sometimes, I feeling like a motel cleaner not a support worker.” [SW3]

### *3. Skill development, training and goal setting*

A particularly strong emphasis was placed on the role of teaching and skill development by the support workers. The support workers interviewed considered that they spent a considerable amount of their time aiding service users learn simple day-to-day skills, and helping them set clear goals and future directions.

“I guess I view myself as a teacher of life skills, who offers guidance for the future.” [SW8]

“Goal planning is important, particularly for day-to-day stuff like shaving and washing. For some clients it’s about showing them how to do it, n’ for others it’s about reminding them to do it.” [SW3]

### *4. Community reintegration*

Inherent in the title of the community support worker is their role in supporting service user’s become reintegrated into the community. This element of their perceived role was strongly linked to both working alongside the service user and skill development.

“To walk along side them” [SW8]

“Connectiveness to the community” [SW11]

### *5. Administration*

Administration was identified as a “necessary evil” of the support workers role. Over half of the participants identified an increase in the amount of time spent on administrative tasks over the duration of their employment. A number of participants viewed this increase in reporting to be detraction from their primary task of service user support.

“Lots of paper work, up to 40 percent of my time I have you know” [SW3]

“...satisfy reporting requirement for the job...” [SW7]

### *Research Validity Measure Results*

Feedback received from the focus group validated the findings reported from the semi-structured interviews. The group endorsed the five identified roles for mental health support workers. The group commented on the accuracy of the comments drawn upon and their alignment with their own perceptions of the Mental Health Support Worker role in New Zealand.

## **Discussion**

The overarching purpose of this paper was to establish the perceived role of mental health support by workers currently employed in this position. Analysis of transcripts from the individual interviews

revealed five predominant themes across all research participants. As a validity measure, a focus group of senior support workers was asked to offer their comments and endorsement of the identified themes.

As has been clearly identified within a large body of mental health literature the development and subsequent maintenance of a therapeutic relationship as paramount to the success of positive outcomes. This level of importance has been identified as no different in the role of the mental health support worker. Particularly strong emphasis was placed on the role of trust in the therapeutic relationship, with several references to how a high level of trust was required between the support workers and the service user in order to have a meaningful and effective relationship. Meaningful and effective relationships were viewed as therapeutic relationships that was both supportive and goal-orientation. Although the terms support or goal-orientated were not identified as clear roles of the work support, they are implied throughout four of the five roles articulated, with administration being the exception.

Goal planning and implementation are inherent features in the process of working along side services users, assisting their social skill development and as a part of community reintegration. In order to achieve successful outcomes the goals and associated processes need to be clearly identified by way of a comprehensive needs assessment. A function of the support workers role which was not identified by participants interviewed, which lends itself to warrant further investigation. Does the undertaking of service user assessment fall outside their scope of practice? Or is it not deemed as a critical feature of their current work. Either way, goal and support planning needs to be built on the foundation of a well constructed assessment.

Built on top of the therapeutic relationship and support/goal setting process, is the role of the support worker to work in collaboration with the service user. In effect they perceived their role as one of support and working alongside the service user. It was very clearly articulated that their role was one of collaboration and partnership, and not one of work *for* the service user. This concept in itself raised a number of philosophical conversations as to the degree of support and guidance one should offer. At what point do you start to withdraw support? How much guidance do you provide? Such questions are not easily answered, however a general consensus that all service users will vary in the degree of support and intervention required and, as such, need to be treated as individuals was concluded. Similarly the individuality of service users was referred to when considering skills development and training. The required level of support and training/education offered would be determined from a current assessment of service users needs, providing the foundation to tailor a package of support. In a circular fashion the individual approach reinforces the therapeutic relationship and strengthens the whole process increasing the likelihood of a successful outcome.

Finally numerous comments were made regarding the time spend on administrative tasks and the perceived increase in the role over the past two year period. Various comments were made regarding the increase focus on quality reporting and documentation to meet sector standards and funding requirements. Interestingly the increase in Information Technology and the transition from paper to electronically based recording was viewed as problematic. Identified areas for consideration ranged from the time-consuming nature of IT based work, primarily due to limited staff skill, through to ethical issues that have been raised. Narratives of this nature clearly identify the need to up-skill the current workforce to match the present technological direction of mental health services.

Based on the narratives obtained the group of support workers interviewed have a clear perception of their role as support worker in mental health services. However, there is plenty of scope for further research such as the examination of allied mental health disciplines for instance community social workers and community mental health nurses, and how these roles compared to the role of the mental

health support worker? What is the perception of the social workers and community mental health nurses of support workers? How can these disciplines compliment one another to best support service users? As such we have only scratched the surface in determining the role of the support worker in the provision of mental health services in New Zealand.

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# Deinstitutionalization or Disowning Responsibility

*'The more things change, the more they remain the same.'*  
*Alphonse Karr.*

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**Abstract:**

The well intentioned deinstitutionalization movement which started with a noble aim of treating and rehabilitating mentally ill patients in community itself, so to reduce human rights violations and mitigate their sufferings, has almost failed to achieve its aim. Human right violations which are supposed to occur behind impregnable walls of mental hospitals, occurs right in front of opened eyes of society, as a result of which mentally ill patients suffers in jails, prisons, beggar's home, shelter homes and streets. These problems can be solved by building more mental hospitals of a small size with an open ward facility and rehabilitation center; providing employment to mentally ill patients, building more halfway homes, quarter way homes, daycare centers, sheltered workshops; providing a housing facility to the improved patients; establishing the special courts which deals with the cases pertaining to mentally ill on a preferential bases and along with it enacting the laws to protect rights of mentally ill patients.

**Key Words:** Deinstitutionalization, Trans-institutionalization, Human rights violations, Mental Hospitals, Psychosocial Rehabilitation

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## Introduction:

Today new trend is towards the deinstitutionalization of mental hospitals, means treating the mentally ill patients in a community itself. The policy of was deinstitutionalization was started in mid 1970. In 1963, it was believed that state mental hospitals were too often institutions for quarantining the mentally ill. In response to this perceived mental health problem, Congress passed the Community Mental Health Centers Act to move the mentally ill out of prolonged confinement in overcrowded state custodial institutions into voluntary treatment at community mental health centers. On Oct. 31, 1963, President Kennedy who believed mental hospitals as 'snake pits' signed the Community Mental Health Centers Act into law. The policy was said to be initiated by concern for mentally ill patients. But economic consideration was not rule out. However policy of deinstitutionalization has failed miserably. President Bush's New Freedom Commission on Mental Health has described American public mental health system as "in shambles" (Mental Health Commission Report, 2003). The results from the National Alliance for the Mentally Ill's (NAMI's) national survey of its membership were also disappointing, it illustrated the failure of the mental health system (Hall et al. 2003). Here I have tried to discuss that how deinstitutionalization movement is affecting the mentally ill patients in both developing as well as the developed countries alike.

## Problems

### **Deinstitutionalization or Trans-institutionalization:**

An estimated 4.5 million Americans today suffer from the severest forms of brain disorders, schizophrenia and manic-depressive illness. And out of 4.5 million 1.8 million or 40 percent are not receiving any treatment on any given day, resulting in homelessness, incarceration, and violence. And one of the reasons for this condition is a failure of the deinstitutionalization policy (Fact Sheet, Treatment Advocacy Centre). So it is hardly surprising that approximately one third of homeless persons suffer from severe and disabling mental illnesses (Morrissey & Dennis, 1986; Morrissey & Levine, 1987). In Oklahoma researchers are examining whether there is a correlation between the growing number of suicides and the downsizing of the state mental hospital (Borenstein, 2001).

Same facts are echoed in testimony of US Congressman Ted Strickland (Strickland, 2000). According to him thousands of mentally ill patients are being dumped out of state hospitals into communities that do not have the adequate services to receive them. These efforts known as "the deinstitutionalization movement", has resulted in trans-institutionalization, in which huge numbers of mentally ill individuals lands in jails, prisons, homeless shelters, and flop houses. No wonder in one study done recently, around 40% inmates of 'Beggar's Home' were having mental illness (Thakker et al; 2007).

The deinstitutionalization policy, which is improperly implemented is acting like a misguided missile, because of which the helpless and defenseless inmates of the mental hospitals begs and roams on roads and footpaths; takes refuge in shelter homes and beggar's homes; starves on streets and eats from garbage bins; are jeered in society and physically, verbally and sexually assaulted in alleys; languishes in jails and suffers in prisons; shivers in cold and simmers in heat; and sleeps on a bed of earth with a blanket of sky. We have shifted problems of mental hospitals to the streets, jails and shelter homes. While making backyards of our mental hospitals beautiful, we have made our streets ugly. The process of deinstitutionalization has turned deadly. There

seems to be some truth in a saying that deinstitutionalization caused people to “die with their rights on”.

### **Dangers of Half Treated or Neglected Patients:**

Deinstitutionalization which has now become synonym for neglect was supposed to be about creating a new system of services and supports that would allow people with mental illness and mental retardation to thrive in their communities outside of hospital settings during all of the times when they did not need hospital services (Bernstein, 2007). However purpose of the deinstitutionalization has not been served.

A study done by Klassen(1988) and O’Connor(1990) found that approximately 25%-30% of male subjects with at least one violent incident in their past are violent within a year of release from the hospital. In 1993, sociologist Henry Steadman studied individuals discharged from psychiatric hospitals. He found that 27 percent of released patients reported at least one violent act within four months of discharge. Another 1992 study, by Bruce Link of Columbia University School of Public Health, reported that seriously ill individuals living in the community were three times as likely to use weapons or to "hurt someone badly" as the general population. In recent times, a MacArthur Foundation study done by Eric Silver(2000) found that people with serious brain disorders committed twice as many acts of violence in the period immediately prior to their hospitalization, when they were not taking medication, compared with the post-hospitalization period when most of them were receiving assisted treatment.

According to a 1994 Department of Justice, Bureau of Justice Statistics Special Report, "Murder in Families," 4.3 percent of homicide committed in 1988 were by people with a history of untreated mental illness. In 1998, law enforcement officers were more likely to be killed by a person with a mental illness (13 percent) than by assailants who had a prior arrest for assaulting police or resisting arrest (Brown et al, 1998). Swanson et al. (1990), in commenting on their ECA data, stated, public fear of violence committed by the mentally disordered in the community is "largely unwarranted, though not totally groundless" (p. 769). This policy of deinstitutionalization has rendered vast swathe of mentally ill patients-dangerous to self or others- untreated or homeless.

### **Prisons or Mental Hospitals**

There are more persons with mental illness in jails and prisons than there are in state hospitals (Torrey, 1992). At least 9,000 people with psychiatric disabilities are released annually from New York jails and prisons without adequate housing or support services(Martell,1995). Same facts are confirmed by researchers in other way when they found that as many as 40 to 50 percent of clients in the community mental health system might have a history of criminal arrest (Solomon, 1999). There is direct relationship between closing of mental hospitals and opening of new prisons. According to the U.S. Department of Justice, 40 mental health hospitals have closed in the past decade. During the same period, 400 new prisons have opened up (The Olympian (Washington), October 9, 2003).

The condition in a developing country like India is not so different. The writ petition filed in Supreme Court of India by Ms Sheela Barse, a social activist claimed that many children and adults were committed to jail in Calcutta as lunatics were not mentally ill at all. (Supreme Court in Writ Petition (Crl) No 237/1989. Sheela Barse versus Union of India and others, August 17, 1993) .Some were normal, some temporarily under stressor undergoing a phase of mental disturbance, and a few were mentally retarded. The commission appointed by the Supreme Court in response to this petition echoed the same facts. It said that when a mentally ill is sent to jail,

which doesn't managed them as a sick person, it results in deprivation of liberty in several ways which is more excessive than is required either for the protection of the mentally ill person or for the safety of society. The commission also rued over the fact that jails had no specialist psychiatrist position. The visit of psychiatrist was weekly fortnightly or monthly but rarely daily. And some districts even lacked that facility. Former chairman of the National Human Right Commission, Justice Ranganath Misra had issued notices to chief ministers of all the states some years ago, saying:" No mentally ill person should be kept in any jail of the country after October 31, 1996". Still there is no improvement in condition. The caseloads are astronomically high, people routinely fall out of the community mental health systems, and over the years the number of people with mental illnesses who are put in jails and prisons has skyrocketed (Bernstein, 2007).

## Solutions

### **To Give Work In Appropriate Industry:**

In Chinese language a synonym of difficulty is opportunity. When giving a work to mentally challenged patients, our aim should be to transform their limitations into the strengths. This has been successfully demonstrated by Niseeth Mehta, CEO of 'Microsign Products' a company located in Bhavnagar, and produces plastic fasteners and supplies to the quality conscious companies like 'Volvo', 'Mercedes', 'Tata Motors', Helwett-Packard and 'Reliance Industries'. Although 'People with Disability Act, 1995' (PWD, 1995, India), reserves three percent jobs for differently abled people. The company's 60 percent staff is differently abled. The person whose hearing is impaired is given a job at noisy engineering machine. Similarly intellectually challenged boys have been assigned a job-which any other person would find monotonous- which doesn't affect their productivity and motivations. This doesn't mean that one should compromise with a quality of work. The Company has almost zero attrition rates and has met tough 'ISO-9002' and 'QS-9000' quality control standards.

Similarly a person with autistic disorder, who does repetitive works or activities, can be assigned monotonous tasks, which normal person may abhor performing, but a mentally ill patient may enjoy it. The Day care centers, halfway homes and quarter way homes should be turn into the production houses and manufacturing units of goods and articles. A person who has recovered completely or has a single episode of schizophrenia can be appointed as a supervisor who can better empathize and understand the problems of mentally ill patients.

### **Advantage: Western countries:**

According to facts compiled by Dr. Michael Friedman, the Director of the Center for Policy and Advocacy of the Mental Health Associations of NYC and Westchester, from 2000 to 2030 the 65 and older population in the US will double from 35 million to 70 million and comprise about 20% of the American population (Friedman, 2006). In the UK in 2004, there were approximately 4 working age individuals (aged 20-64) for every 1 person aged 65 and over. By 2056 this ratio is predicted to fall to about 2:1(Tetlow, 2006).

In the western countries, where the population is stagnating or declining, providing an employment to the mentally ill patients is a good strategy to counter a labor shortage which is going to arise in future. Employment provides not only a monetary recompense but also 'latent' benefits — non-financial gains to the worker which include social identity and status; social contacts and support; a means of structuring and occupying time; activity and involvement; and a sense of personal achievement (Shepherd, 1989).



Thus by gainfully employing mentally ill patients we can surmount the challenge of labor shortage, which is going to arise in future. Thus we can transform not only individual's limitations but also developed nation's limitations into the strength.

### **Government of Gujarat Policy: Without Tender Purchase:**

The other measures that government can take are to provide the incentives to the industries, which employ mentally ill or mentally challenged people. The Government of Gujarat (India) has given example worthy to emulate. It has issued a circular according to which goods and products made up by 'Rehabilitation centers' of 'Hospitals for Mental Health's' can be purchased without issuing the tenders. The other benefit government is providing is tax benefit and free bus and railway pass at a concession rate which help to ease burden on patient's family.

The other thing government can do is to provide subsidies or tax sops to industries which employs differently abled people. And in these efforts government is not losing any tax revenue, because it's social and financial responsibility to rehabilitate the patients is carried out by the industries and in this way Government's time and energy both are saved.

### **To Start More Day Care Centers and to Provide Housing Facilities:**

Despite consistent evidence that access to housing and services significantly reduces hospitalizations, incarcerations, shelter use, and other expensive emergency interventions, there is a reluctance to adequately increase housing stock (Culhane, 2001). Subsequently, people with mental illness are often forced to wait years in expensive and inappropriate institutions, prisons, homeless shelters, and other emergency settings before they gain entry to housing (Stricevic, 2004). In a prospective study, Belcher (1989) found that 36% of the mentally ill patients discharged from a state hospital became homeless, at least temporarily, within six months of their discharge. Homeless people with either mental illness or substance abuse problems are more likely to return to institutional care if they are not provided with adequate housing (M. V. Kline et al., 1987; Lipton, Nutt, & Sabatini, 1988; Wittman, 1989).

In USA the Fair Housing Amendment of 1988 extended protections of federal fair housing legislation to people with disabilities. It forbids discriminatory intent or effects of regulations concerning housing for mentally ill individuals. However situation is still grim. While there are at least 60,000 adults living with a psychiatric disability throughout the New York State who need housing, only 23,731 units of community-based housing have been developed for this population (Residential Indicator Report, 2004). As Koegel and Burnam (1988) pointed out, we must concentrate on creating environments rather than instituting treatment programs. Structure, support, and protection may be particularly critical for the most vulnerable subgroups of the homeless population, and homeless persons themselves often seek these elements (Drake et al., 1989).

The good rehabilitation strategy would be to start the more day care centers attached with a rehabilitation center. The strategy would have a dual advantage, the patient would remain in the institution in a day time so their relative wouldn't have to worry about him and in night he may return at his home so he can also live in the society. The patient would be gainfully employed so he would also have a job satisfaction. The other thing is chance of relapse would also decreased as there is reduced chance of exposure to 'Expressed Emotion (EE). As patients in high expressed emotion settings were more likely to relapse (56% compared with 17% for low expressed emotion)(Leff & Vaughn, 1985).

A scheme may be designed for the rehabilitation process for those who are not having any

backing, or lack of support in the community. The Scheme may be on the basis of quarter way homes (Supported Shared Home-Like Accommodation) for all patients ready to be discharged, but are not being discharged due to family not taking them back, or lack of support in the community. They can be placed in a home-like accommodation created on the hospital campus itself (Orders of Supreme Court of India in a Civil Writ Petition No 334/2001 & 562/2001, Saarthak registered society and ANR versus Union of India and ORS, 12<sup>th</sup> April 2002). This accommodation could be an existing ward converted to have a home-like environment, wherein patients can be taught of house keeping skills, cooking, shopping and can also be encouraged to take up responsibilities in the hospital for which they should be paid for and then gradually encouraged to go to the community for the work.

### **Empowering Mentally Ills by Means of Appropriate Laws**

The Government of India has passed 'People with Disability Act', 1995(PWD ACT, 1995) to protect rights of mentally ill patients. Next important step is a proactive role of court which by giving bold judgments can set precedents that would help to mitigate suffering of mentally ill patients. In one such instance one employee who developed schizophrenia was terminated from the job. The Honorable Bombay High Court, upholding section 47 of the PWD Act which deal with nondiscrimination, ruled that the authorities should either shift employee concerned to another post with the same pay scale and service benefits or create supernumerary post until a suitable post is available(Times of India 17th November Ahmadabad Times Edition, 2004).

A similar bold judgment was delivered by the Honorable Supreme Court of India on 24/10/2007, in favor of under trial having mental illness. A supreme court of India's bench said that all cases will be closed against those mentally unfit offenders who have been in custody for periods more than the maximum punishment prescribed for the offence allegedly committed by them. The Bench also ruled that those accused of serious offences that carry punishments of life imprisonment or death will be released on bail if they have undergone five years in custody. (Indian Express 24th October 2007). This will help to protect people like Machal Lalung, the 77 years old who spent 54 years in mental hospital at Gauhati, in Assam, as an under trial, despite of being declared 'fit to stand trial' twice(Time of India, 11th January 2006 Ahmadabad Times Edition). He was however lucky because when Honorable Supreme Court of India came to know about this case they promptly ordered to discharge him and also directed the government to pay 3 hundred thousand rupees of compensation. Many such laws and judgments are needed to protect rights of mentally ill patients

Other things that can be done is to train the police on how to identify the mentally ill patients and direct them into available treatment facility. The government can also fund jail and prison programs that screen, evaluate and treat mentally ill inmates

### **Establishing 'Mental Health Courts':**

One of the important steps is to create mental health courts to direct non-violent mentally ill defendants out of the revolving door of recidivism into long term, wrap-around treatment (Strickland, 2000). The America's Law Enforcement and Mental Health Act (H.R. 2594), which has provision to establish 'Mental Health Courts' in order to direct nonviolent mentally ill offenders out of jail, into long term treatment, is right step in direction to protect right of mentally ill patients. Mental health courts are uniquely effective at reducing the recidivism of seriously mentally ill offenders because they use the power of the criminal justice court to ensure that the defendants receive long term mental health treatment (Strickland, 2000).

### **Establishing More Mental Hospitals with Adequate Staff Strength:**

There are now 37 psychiatric hospitals in India with total bed strength of 18,024 (National Human Rights Commission, 1999). The beds are grossly inadequate in comparison to number of patients and population. It has been seen that despite of development of new drugs, in 30 to 40 of cases prognosis of schizophrenia is poor. As Lehman et al. (2004) noted, "Despite the availability of these treatments, most patients remain somewhat symptomatic and/or vulnerable to relapse. Persevering impairments are common, and long-term outcome, while heterogeneous, still represents significant morbidity for most patients".

In large-scale follow up studies of adult schizophrenia patients, outcome was good in only 25 percent of patients; about 50 percent achieved at least partial remission, and 25 percent remained permanently hospitalized or grossly impaired (Mason 1995, Harrison 2001). When these chronically ill patients are kept in a community rather than in the institute, not only productivity of mentally ill patients is affected but also productivity of his family members is affected.

The prevalence of schizophrenia in general population is one percent, out of which 30 to 40 percent have a poor prognosis. It means that 0.3 to 0.4 percent of population is chronically mentally ill. If we assume that one chronically mentally ill patient affects average 5 members of his family, leave alone his neighbors with whom he resides. It means that about 2 percent of population is affected by the illness directly or indirectly. MacGilloway et al (1997s) reported that 30 to 60 percent caregivers of psychotic patients had significant distress. These findings are similar to finding of Heru and Ryan (2002) study which reported that 72% of caregivers of recurrent mood disorders report positively for depressive disorders.

The solution is to establish more psychiatric hospitals with adequate staff strengths in each and every district and county rather than to build mammoth hospitals which usually have poor human right records and are difficult to manage. The bed strength of hospitals should be ideally between 50 to 100 patients. There should be a facility of open ward in which a family member can stay with patient. So hospital would be under an indirect vigil of public, which in turn would reduce incidence of human right violations and would make atmosphere similar to that of other general hospitals. The hospital should also have a rehabilitation complex, which will help in rehabilitation of patients in society.

### **Assertive Community Treatment:**

In case of patients who are improved but repeatedly relapse into illness. Assertive Community Treatment is best solution which will reduce admission rate and lessen burden on psychiatric hospitals. Assertive community treatment includes a mobile interdisciplinary treatment team comprising a psychologist, a psychiatrist, a social worker, a case manager and a nurse that establishes close, consistent relationships with the individual, providing him with a high level and scope of services and supports if needed and backing away when he is doing better (Berstein, 2007). Mobile treatment at the doorsteps would also help patients who cannot come for regular follow up for treatment because of their inability to afford bus fare or train fare (Sheth, 2005).

### **Conclusion:**

The outpatient mental health system appears to be at least as saturated with criminally involved individuals as the criminal justice system is with mentally ill individuals and it shows almost a failure of policy of deinstitutionalization. We must wake up before problem created by policy of

deinstitutionalization backfires and explodes on a face of society. To prevent jails and streets into the de facto asylums for the mentally ill and to prevent the overburdening of relatives of mentally ill patients this policy need rethinking. This doesn't mean we should deride the policy of deinstitutionalization, which was formulated to counter the perils of institutionalized life, but process of deinstitutionalization should be with a humane face. The pendulum which went to one extreme of institutionalization should no go to other extreme of deinstitutionalization. The delicate balance between two processes is necessary for betterment of our patients. We must have patience till a sure cure of mental illness is found. When it is found, someday we would be able to disband psychiatric hospitals like a TB sanatoriums of past, which were made redundant by discovery of effective drugs. The truth is, by helping the seriously mentally ill we help ourselves. As one wise sage wrote, 'No one will be saved till all are saved'.

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# Has Malaysia's Drug Rehabilitation Effort been Effective?

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## Abstract

The review of Malaysia's intensive drug rehabilitation program indicates that it is not working in that the country recidivism rate is still over 50%. Furthermore, methamphetamine and ecstasy has recently been introduced in the country, and this has worsen the country's drug problem. The author provides the reasons for this failed rehabilitation effort.

Key words: heroin, marijuana, Malaysia, death penalty, recidivism

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## Introduction

Malaysia, a country in Southeast Asia, has a population of 24,821,286 million people, and gained its independence from Great Britain in 1957 (Central Intelligence Agency, 2007)). It is a racially mixed country in that 55% of the population are Malays, 32% Chinese, and 8% Indians (Central Intelligence Agency, 2007). Malaysia is an Islamic country, and all the Malays are Muslims. Even though most of the population of the country is forbidden from drinking alcohol, Malaysia is the tenth largest consumer of alcohol in the world (Arokiasamy, 1995). This high consumption pertains to the non-Malays in that 34% of them are viewed as heavy drinkers. (Arokiasamy, 1995). Of these two groups, alcohol dependence appears to relate more to the Indians because of poverty and the easy access to alcohol (Arokiasamy, 1995). In fact, the average consumption of alcohol by Indians is 14 liters a year, and the average age of alcohol dependence is 22 years (Arokiasamy, 1995). Regardless of this data, the country does not view alcohol as a problem, and except for a few AA groups in the large cities, there is really no treatment services available for this client population.

In 1983, Malaysia declared its drug problem a national emergency, and enacted severe enforcement sanctions. That is, anyone convicted of trafficking (based on the amount of the drug in the person's possession when he or she is arrested) was sentenced to death. This pertained to 15 grams of heroin and 200 grams of cannabis. Further, if a person was arrested for possession, he or she would be sent to a governmental rehabilitation center for two years. The individual was also registered as a drug offender with the government. At that time, the drugs of abuse were heroin, opium and cannabis. Malaysia has a policy of "cold turkey" detoxification for a person addicted to an opiate. Specifically, a person is placed in small cell for a week where he or she goes through withdrawal. Once the withdrawal ends, the person is medically examined and sent to a rehabilitation center. The only exception to the "cold turkey" detoxification" is if the individual is 55 years of age or older or has medical complications. If this is the case, he or she is admitted to a hospital, and goes through withdrawal with medication. Presently, there are 29 governmental rehabilitation centers in Malaysia, of which one is for women. It should be noted that 97.3% of the persons incarcerated for

drug possession in the country are male, between the ages of 22 to 29 (Ministry of Home Affairs, 2005).

Once discharged from the rehabilitation center, the person has one year of probation where he or she has two urine tests a month. If the test is positive, the person is required to go for counseling. Even though the test is positive, the drug abuser would not be sent back to a rehabilitation center, and this would only occur if he or she is arrested again for possession. As stated, at the beginning of the country's stringent enforcement policy, the drugs of abuse were heroin, opium and cannabis, with most offenders using heroin intravenously (66.3%) (Ministry of Home Affairs, 2005). Based on governmental studies, the reasons given for drug abuse pertained to peer pressure and poverty (Scorzelli, 1989).

The problem of heroin abuse in Malaysia is further complicated because of HIV and Hepatitis C. Because of the high incidence of IV heroin usage, the country has a large number of people infected with HIV. In a survey of 300,241 registered drug users from 1988 to 2006, it was found that 18.49% were infected with HIV (UNICEF, 2007). In another study by the National Institute of Drug Abuse (2006), 177 male heroin users who were being treated in a rehabilitation center were medically examined. Of this group, 19.2% had HIV, 89.9% Hepatitis C, and 15.7% had tuberculosis. Also, only 8% of these men said that they used a condom.

### Treatment Program

The treatment provided by the rehabilitation center is based on the model of the therapeutic community. The therapeutic community is a hierarchical model with treatment stages that reflect increased level of personal and social responsibility. There is peer influence that is mediated through a variety of group processes. The treatment stages in the rehabilitation centers in Malaysia are identified by the color of the inmate's shirt. The lowest or first level is a red shirt, and the inmate can progress to a yellow, green and white shirt. The inmate remains a red shirt until he or she has been at the center for four months. The yellow shirt involves eight months, and this is followed by another eight months as a green shirt. When the inmate wears a white shirt, he or she has only four months to serve at the rehabilitation center. If an inmate tries to escape, he or she is given a blue shirt to wear. In a way, a blue shirt stigmatizes the person since he or she is at the lowest level in the rehabilitation center. At the beginning of the person's commitment to a rehabilitation center, he or she is involved in paramilitary drills and callisthenics for several hours a day, and for Muslims, religious instruction daily by an Imam. Those inmates who are not Muslims have religious services once a week. As the inmate progresses to higher levels, he or she has less physical activity, and receive counseling (individual, group and family) and vocational training. With respect to the latter, most of the inmates are either un or under-employed when they are arrested (Scorzelli, 1989). However, the vocational training provided does not involve areas of high technology, but consist of such things as, rattan making, shoe repair, mushroom farming, brick laying, welding, small engine repair. Therefore, there is little employment status or career mobility when the inmate is released.

In 1986, the government started to keep records of recidivism, and using 1986 as the baseline, recidivism in the country is over 50%. In a recent study by UNICEF (2007), there were 22,811 registered drug users in 2006, and 12,430 (54.5%) were repeat offenders. Although the reason for this high recidivism is not known, some believe it is due to the treatment provided to the inmates (Office of Home Affairs, 2005). This pertains both to the low level of vocational training, and the qualifications of the counselors and religious instructors. That is, many of the counselors are not professionally trained, and they and the religious instructors often have little knowledge about drug abuse. In addition, the one year probationary period is poorly managed, and many discharged inmates simply vanish and never participate in the process. In contrast to this, is the other view that relapse is part of the disease of drug addiction, and since recidivism is based on drug usage since 1986, the rate would be high (a person could relapsed after 10 years of sobriety and would still be included in the statistics).

### New Drugs of Abuse



Within the last five years, Malaysia's drug problem has worsen with the introduction of methamphetamine (referred to as sybu) and ecstasy. The death penalty remains for both of these drugs if a person is apprehended with 50 or more grams of the drug(s). According the government, sybu comes from the Philippines and ecstasy from Thailand (Office of Drugs and Crime, 2003). Reasons given for the introduction of these new drugs concern the fear of contracting HIV from IV heroio use (Ministry of Home Affairs, 2005). Although heroin is still the drug of choice, there are reports that 60% of the inmates at a rehabilitation center in Sabah are methamphetamine abusers (Ministry of Home Affairs, 2005). To complicate the situation more, there have been reports of ketamine and cocaine abuse. In terms of cocaine, the drug is still a rarity in the region.

These recent changes in the drug usage in Malaysia has resulted in some treatment changes. First of all, methadone maintenance was introduced a few years ago. Yet, this treatment is only for those persons who volunteer and have not been arrested for drug abuse. Those arrested still go through cold turkey detoxification. Secondly, there has been the development of over 60 private treatment facilities. Again, these are only for those persons who volunteer for treatment and have not been arrested, or for those who have been discharged from a rehabilitation center. Many of these facilities have a religious orientation (Islam or Christian), and like the governmental rehabilitation centers, are based on the therapeutic community model. There is no data yet on the success of the methadone maintenance program or the effectiveness of the private treatment facilities.

### Changing the Current System

To change the current situation in Malaysia, it is the belief of the author that there has to be a change in the nature of the vocational training, and the treatment approach. As indicated by the literature (Dongus, 2005; Greenwood,, Woods, Guydish, & Bein, 2001; Huvvard, Craddock, & Anderson, 2003; McLellan, et al., 1999; Sindelar, Jofre-Bonet, French, & McLellan, 2004) there is a relationship between viable employment and drug treatment success. Work appears to be a reinforcing factor in helping a recovering drug abuser maintain his or her sobriety. Based on the importance of viable employment in the rehabilitation of the client who abuses drugs the vocational training provided at the rehabilitation centers need to change. Specifically, training as computer programmers or electronic technicians may provide a better incentive then rattan making for inmates to remain drug free upon their discharge. Furthermore, the implementation of a transitional or supported employment model would also be helpful. White shirted inmates who appear committed to stop their drug usage could be identified and sent to large corporations to work while they are still incarcerated.

This on-the-job training would help make them aware of the world of work, and the opportunities that are available in the private sector. Also, there is no reason while outstanding candidates could not be hired by corporations prior to their discharge. Lastly, the development of self-employment options for the inmates could also make the employment options upon the inmate's release more viable. In terms of further education, there may be a problem because of the country's educational system. Modelled after the United Kingdom, a student is required to take a series of tests, beginning at age 12. If he or she fails this standardized test, he or she can only attend school until 15 years of age. The second exam is given at 15 years of age, and if a person fails the examination, he or she must leave school at 17 years of age. The last examination, which is for college admission, is offered when the student is 17 years of age, and if he or she fails, his or her education ends. Nevertheless, there is a possibility that there may be some inmates who have progressed far enough to take some college classes. Therefore it is felt that changing the nature of training and providing an opportunity for transitional employment would be important factors in helping a person maintain a drug free life style.

In terms of treatment services, it is possible that a more intensive treatment model is needed. One such intensive program is the matrix treatment model. The matrix model was developed as a response to the cocaine epidemic of the 1980's. The goals of the matrix model are to achieve the following: cease drug use, retain the client in treatment, help the client learn about issues that are critical to addiction and relapse, receive

direction and support from a trained therapist, receive education for family members affected by addiction, have the client become familiar with self-help groups, and receive monitoring by urine and breath analysis (Rawson, et al., 1995). The components of the model involve therapist support, group/individual counselling, 12-steps, relapse prevention and education, family education, and monitoring whether the person has used drugs (Rawson, et. al, 1995). An important part of the program involves the training and treatment manuals that describes a protocol for evaluating the effectiveness of the intervention. In fact, the National Institute of Drug Abuse (2006) indicated that 5,000 cocaine and 1,000 methamphetamine addicts have participated in this treatment model. Further, research has indicated that there has been a significant decrease in drug abuse among the participants (National Institute of Drug Abuse, 2006). An important factor in implementing this model is that the counsellors be professional trained, preferably with a master's degree. As of present, most of the counsellors in the treatment centers do not have a master's degree. Because of this need, many of the universities in Malaysia are developing graduate programs in drug counselling.

Based on a review by the author, Malaysia's attempt to curtail its drug problem does not appear to be working. The reasons for this failure appear to pertain to low level of vocational training provided to the inmates, as well as the diluted treatment services that they receive. Fortunately, the government has acknowledged these problems, and are attempting to change the services received at the rehabilitation centers.

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# The Impact of Group-as-a-Whole Work on a Severely Mentally Ill, Institutionalized Population: The Role of Cohesiveness

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## Abstract

This study explores the impact of a group-as-a-whole (Tavistock) processing group on 11 severely mentally ill patients in a long-term care facility. We assess the influence of the group-as-a-whole model in developing group cohesiveness and reducing anxiety and depression for members. Research indicates that group cohesiveness is a necessary precondition for effective therapy (Dion, 2000; Yalom, 2005). The process of depersonalization characteristic of institutionalized settings makes cohesiveness even more critical to therapy in these settings (Rosenhan, 1973). In our study, the experimental group, the group receiving group-as-a-whole treatment, showed a significant increase in group cohesiveness and a significant decrease in anxiety. The control group, a comparable group but without group-as-a-whole treatment, showed no significant changes at all.

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## Introduction

Widespread opinion says that severely mentally ill clients reap no benefit from deep psychological processing. Some attribute this absence of benefit to the lack of ego strength of severely mentally ill clients, their lack of capacity for insight, or to a general lack of relevance or usefulness of clinical depth psychology. Our study supports the conclusion that under certain conditions these clients do benefit from deep psychological processing. This conclusion offers hope given the intense needs of this highly isolated and neglected population.

We are also responding here to a need for empirical research. We need this kind of research on the clinical use of depth psychology, especially concerning the severely mentally ill. There is a lack of empirical research based on depth psychology partly because it is difficult to do such research. It is difficult, for example, to measure and interpret subjective states, as opposed to concrete behaviors. In addition, there is a lack of research on how group-as-a-whole work can be used with the severely mentally ill (Hazell, 2005). Most of the work available on the group-as-a-whole methodology involves qualitative descriptions of group process, not empirical studies conducted with control groups (Leszcz, Yalom, & Norden, 1985).

In this study, we hypothesize that the “group-as-a whole” therapeutic model (a deep processing model of group therapy) contributes to the development of group cohesiveness, which leads to positive therapeutic outcomes, including a reduction in anxiety and depression, in the treatment of a severely mentally ill, institutionalized population. As background, we will first discuss three of the study’s components: 1) the concept of group cohesiveness and its importance. To begin with, we have found cohesiveness important here because of the isolation experienced by the severely mentally ill, 2) the “group-as-a-whole” therapeutic model, and 3) some reflections on the need for this model in responding to the severely mentally ill population. Indeed, our study emerged out of the attempt to meet the deep and extensive needs of this population, a population whose entire treatment often consists of little more than medication monitoring.

## Group Cohesiveness

Group cohesiveness, according to Yalom, Houts, Zimerberg, & Rand (1967), predicts successful outcomes in group therapy. The development of cohesiveness appears to have a curative effect (Yalom, 2005). Marmarosh et al (2005) concurs, finding that cohesiveness is a primary group factor, “ ‘directly related to curative group factors such as “collective self-esteem” (the self-esteem one gains by being a member of a group) and “hope for the self” (similar to optimism)”. What is group cohesiveness? Bion said (1951) that we are group animals at war with our groupishness. While as group animals we desire to be in groups, we also fear groups and what they can do to us and others. There is a field of forces that each human being must negotiate—forces pulling us towards the group and forces pulling us away from the group. The net effect of this force field results in the individual’s level of membership or belonging to a group. When this force field is

aggregated across all of the members of a group, one could call the result the group's cohesiveness. For Bion, to come to grips with these group phenomena is to begin to understand the dynamics of a group. Thus the concept of cohesiveness stands at the center of his work and also of much of the work done by those he influenced. Bion's perspective on cohesiveness suggests the complexity of the concept and the difficulty of measuring it.

Following Bion, other researchers have examined ways of increasing cohesiveness (Burlingame et al 2001), while still others have wrestled with the fact that the concept of cohesiveness is multifaceted or potentially multifactorial. Dion (2000) provides an excellent review of the multiple conceptualizations of the concept of cohesiveness in an attempt to shift it from the field of forces concept that we find in Bion (1951) and Lewin (1935, 1936) to a multifactorial dimension. In so doing he helps locate different forms of cohesiveness as they relate to different measures. Dion finds Carron's (1988) model a useful template and uses it to postulate cohesiveness that may emanate from social factors, task factors, attraction and integration. He further identifies cohesiveness that may result from the cognitive processes of self-categorization as elaborated by Hogg (1992). Again, we wish to emphasize the complexity of measuring cohesiveness.

Because we discovered that all of the participants in the experimental group had experienced trauma, we considered the relationship between trauma and group cohesiveness. In this regard, we found the writing of Hopper (2003) to fit the patterns that we observed. Hopper theorizes that when a group contains a significant amount of serious trauma amongst its members there are two adaptive mechanisms that are frequently observed. These two mechanisms he derives in part from Tustin (1981). Hopper calls them forms of "incohesiveness." In the first form, the members seem to retreat into their private shells. There is a hyper-individuality, a minimization of emotional contact, and a shunning of interpersonal merger. A metaphor captures the "feel" of this group: it is a constellation of billiard balls—highly separated, bouncing off of one another, but never changing in their internal structures. They have become closed systems. Trauma, in this kind of "incohesiveness," results in an autistic-like lack of contact in the group. At the other extreme, trauma in a group may result in the adaptation of "massification/aggregation." In this form, the group behaves as if it were an undifferentiated mass. This is the polar opposite form of incohesiveness. There is a feel of merger or fusion, as if boundaries between self and other in the group have been obliterated. One might feel that there is a high level of cohesiveness in the group, but it is important to recognize that this cohesiveness depends on a covert agreement that there should be little or no self-other differentiation. Our concern with these dynamics of incohesiveness concerns the unworked trauma in the group. The forms of incohesiveness under discussion theoretically dissolve as the members work through the trauma (Hopper, 2003).

What we can see, even from such a brief review as the foregoing, is that cohesiveness as a concept is: (a) probably very important in the way it affects group outcomes (b) complex insofar as it is an aggregate of opposing forces (Bion, 1951), apparently multifactorial, and has different effects on groups at different stages of group development (Dion 2000), and (c) needs further research, despite the fact that some valiant efforts have already been made. Despite these difficulties, we decided to measure cohesiveness in this study (Evans & Jarvis, 1986) and its potential impact on anxiety and depression.

### The Group-as-a-Whole Model

The importance of cohesiveness to group therapy pertains to those who work in the Tavistock (group-as-a-whole) tradition because implicit in this very mode of working is the assumption that there exists a group to which everyone in the room belongs by virtue of being connected to the "group mentality" (Bion 1951). The very wording of the "consultations" from the group-as-a-whole

oriented consultant (e.g., “The group is engaging in a fantasy that only one member is feeling angry right now”) assumes a high degree of unconscious cohesiveness regardless of the stated sentiments of the group members.

In the Tavistock model, consultant interpretations address processes operating outside the current awareness of the group. Thus, the model involves some integration of psychodynamic theory. The exact nature of the theory is not prescribed, but one frequently finds elements of traditional psychodynamic and object relations theory in Tavistock consultations (Hazell, 2005). As an example, a consultant operating in the Tavistock tradition might perceive a group that discusses a trip to a restaurant as possibly avoiding the task at hand. A possible group-as-a-whole interpretation might be, “This group is anxious about addressing something in this room and wishes to move far away from it, to go out to eat so to speak rather than to address it.” In this case, the consultant was made aware of the group’s flight from the task by the focus of various members’ comments on events outside of the group’s process. The consultant’s interpretation was designed to bring the focus of the group’s discussion back to the dynamics emerging in the here and now. Sometimes, as in the groups under consideration in this study, this task is yoked to another task, such as the examination of interpersonal relationships.

We believe that the curative gains noted in our first study (Semmelhack, Hazell, & Hoffman, 2008) at least partially result from the development of cohesiveness through the group-as-a-whole methodology. The consultant’s interpretive approach, which emphasizes the group-as-a-whole versus any individual member, reinforces a sense of interconnectedness, even if this sentiment is not overtly expressed by group members. Furthermore, the group appears to reduce its propensity for scapegoating due to the discussion of this issue. This contributes to the creation of an atmosphere conducive to sharing and confronting painful issues. An increased capacity to confront and work through these issues ultimately suggests an increased sense of cohesiveness and may contribute to a reduction in anxiety and depression. We were therefore not surprised that the current study indicates that the group-as-a-whole method increases group cohesiveness.

### The Need for This Treatment

The group-as-a-whole treatment model shows special promise for helping the severely mentally ill in nursing home settings (the context of our study). In the United States, the population of individuals diagnosed with severe mental illness residing in these facilities is growing (Many of these clients are under the age of 65) (Jervis, 2002). Institutionalized settings such as nursing homes have a depersonalizing and dehumanizing effect, in essence creating a sense of “incohesiveness” (Rosenhan, 1973). Many nursing homes create environments which provide routine care limited to maintaining medication compliance. The dramatic sense of “incohesiveness” fostered in these settings leaves clients either isolated with few opportunities to engage in authentic interpersonal relationships, or as part of an amalgamated mass with little sense of individuality. This institutionalized mass is often labeled the “patients” or the “mentally ill residents.” Either isolation or “massification” negatively impacts on an individual’s sense of emotional well-being, contributing to anxiety and depression. Yet the treatment focus is typically medication management with few opportunities for clients to explore their need for positive relationships, or the impact of isolation on their psychological well-being (Edelson, 1970a; 1970b). Group-as-a-whole treatment may relieve some of the anxiety and depression that the mentally ill face in the nursing home environment. It is astonishing to discover the tragic reality of how many nursing home residents have been abused and need treatment for trauma. Studies consistently show a 50-80% prevalence rate of physical and sexual abuse among individuals who later acquire a diagnosis of mental illness (Stefan, 1996). According to Briere (2004), 35-70% of institutionalized female mental health clients have sexual abuse histories. From a treatment perspective, these histories are frequently ignored. We need to

provide treatment modalities other than medication management to address the abuse and neglect histories of institutionalized individuals.

Finally, the group-as-a-whole model may be useful for treating the severely mentally ill in many places besides nursing homes. This is both because most environments encourage the isolation of this group and because the members' isolation is part of their inner world as well as their relation to the external world.

## The Study

### Setting

The groups studied (experimental and control) took place in a nursing home with more than 350 male and female adult clients, all of whom had been given a major Axis I diagnosis according to the Diagnostic and Statistical Manual of Mental Disorders Text Revision (DSM-IV-TR) (American Psychological Association, 2000). The population ranged from 40 to 90 years of age. The average stay in the facility was 5 years (D. Nelson, personal communication, June 19, 2007). Individuals residing in the facility had few treatment options other than attending medication management groups and participating in activities such as bingo and cooking class (these are seen as treatment options).

### Participants

Twenty clients were referred for participation in the experimental group by the social services department. Potential members were interviewed by the group's consultant (a licensed clinical professional counselor and clinical psychologist). In 45-minute interviews with each referred member, the investigator described the purpose and structure of the group and asked members if they were willing to sign a consent form.

Among the 20 individuals who were referred, 11 consented to participate. These 11 severely mentally ill members had been given Axis I diagnoses as follows: three with paranoid schizophrenia, two with major depression, four with schizoaffective disorder and two with bipolar I disorder. None of the participants had an Axis II diagnosis. All of them had experienced childhood trauma, including sexual, emotional, or physical abuse, or neglect. Additionally, they all had made at least one suicide attempt. (The pervasive histories of trauma and suicide attempts reported among members, as suggested, is shocking. Clearly, there is a serious need here for therapy and research.) The membership ranged in age from 30 to 78. All members had at least average intelligence, which had been measured upon admittance into the facility through the administration of a Kaufman Brief Intelligence Test (K-BIT) (Kaufman & Kaufman, 1990). Members of the control group were selected from the same nursing home population. They were matched with the experimental group for gender, age and intelligence. Additionally, members of the control group had similar Axis I diagnoses. They showed an absence of Axis II diagnoses, as well as a history of suicide attempts and trauma. Control group members were not engaged in any form of group psychotherapy other than a medication management group and participated in activity groups, including bingo and cooking class.

The final sample consisted of 23 clients (10 men and 13 women) with Axis I diagnoses living in a long-term care facility. The sample was divided into two groups, control (5 men and 7 women) and experimental (5 men and 6 women). All participants were European American. Instruments: Beck Depression Inventory-Second Edition (BDI-II) (Beck, Steer & Brown, 1996).

This self-report measure required participants to rate how they felt over the past two weeks regarding 21 depressive symptoms and attitudes, including sadness, loss of pleasure, and self-

dislike. The participants rated each item on a 4-point scale from 0 (currently not experiencing that symptom/attitude) to 3 (experiencing a high degree of that symptom/attitude). Each participant's score was acquired by totaling all 21 items. In terms of reliability, Groth-Marnat (2003) showed high levels of internal consistency for the BDI-II ( $\alpha = .91$ ) in a psychiatric population. Beck et al. (1996) found a significant test-retest correlation of .92 ( $p < .001$ ). Studies have found support for the validity of the BDI-II. For example, the assessment of content, discriminant, concurrent, and factor analysis with psychiatric patients has been favorable (Groth-Marnat, 2003). With regard to convergent validity, the BDI-II was assessed by administration of the BDI-1A and the BDI-II to two sub-samples of psychiatric patients (Beck et al., 1996). The administration of the two versions yielded a significant correlation of .93 ( $p < .001$ ).

Beck

Anxiety Inventory (BAI) (Beck & Steer, 1993).

Participants were asked to read a series of 21 common symptoms of anxiety, including feeling hot, unable to relax, and nervous. They were asked to rate the degree to which they had been bothered by each symptom over the past week, including the day of testing, utilizing a 4-point scale ranging from 0 (not at all) to 3 (severely). Total scores were obtained by adding each participant's ratings on all 21 items. Reliability measures for the BAI show high levels of internal consistency ( $\alpha = .92$ ) with psychiatric populations (Hewitt & Norton, 1993). Beck, Epstein, Brown and Steer (1988) also found test-retest reliability to be significant, noting the correlation between intake and 1-week BAI scores to be  $r = .75$  ( $p < .001$ ). Studies have supported the test as a valid measure of anxiety with psychiatric patients, and they have considered the test to have appropriate discriminant validity with other measures of anxiety (Beck et al., 1988). An analysis of concurrent validity showed 1) a correlation of the BAI of .51 ( $p < .001$ ) with the Hamilton Anxiety Rating Scale--Revised and 2) a correlation of the BAI of .51 ( $p < .001$ ) with the anxiety subscale of the Cognition Checklist. The correlation between the BAI and the BDI was  $r = .48$  ( $p < .001$ ) (Beck, et al., 1988).

### Cohesiveness

Cohesiveness was measured by a modified version of the Group Attitude Scale (Evans & Jarvis, 1986). The questionnaire consists of a 20-item self-report study. The items on the instrument relate to several aspects of cohesiveness, including attractiveness, belongingness, task identity, popularity, and well-being. They thus address the broadness of the concept of cohesiveness. The measure required the participants to respond to statements such as, "People in my work group work together well," and, "I feel like I am really part of my group" before and after the ten week treatment period by placing an "X" on a continuous scale labeled from 0 to 100. Specifically, members of the control and experimental groups were asked to indicate how they felt about group membership at the time the measure was administered. In several studies of the original Group Attitude Scale the measure coefficient alpha has ranged from .90 to .97 in various points in the lives of groups studied. The validity and reliability data obtained to date on the scale suggest that the instrument has promise as a measure of attraction/ sense of belonging to a group (Evans & Jarvis, 1986).

### Procedures

Structure of the group. In this study, boundaries in terms of structure, task and role were clearly stated for the membership verbally and in writing during an introductory session. The group was held at the same time each week for a 60-minute period in the counseling room. It ran for 10 weeks. Members had an opportunity to exit at any point during the 10-week period. However, all 11 original members remained in the institution and opted to participate in the group for the 10-week period. As outlined in our earlier study (Semmelhack, Hazell & Hoffman, 2008), a 10-week module consisted of four types of activities: the Opening Activity, the Here and Now Activities, the Discussion Activity and the Application Activity.



The Opening Activity (session one) was designed to orient group members to the task at hand and the roles in the group, to review basic concepts concerning groups and to reinforce the importance of confidentiality. The goal for each session was for members to increase group connectedness. This was to be done by exploring together group-as-a-whole events. The Here and Now Activities (sessions two through five and seven through nine) constituted the major work of the group, in which members learned about themselves and the group through direct participation in the intra/inter psychic group process. (Unlike in traditional psychodynamic therapy, in group-as-a-whole work the unconscious is explored as it manifests itself in the here and now.) A member might come to discover, for example, a role she has been unconsciously playing in the group and its effects on how others respond to her. The intensity of affect expressed by members during these activities required a 30-minute tension-reduction period immediately after each session. During this period, the consultant was available for one-to-one consults with members who experienced painful affect during the preceding group session. The Discussion Activity (session six) served as a container of painful affect that could emerge due to severe psychopathology and obstruct the task (Hazell, 2005). In this session, the consultant and observer were prepared to step out of role and address members' questions directly. (Ordinarily, the consultant interprets group activity, but does not directly discuss it. This contributes to the members' active, increasing interpretation of their own experience in the group.) The Application Activity (session ten) focused on applying experiences in the group to experiences that members have in other groups to which they belong.

The formal roles in the group included those of consultant, observer, member and external consultant (Simmelhack, Hazell & Hoffman, 2008). The consultant (a licensed clinical professional counselor and clinical psychologist) had the task of attempting to make contributions to the group that would further the goal of increasing connectedness. These contributions were intended to be interpretations of group dynamics taking place outside the awareness of the group. The observer (a graduate student) remained silent throughout the sessions and simply observed the group's process to gain a better understanding of what goes on in any group (Hazell, 2005).

Group members participated with the same goal as the consultant. Ultimately, it was hoped, a decreased sense of isolation would contribute to an increased sense of group cohesiveness and positive therapeutic outcomes including a reduction in depression and anxiety. The outside expert (external consultant), who had no direct contact with group members, helped the consultant to deal with transference and counter-transference issues through the weekly analysis of transcripts of the group's process.

Administration of study measures. Participants in the treatment group were given the BAI (Beck & Steer, 1993; Beck, Epstein, Brown & Steer, 1988), BDI-II (Beck, Steer & Brown, 1996) and cohesiveness measure (Evans & Jarvis, 1986) by a member of the social services department before the group began (Time 1). The group ran for 10 weeks, at the conclusion of which participants were again given the BAI, the BDI-II (Time 2) and the cohesiveness measure. A member of the social services department distributed the tests to group members immediately after the end of the ten week module. She collected the completed tests within 2 hours after the end of the group.

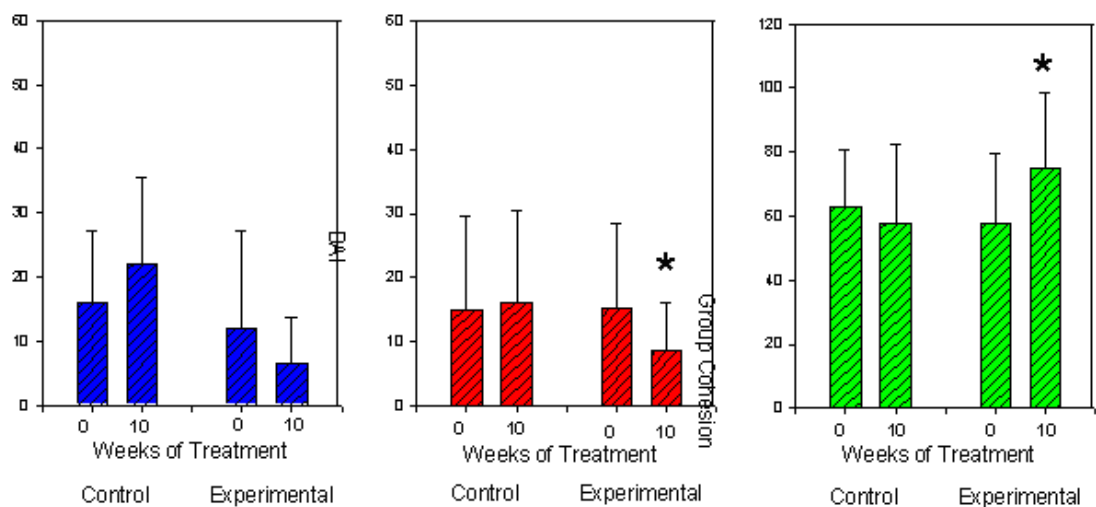
### Statistical Analyses

Data are reported as mean + standard deviation. Changes in anxiety, depression and cohesiveness over the ten week treatment were evaluated by paired t-tests. Correlations between the change in cohesiveness and the final depression and anxiety measures were determined by Pearson Product Moment correlations.

## Results

The effect of group treatment on depression, anxiety and cohesiveness is shown in figure 1. In the control group there was no significant change in depression, anxiety or cohesiveness over 10 weeks. In the experimental group there was a trend for depression to decrease during the 10 week treatment period, but this trend was not significant. There was a significant decrease in anxiety and a significant increase in cohesiveness during the treatment interval. These results indicate that during 10 weeks of treatment with group-as-a-whole therapy anxiety decreased and cohesiveness increased.

**Figure 1** BDI-II, BAI and cohesiveness scores in control and experimental groups at baseline and after 10 weeks of treatment.

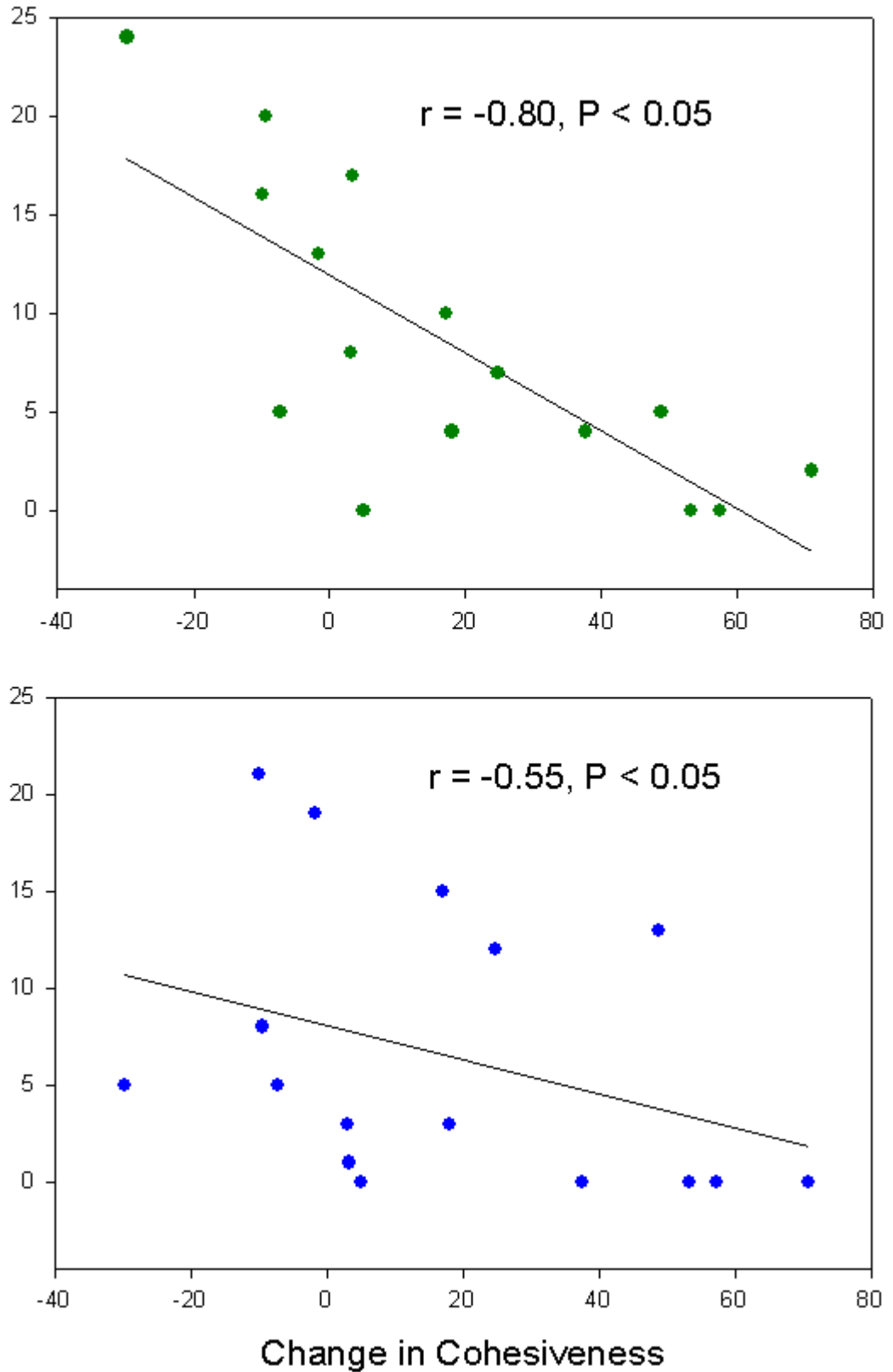


Mean + SD. \* =  $P < .05$  compared to 0 weeks within each group. There was a significant decrease in anxiety and an increase in cohesiveness in the experimental group with 10 weeks of treatment.

As a measure of test-retest reliability, Cronbach's alpha was evaluated for depression, anxiety and cohesiveness scores before and after the 10 week period in both groups considered together. For depression alpha was .56, anxiety: alpha = .58, cohesiveness: alpha = .41. Considering the small sample size, these results suggest that scores were consistent for individuals from the first to the second measure.

In addition to measuring the changes in depression, anxiety and cohesiveness over 10 weeks, we also determined the interaction of these measures within individuals. There was a significant negative correlation between the change in cohesiveness from 0 to 10 weeks and the anxiety level of each patient at the end of 10 weeks (fig 2). In addition, the change in cohesiveness was negatively correlated to the final level of depression at the end of the study.

Figure 2 Final anxiety scores



Final anxiety scores (top graph) and depression scores (bottom graph) at 10 weeks of treatment plotted as a function of the change in cohesiveness from 0 to 10 weeks. Pearson product moment correlation is given with significance level. Both anxiety and depression scores at the end of 10 weeks of treatment were correlated with the change in cohesiveness.

## Discussion

Doing group psychotherapy may improve a severely mentally ill, institutionalized patient's affective state over time (Semmelhack, Hazell & Hoffman, 2008). The current study explored the effects of group-as-a-whole processing on the development of a sense of cohesiveness as well as on symptoms of anxiety and depression in 11 severely mentally ill institutionalized clients over 10 weeks, utilizing BDI-II, BAI and a modified Group Attitude Scale as measurements. Members of the experimental group showed a significant decrease in anxiety and a significant increase in cohesiveness across the 10 week treatment period. There was no significant improvement in depression. Individual depression and anxiety scores for each patient at the end of the study were also negatively related to their cohesiveness scores. This suggests that higher depression and anxiety levels in individual patients may inhibit their ability to fully interact in the treatment process. These results are consistent with Yalom et al.'s (1967) perspective that the degree of cohesiveness evident in a psychotherapy group contributes directly to therapeutic outcomes. The current findings with respect to anxiety and depression are consistent with our earlier research over a 30-week period (Semmelhack, Hazell & Hoffman, 2008).

Our study responds to the depersonalizing effect of being held in an institutional setting, which contributes to a sense of "incohesiveness." Members isolate and cannot bring about a sense of interpersonal connectedness, or they lose their individuality by becoming enmeshed in a mass labeled "patients," or the "mentally ill residents." In either case, there is not the development of a sense of cohesiveness thought to be critical for a positive therapeutic outcome (Yalom, 1967). The findings in our study point to the utility of the group-as-a whole model in fostering a sense of cohesiveness.

A cohesive group appeared to evolve in this study, contrary to the assumption that the "group-as-a-whole" approach does not facilitate psychological growth with this population (Nichols & Taylor, 1975). Nichols and Taylor suggest that the Tavistock focus on the whole group versus the individual more likely increases than decreases anxiety in the group participants. This assumption has now been challenged by research findings suggesting that the group-as-a-whole model may in fact facilitate the population's capacity to acknowledge feelings as well as their ability to foster positive interpersonal relationships (Hazell & Semmelhack, 2001; Semmelhack, Hazell & Hoffman, 2008).

As stated earlier, the group-as-a-whole method contributes to cohesiveness through its interpretive style, which, emphasizing the whole group versus any given individual in the group, assumes a high degree of unconscious cohesiveness. The consistent use of group-as-a-whole interpretations in response to comments made by individuals highlights the notion of a "group mentality" (Bion, 1951). The interpretive reinforcement of the unconscious dimension of the group's interconnectedness may lead to its enhancement and ultimately the explicit recognition of cohesiveness by group members. Lastly, the emphasis on the whole group versus any individual member may reduce the possibility of being scapegoated, thus making the group a safer place to share painful thoughts, feelings and memories. This in turn may increase cohesiveness further.

### Study Limitations

Reactivity given the repeated measure design of this study may have been a potential weakness influencing outcomes. For example, results may have been influenced by the fact that over time members gained a familiarity with the tests given and awareness that they were part of a study. Client mood may also have been influenced by other activities or events in clients' lives. It is also possible

that the increased attention given to the experimental group impacted positively on the outcome measures rather than the intervention itself. A confounding variable could have been the presence of an observer. However, because she remained silent, the observer most likely had a limited effect on outcomes. Another weakness of the study is the small sample size because it may have attenuated our ability to see significant differences between groups. The fact that the results with respect to anxiety were consistent with our earlier study, however, is important to note when considering this limitation. Because group participants were not ethnically diverse, the ability to generalize the results to diverse populations is limited. Lastly, we recognize that cohesiveness is a very complex variable and that the measure utilized may have been limited in its capacity to identify the dimension of cohesiveness linked with therapeutic change. (Hornsey, M.; Dwyer, L & Tian, O, 2007).

## Conclusion

There is a need for new treatment options for severely mentally ill individuals in long- term care facilities. This population is growing and there are few therapies available other than medication management. The intense depersonalization and isolation which this population suffers from likely contributes to anxiety, depression and the experience of alienation. Ultimately, it is hoped that the group-as-a-whole approach facilitates the evolution of a safe context for the task of developing greater group cohesiveness. To further support the efficacy of the model presented, more research is needed. The results need replication. We need studies exploring the impact of a longer treatment period on the development of group cohesiveness. And finally, the utility of the model with diverse populations of severely mentally ill clients needs to be explored.

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# Psychosocial Rehabilitation: A Descriptive Case Study Of A Therapeutic Community

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## Abstract

Athma Shakti Vidyalaya, is a therapeutic community, for persons suffering from chronic mental illness like schizophrenia that is based on the philosophy of transactional analysis and Reparenting model of psychotherapy. The present study utilizes the descriptive type of holistic-single case study design to delineate the structure and function of an organization, highlighting the unique approach used in the rehabilitation of the mentally ill, both from the psycho social and socio-cultural perspectives.

**Key words:** chronic schizophrenia; psychosocial rehabilitation; therapeutic community.

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## Introduction

One of the most severe and challenging diseases to deal with in the field of abnormal human behaviour is schizophrenia. Carson & Butcher (1992) define it as: "the schizophrenias are a group of psychotic disorders characterized mainly by gross distortions of reality; withdrawal from social interaction; and disorganization and fragmentation of perception, thought and emotion" (Pp. 428).

The definition is elaborated and described in ICD -10 as: The schizophrenic disorders are characterized in general by fundamental and characteristic distortions of thinking and perception, and by inappropriate or blunted affect. Clear consciousness and intellectual capacity are usually maintained, although certain cognitive deficits may evolve in the course of time. The disturbance involves the most basic functions that give the normal person a feeling of individuality, uniqueness, and self-perception (CDDG, 1992: Pp. 86). Treatment of schizophrenia has three main components. First, there are medications to relieve symptoms and prevent relapse. Second, education and psychosocial interventions help patients and families cope with the illness and its complications, and help prevent relapse. Third, rehabilitation helps patients reintegrate into the community and regain educational or occupational functioning. The real challenge in the care of people suffering from schizophrenia is the need to organize services that lead seamlessly from early identification to regular treatment and rehabilitation (WHO report, 2001, Pp. 68).

Acute syndrome schizophrenics generally do well with medications and psychosocial interventions. But when patients have poor social adjustment and behavioural defects characteristics of chronic schizophrenia, they require more elaborate after-care programme, which is provided in rehabilitation set-up. Maintenance Drug therapy plays an important part, but the main emphasis is on a programme of rehabilitation tailored to the needs of the individual patient (Gelder et al, 1996).

Therapeutic Community is a tertiary preventive measure to reduce the impact of maladaptive behaviour and making the rehabilitation efforts more from the environmental approach (Carson & Butcher, 1992).

The Therapeutic Community movement originated as Northfield Experiments in North field hospital, Britain to treat soldiers suffering from psychoneurosis during the Second World War. The pioneer of the Northfield Experiments, Tom Main (1946) defined Therapeutic Community as an attempt to use a hospital not as an organization run by doctors in the interests of their own greater technical efficiency, but as a community with the immediate aim of full participation of all its members in its daily life and the eventual aim of re-socialization of the neurotic individual for life in ordinary society (Pp. 67).

Maxwell Jones (1959) developed these ideas further at the Henderson Hospital and described a Therapeutic community as distinctive among other comparable treatment centers in the way the institution's total resources, both staff and patients', are self-consciously pooled in functioning treatment. This implies, above all a change in the usual status of patients in collaboration with the staff, they now become active participants in the therapy of themselves and other patients and in other aspects of the over-all hospital work in contrast to their relatively more passive, recipient role in conventional treatment regimes (Jones, 1973, Pp. 427).

Even though TC's are extension of hospital and after care centers with more freedom and humanitarian treatment, they differ in their values and treatment process. Kennard (2005) observes therapeutic community as follows:

In one sense TCs can be seen as all about continuous risk assessment and management, where episodes of destructive behaviour or threats of it are regularly discussed, analysed and commented on by staff and clients in the small and large groups. In another sense TCs can be seen as allowing levels of risk that units with seclusion rooms, close observation policies and rapid tranquillisation avoid- at the cost of no one learning anything about changing self-defeating ways of thinking, personal responsibility or concern for the effects on others (Pp. 1).

Objectives and philosophy of Athma Shakti Vidyalaya: A therapeutic community  
'Chronic schizophrenia and other severely mentally ill people need an intervention that offers more than mere psychosocial rehabilitation, thus placing an emphasis on community living with a holistic approach'.

It was with this objective that a group of parents and relatives of a few young adults who were having serious mental illnesses came together in 1979 to discuss along with Jacquee, L.Schiff and Fr. Hank Nunn and other renowned therapists the possibilities of opening a therapeutic community in Bangalore and established Athma Shakti Vidyalaya Society (ASV). ASV was founded on the premise that young people suffering from any mental illness can, through community living and therapy, come to the realization of their ability to function responsibly and with gratification.

The members of the community learn to recognize and become aware of unhealthy aspects to their personality through their interactions with other members. There is a continuous emphasis that no matter what their problem is, they are OK. The members are made to feel responsible for the harmonious functioning of the community by helping in keeping it clean, cooking, washing, eating together, respecting one another and on the whole enjoying the process of getting well.

### Setting:

Athma Shakti Vidyalaya (ASV), a residential therapeutic community, is based on the principles of democratic therapeutic communities and theory of Reparenting (Cathexis) model of Transactional Analysis. ASV accommodates a maximum of 24-26 male and female patients or residents called 'kids'. The majority of population at present is Indian. Generally the community welcomes patients from any part of the world. The population comprises of chronic schizophrenia, chronic bipolar affective disorder and severe personality disorder (predominantly borderline type) patients. Community also treats dual diagnosis cases.

Clinical staff group involves clinical psychologists, psychotherapists, counselors, junior staff, trainees and one consulting psychiatrist, who believes in an eclectic approach of integrating medical and psychosocial model. The community maintains international standard of 2:1 patient-therapist ratio. This ensures the availability of clinical staff to every patient at any required time.

The community provides holistic care to the patients. Holistic mental health believes in total mind-body integration in the healing process rather than just alleviating symptoms of a specific illness.

Athma Shakti Vidyalaya has treated hundreds of mentally ill persons for the past twenty-seven years and in 2003, became member of the 'Community of Communities', an international supervising agency in the field of therapeutic communities.

### Initial Interview: Getting into organizational culture

The client first meets with the Director and the Clinical Psychologist. The client and those accompanying them are then shown around the house and given information about the treatment methods and process. Clarity of expectations from the patient and the family is noted. A written record about the person's previous treatment is handed over. The same is discussed in the staff meeting and a decision taken on the basis of interviewer's observation and treatment record.

### Treatment Process: Cultural de-stressing

Athma Shakti Vidyalaya believes in holistic and eclectic approach in dealing with the persons suffering from chronic mental illness. The following is an elaborated description of the treatment process.

**Intake Procedure:** On the first day one of the residents of the community is allotted to the new client as a 'buddy' who will help to explain the routine about the house. Depending on the initial interview the client either comes in as a day patient for 3-5 days as a trial period or is immediately admitted. During the first couple of weeks the client is given time to adjust themselves to the community members and routine. One staff member is responsible to get feedback form staff and residents on a daily basis on the new community member's potentials, limitations and other behavioural observation.

Clients' feedback on his/her experience will also be given equal importance.

**Welcoming:** Welcoming is done on the first day in the traditional way using arathi, offering lemon and garlanding to the patient. Then all the community members introduce themselves to the new client. This is based on Indian tradition and also shows the acceptance of a person as they are, rather than a person with illness or a psychiatric label.

**Assessment:** This involves a detailed case history of the patient from informants and from patients, if necessary and psychological testing. Some of the tests administered are: Minnesota Multiphasic Personality Inventory (MMPI), Bender-Gestalt Visuo-Motor Test, Sentence Completion Test, Human- Figure Drawing, Rorschach Inkblot Test and Wechsler Memory Test.

**Making a Contract with the Community:** After the new resident overcome his/her initial adjustment difficulties, the new member makes a verbal contract in which he/she states that he/she will abide by the rules of the community and use the resources of the community to get well and be involved in helping others get well. This is done in the presence of the whole community.

**Forming a Mentor Group:** Forming a 'mentor group' consisting of a few staff members with whom the person thinks he/she would be most comfortable with is the next step. The mentor group will closely work with the person right through his/her treatment in the community.

**Mentor Group Meetings:** The mentor group meets to discuss and formulate a treatment plan. This begins with a review of the initial expectations set based on the diagnosis and observed behavioural difficulties. Expectations are prioritized and broken down into smaller short-term goals for a period of 6-8 weeks.

Usually, within the first three months of the patient's arrival in the community, his/her therapeutic issues come into focus. There are different programmes planned for the resident depending on the problem manifested.

**Review and Evaluation:** The mentor group will do review and evaluation after 8-12 weeks. The outcome of this meeting will determine the setting of new short-term goals or following up with goals that have not been achieved. Once a year, the residents are assessed on different rating scales to get an overall picture of his/her functioning within the community.

**Report:** Report of the review is sent to the family and meeting with the family organized if required.

**Farewell:** A farewell to the resident is organized at the end of his/her treatment in the community. This is a big affair in the community as each residents getting well is celebrated by everybody.

**Follow up:** The patients keep in touch with the community regularly through telephone, e-mail, letters and visits. They will always remain as members of the 'larger family'.

Dynamics of treatment: Integrating the fragmented.

In the following pages, the different therapeutic activities are described. Many of them are related to the basic philosophy of the ASV in particular and therapeutic communities in general.

### Individual psychotherapy: Every one is unique

Dealing with severe mental illness like schizophrenia requires interventions from many perspectives. Research studies have proved that 'integration of intensive insight-oriented individual psychotherapy and reality-adaptive supportive psychotherapy depending on the individual patient's need' is more effective. The use of pragmatic and broad based psychotherapy that relies at various times on supportive, directive,

educational, investigative, and insight-oriented strategies applied flexibly depending on the individual patient's type of illness. This approach is popularly known as 'flexible psychotherapy' (Fenton & Cole, 1999), is very much adapted at ASV as part of individual psychotherapy.

**Nurturing:** Access to unconditional positive regard nurturing is another important aspect of Reparenting (Schiff, 1969, 70, 75). Parents cannot nurture their children without being physically close to them, hugging them, and holding them. Gowell (1979) writes on Nurturing, "this nurturing is usually in the form of nonsexual physical contact. This means that the individual will ask for, and get experiences of being held in a caretaker's arm or lap, being massaged, getting his head stroked..." (Pp. 120-121). Nurturing is the core of ASV's therapeutic process. It not only provides comfort and care, but also gives the resident an experience of safety, security and being accepted unconditionally.

Not all the staff will give nurturing or non-sexual physical contact to each and every resident. It is based on the rapport and each one's perception and comfort. If either therapist or resident is not comfortable to give or receive nurturing, then it won't be given until they resolve their discomfort.

**Nurturing or Non-Sexual Physical Contact (NSPC)** is nonverbal in nature. Here therapists come from a parental position and nurture the resident, to fulfill his/her regressive needs. Usually it is in the form of physical contact, where the resident puts his or her head on the therapists lap and receives nurturing. Stroking is similar to contact, which includes gentle massaging the patient's head or back. Holding is similar to mother holding her baby, which makes the distressed or insecure person feels accepted and get the warmth and unconditional positive regard from the therapists.

#### **Groups: Reality met through consensus:**

Similar to the objectives of the group therapy in other mental health set ups for schizophrenia (Fenton & Cole, 1999), group therapy here focuses on expressing similar experiences and clarifying one's doubts. Many conflicts among patients are dealt in groups. T.C.s based on democratic principles, so any issue, which is significant to the either one or more member of the community also brought up in the groups. Again group therapies interact and facilitate other therapeutic process. It is also a forum for concerned confrontation and feedback.

**Treatment groups:** This group meets once a week. An average group comprises six or seven residents and two-three facilitating therapists. The residents mentor group is where he/she makes his/her short and long range plans regarding his treatment and in the treatment group he/she is consistently guided as to the manner in which he is meeting his goals and these are reviewed after a few months to check whether the goals set by him/her have been reached. He/she thereby progresses to set new goals for the next few months. These goals could range from simple behavioural changes that usually are the case in the earlier stages of treatment to more complex decisions and interactions at a later stage of treatment.

**Cognitive retraining group:** Persons suffering from schizophrenia may display cognitive impairments, which affect their social skills and functioning. In order to regain and reinforce these mental faculties, retraining is done on a gradual basis, which is similar to other modes of cognitive remediation (Green, 1992; Liberman & Green, 1992; Spaulding, 1989; Spaulding & Sullivan, 1992; Spring & Ravdin, 1992).

**Peer group:** This is a group designed for clients to freely share information among themselves and discuss problems and disputes that arise and provides a forum for exchange of ideas and feelings on any topic related to the day-to-day functioning of the community. It is also a group for planning the different household responsibilities that members have to undertake for the smooth functioning and cleanliness of the community.

**The girls' group and the boys' group:** All male patients and male members of staff are involved in the boys' group and the girls' group is similarly formed. It meets once a week or whenever necessary to discuss matters

relevant to sexual issues, identity issues, appropriate ways of relating to members of the opposite sex, appropriate ways of dressing, etc. Therapists offer role modeling and give parenting in areas where information is lacking. The primary focus is to achieve group cohesiveness and provide an arena for members to share their problems, interests and a variety of different concerns they have in common.

**SOS group:** SOS or Studying of Ourselves is a group, which allows intensive interaction on the prescribed issues from therapists as well as patients. Here even therapists can set goals for themselves and take personal responsibility at an equal level with the residents.

**Fun group:** This group is for patients whose contact with reality is poor and who tend to withdraw from others. They are kept involved for an hour during which they are expected to pay attention and participate in an indoor game, singing, word building and dancing.

**Neuro Linguistic Programming (NLP):** Neuro linguistic programming is a newer discipline of helping to people to change their thought process, feelings and behaviour. Dr. John Grinder and Richard Bandler originally founded NLP in 1970s (Bodenhamar & Hall 1999). In the NLP group, the approach towards finding each one's map's model for different world realities is done by giving a series of questions that would elicit responses relevant to each individual. Once the questions are answered, each one reads their answers in the group. Meta-modeling leads to further clarity and understanding, which the person uses to make new choices to improve themselves.

**Yoga and cyclic meditation:** Simple yoga exercises and cyclic meditation taught by experts of yoga helps in keeping the residents' active and focused. Director, Fr. Hank Nunn, conducts yoga and trained residents conduct the cyclic meditation.

#### **Family therapy:**

There is scope within the treatment process for contact with members of resident's family. Over the months, through visits and therapy sessions, family members are drawn into the evolving growth of the resident. Some family members also undergo counseling regarding their issues in dealing with the patient. The process is similar to other family therapy approaches (Haley, 1962; Satir, 1967; Minuchin, 1974).

#### **Recreational activities: Games as therapy**

ASV provides opportunity for a lot of indoor games for its residents. Some of the games are not only a pastime but also stimulate the cognitive faculties. Residents play amongst themselves and also with staff. All staff and residents birthday will be celebrated in the community. This is a forum for singing and dancing and often ways to express talents. Residents also taking leadership roles like being the Master of Ceremonies at parties. Football and cricket are two out door games where the boys participate with lot of enthusiasm.

Daily routine activities: Can cleaning be therapeutic?

A regular part of each resident's routine involves cleaning an allotted part of the house and sharing in preparing breakfast for the community. All these activities are taken care of by residents in an organized way. It doesn't mean that all these activities would go smoothly; there are many incidents of conflicts and frictions. But these are resolved either individually or in groups. Some conflicts have to be dealt in community meetings. Such involvement helps to gain a sense of belongingness to the community and need to take care of our surroundings, like how we take care of ourselves. Many chronic schizophrenics, due to their pre morbid personality or illness factor, don't initiate or concern for either self-hygiene or environmental hygiene. If somebody doesn't do their jobs, will be confronted either individually or in groups. They also get feedback from peers regarding their passive behaviours.

### Journal writing: ‘Registering’ the therapy

Residents are expected to maintain a daily journal. Here they record anything significant in their routine activities, individual therapy, group therapy, any specific incidents like party, welcoming ceremonies, farewell or violent outbursts of peers. The last section is comments by therapists. Journal writing depends on the residents’ level of functioning and there are other structured programmes for the more dysfunctional ones.

### Structures: Norms for containment

Rules and regulations provide a structure for safety and harmony in the family and society at large. Non-adherence of these structures results in consequences. In the same way the basic foundation of the treatment in the community is the schedule and structure of the daily operation of the community and the daily functioning of the individual patient. They are encouraged by the staff to identify their needs and reassured that the same may be met in healthy ways instead of escalating in order to be noticed or taken care of. “Acting out” at any level is not tolerated and goal oriented consequences are defined with the clear objective of providing safety and security and as a way of encouraging personal responsibility to change.

Structures in the community are both rigid and flexible. It is rigid when it pertains to non-negotiable, core values like violence or stealing and flexible in moving around within the premises.

Within the broader framework of community structures, residents are assessed and they qualify into one of the following:

**Responsible person:** A member of the community, who can take care of himself and able reach out at times of distress and also able to help other peers and staff in the relevant context. He/ she is also ready to get a job and return to mainstream. Trainee staff also has to become responsible person to take care of dysfunctional people in the community.

**Reasonable person:** A member of the community, who can take care of himself or able to reach out at times of distress, but not yet in a position to help others to the extent. All the trainee staff join the community as a reasonable person.

**Functional person:** A member of the community, who is independent in self-care and able to perform simple jobs in the community, but needs lot of support even under minor stress and has difficulty in interpersonal relationships.

**Dysfunctional person:** A member of the community, who is dysfunctional to the extent that he needed external support in any one or more areas of basic self-care. He/she may also have suicidal, homicidal or running away tendencies, which need to be addressed. They are monitored at close distance and adequate support is given all the time.

**Managing client’s violence: Beyond medical model**

**Restraining:** A special method of restraining has been evolved by using mountaineering rope in circumstances when distressed clients turn violent, to help them have control over their impulses to harm themselves and others. In instances of extreme violence and unpredictable behaviour of a client, restrains are used. These are always the final resort to risk management due to violence. At these times, therapists’ significant to the client are allowed to have structured interactions and caring, which is believed to be more helpful than tranquilizers or closed wards.

**Time Out:** The corner of a room is a place without much external stimulus. A person is asked to face the corner to enable them to settle down from all internal and external agitation and think about what’s distressing them and how they could express and deal with this appropriately in the community.

**Middle of the floor:** This is the middle of the room where the person is put and expected to think of their inappropriate thinking or behaviour and figure out a way to do the same differently and appropriately.

When clients are in the corner or in the middle of the floor harmful objects like their spectacles, bangles, watch, etc. are taken away to reduce possibilities of causing harm to themselves or others. The very organization of living in a community reduces the risk due to withdrawal and solitude.

**Committees within the community:** Adding potentials through cooperation.

The community places considerable emphasis and puts in a lot of effort to provide an environment or atmosphere which is as closely akin to that of a family, in which members have a sense of belonging and also are assigned to specific tasks and responsibilities to ensure smooth running of the family.

Members are encouraged to participate and be actively involved in their own therapy but also to contribute towards a variety of matters that range from looking after the household to organizing each ones' therapy. Each member in the community, both staff and resident is a part of at least one of these committees. Different areas of responsibility are identified and committees formed to oversee the same. Each has a leader and the leaders of each of the committees and the director form the core group.

**The committees are as follows:**

**Therapy Overview Committee:** This committee organizes for each resident to have access to all therapeutic interventions that are available in the community. It organizes the entire documentation process and is responsible for organising in-house training in the basic concepts of TA and counseling. The committee also co-ordinates staff to attend external training programs to learn new methods and approaches in psychotherapy.

**Structure Review Committee:** The main function of this committee is to review general community structures and represent the same in the community meeting.

**Household Committee:** This committee is in-charge of cleanliness, repairs and general maintenance of the house.

**Medical Committee:** The responsibility of this committee is to purchase and stock whatever medication is required. This committee also organizes for people to be taken to the hospital whenever needed and to follow up with the prescribed treatment.

**Party Committee:** This committee organizes all the parties celebrated in the community and to send birthday cards and seasons greetings to all the friends of the community. The committee also organises a variety of recreational activities both in and outside the house. Each committee meets once in three months. Issues arising from these meetings are further discussed in the core group and their decision is followed.

**Staff meeting:**

Staff meetings are held between 1:30 pm to 3:30 pm, Monday to Friday in which all staff presence is expected. The agenda for these meetings varies from staff scheduling to discussions on various residents, which requires pooling information and taking a comprehensive decision to work on.

**Community level meetings:** Forum for open communication

**Daily meeting:** Once a day, all the community members meet together and group facilitator (usually a senior staff member) gives some questions, which help them to use their critical thinking or be aware of their feelings for that day. It is followed by important announcements for the day and other information regarding issues that need to be known to all the members of the community. Jones (1973) emphasizes on community level meetings and called it as 'a basic aspect of the therapeutic community'.



**Weekly meeting:** It is called community meeting, which is similar to daily meeting. Here, apart from daily meeting, review of the previous weeks' significant events including visitors' movements is done. After reviewing, general businesses of the community are discussed. Then comes personal business, where residents can ask for feedback, if they want to change their any specific structures.

### **Staff therapy groups: Does counselor need counseling?**

Working in T.Cs is not a smooth flow. It is quite stressful for the staff both physically and emotionally. They need to feel O.K. before helping others in feeling O.K. Meinrath and Roberts (2004) writes about caring for the staff member; The demands of being a good or ideal staff member can take a tremendous toil of a therapeutic community worker. Deprived clients often seem to ask for every thing that they never had as a child and the community seems to demand an incredible dedication from the staff member (Pp.321). The T.C. kind of work life is likely to lead to 'burn out' syndrome (Freudenberger, 1975), which reduces the performance of the member and counter productive to the T.C. environment.

Another perspective is that a staff member may have his/her own vulnerabilities and inadequacies, which interfere in his/her work, and need to be taken care of. All these factors push the counselor to under go personal therapy, which occurs in staff therapy groups. Staff are divided into four groups depending on their level of experience and seniority in the community.

## **Conclusion**

The present case study, based on holistic- single case design (Yin, 1994), describing the structure and function of an organization gives ample evidence on how a therapeutic community can be helpful in the psychosocial and socio-cultural rehabilitation of persons suffering from chronic mental illness like schizophrenia. Not providing quantitative and statistical data in the present article to show the significance of the effectiveness of the community is a serious limitation, thus rendering scope for further study using different design and methodology. Nevertheless, the study took a different perspective; getting into the content and process of an organization, which equally helps in understanding human behaviour and its modalities of change.

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# Optimizing System & Patient RecoveryRediscover & Recovery: The Shared Journey Project

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## Abstract

**CONTEXT:** Healthcare quality improvement initiatives have become a priority issue across organizations and systems internationally. Ontario is developing a strategic initiative to systematically improve the quality of healthcare delivery. Mental health reform is of specific interest.

**METHODS:** Whitby Mental Health Centre has launched a quality improvement initiative entitled "Rediscover & Recovery: The Shared Journey Project". The objective of this project is to transform the Centre's organizational culture and improve patient care by connecting frontline clinicians with the values and beliefs inherent in the recovery philosophy and interprofessional care.

**FINDINGS:** The following paper offers a comparison of the shared values and principles of the recovery philosophy and interprofessional care, and will describe facilitators and barriers to their implementation.

**CONCLUSIONS:** The benefits of the project will be discussed, as well as implications for rehabilitation practitioners.

**KEY WORDS:** Interprofessional Care, Recovery Philosophy, Quality Improvement, Mental Health

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## Introduction

Whitby Mental Health Centre (WMHC), located in Central-Eastern Ontario, employs over 1,200 people and offers a range of specialized tertiary care mental health programs for individuals living with mental illness (Whitby Mental Health Centre, 2006). The Centre provides both inpatient and outpatient services to approximately 2.8 million people residing within the region. It opened as a mental health facility in 1919, and management of the Centre was transferred from the Ontario Government to a stand-alone public psychiatric hospital on March 27, 2006. A culmination of recent developments has necessitated a significant transformation of clinical care. The Centre's divestment from government governance to a public hospital, the international emphasis on incorporating the recovery philosophy into best practices for mental health (Allott, Loganathan, & Fulford, 2002; Davidson, 2007; Farkas, Gagne, Anthony, & Chamberlin, 2005), the movement toward interprofessional practice for clinical excellence (Akhavain, Amaral, Murphy, & Cardone Uehlinger, 1999; Evetts, 1999; Infante, 2006), and Ontario's initiative to strengthen the mental health system (Local Health Integration Networks [LHINs], 2008; Newman, 1998; Ontario Ministry of Health, 1999) have set the stage to enable the enhancement of clinical front-line care delivery at WMHC. These factors have provided an opportunity to implement "The Shared Journey", a large-scale organizational change initiative that will improve the quality of care provided by the centre. The purpose of this paper is to explore the key factors that will impact the adoption of the recovery philosophy and interprofessional care (IPC) within the current healthcare climate in Ontario.

## Healthcare: Reform & Transformation

Internationally, there is a movement to improve the quality of healthcare. The United Kingdom has published a White Paper on healthcare reform and launched a series of quality improvement initiatives (Thomas, 1998). The United States has identified the need for safer, more effective healthcare services and has made recommendations for system redesign (Kohn, Corrigan, & Donaldson, 2000; Institute of Medicine Committee on Health Care in America, 2001). In Canada, a review of the healthcare system has resulted in recommendations for reform in order to enhance the efficiency and sustainability of healthcare delivery (Standing Senate Committee on Social Affairs, Science and Technology, 2002). Efforts to address local healthcare challenges have begun, and in 2006 the province of Ontario developed the Local Health System Integration Act and created fourteen Local Health Integration Networks (LHINs) in order to plan, integrate, and fund healthcare services (Local Health System Integration Act, 2006; LHINs, 2008). Mental health and addiction services were raised as a priority issue across all LHINs in Ontario. This is indicative of the importance and priority that the province is placing on improving the present state of mental healthcare delivery. The identification of mental health services as a priority issue can be traced back to the first wave of deinstitutionalization in the 1970's, where neither the healthcare system, nor the community was adequately prepared to meet the needs of individuals living with severe and persistent mental illness (Hartford, Schreker, Wiktorowicz, Hoch, & Sharp, 2003). The provincial government has since committed to the reorganization and restructuring of services through mental health reform. Hartford et al. (2003) provide a historical context for mental health care in Ontario and illustrate that until the recent development of the LHINs, mental healthcare system improvement has been slow and changes have been nominal. The Central East (CE) LHIN is addressing system improvement through their Integrated Health Service Plan (Central East [CE] LHIN, 2008). This action plan has identified key areas for healthcare improvement, and has included specific objectives for mental health and addictions. The following areas in mental health have been identified as a priority in the mandate, and will have a significant impact on the type of care that is provided within the region: service delivery, knowledge exchange, interprofessional practice, and staff recruitment and retention (CE LHIN, 2006). WMHC's organizational change initiative to embrace the recovery philosophy and IPC aligns seamlessly with provincial objectives. The LHINs' mandate for mental health system improvement will be supported by the clinical transformation and care provision changes at the Centre.

In order to improve the quality of care provided at WMHC, the Centre has decided to model a change

initiative after the “Reconnecting to Care” project conducted at the Baycrest Centre in Toronto, Ontario (Glouberman, Richards, El Bestawi, Seidman-Carlson, & Teperman, 2007). The Baycrest strategy was a deep change initiative for nursing services and emphasized the importance of clinical competencies and the value of direct care workers. It was initiated in response to the challenge of maintaining a caring and positive work environment when clinicians experience decreased morale. The work culture at Baycrest was reflective of the attitude represented across many non-acute healthcare settings, including the WMHC. Staff felt that they were unrewarded and were trapped in a disconnected, task-driven routine. In order to improve services, Baycrest underwent a “renewal” process where patient care units at the facility were systematically shut down for a period of four weeks. During this time the staff was immersed in an educational program that resulted in a more responsive, more alert, and more dedicated workforce. After the intervention, staff also had a better understanding of their roles, as well as an enhanced awareness of system and process issues. A number of quality indicators revealed that the nursing staff had improved their ability to relate to one another, their patients, and patient families. As WMHC is looking to address similar workforce and organizational culture issues, a similar process will be adopted. However, the “Rediscover & Recovery: The Shared Journey Project” will merge the concepts of recovery based competencies and IPC with specific clinical skills and proficiencies related to the field of mental health. To ensure the successful implementation of this initiative, it is imperative that the organization be prepared to create and sustain a change to clinical expectations prior to anticipating transformation in frontline care delivery. In order to set the stage for change and begin to transform the organizational culture to improve the quality of care delivery, WMHC must address the deeply entrenched values and beliefs that underpin clinical practice at the Centre (Davies, Nutley, & Mannion, 2000).

### Transforming Systems: The Recovery Philosophy & Interprofessional Care

Instituting a new organizational strategic directive through the implementation of The Shared Journey Project will require the adoption of two approaches to care at the WMHC: the recovery philosophy and IPC. This new philosophical mandate will require personnel values and behaviour that are significantly different from traditional healthcare delivery and current practices at the Centre. Historically, mental health care has employed a top-down approach dominated by an expert-driven model, and interventions were based on deficiencies and incapacity (Swarbrick & Brice, 2006). The “medical model” approach to care is based on the absence of disease, pathology, compliance, and in essence establishes a power differential between doctors and patients (Roberts & Wolfson, 2004). In stark contrast, Anthony (1993) and Deegan (1988) describe the meaning of recovery as a shift in thinking from clinical pathology to a strengths-based approach; therefore, instead of focusing on relief from symptoms, emphasis is placed on building self-esteem and finding a meaningful role in society. Deegan (1996) further describes recovery as providing opportunity for choice; empowering people by allowing them to have a voice and taking the time to listen to their story; allowing individuals to provide input regarding service engagement; and by providing opportunity for peer support, peer mentorship, self-help, and mutual support. These concepts have attracted much attention and there has been a movement internationally for system-restructuring in order to embrace the recovery philosophy. Scotland (Scottish Executive, 2006) and New Zealand (New Zealand Mental Health Commission, 2001) have identified core clinical competencies and system indicators for recovery. The United States have developed core concepts of recovery and identified fundamental values and principles (Substance Abuse & Mental Health Services Administration, n.d.). The Canadian government has identified the need for a recovery-oriented system reform, and has outlined a federal strategic implementation plan and a national mental health strategy (The Standing Senate Committee on Social Affairs, Science and Technology 2006). In 2002, the Provincial Forum of Mental Health Implementation Task Forces published a report calling for the recovery philosophy to be the foundation for change in Ontario’s mental health system. Locally, the CE LHIN will help deliver the mandate by improving access to mental health services, reducing stigma and discrimination, enhancing safety, and improving the effectiveness of services (CE LHIN, 2006). It is evident that the recovery philosophy has gained international acceptance and has become the prevailing philosophy for mental health care delivery. The values and principles of recovery will create a foundation for change, and will underpin clinical transformation at WMHC. The Shared Journey Project will improve clinical care and create

partnerships between clinicians and patients that inspire a sense of hope and empowerment, and ensure clinicians are providing meaningful involvement and choice for patients.

The second component of the Shared Journey Project will necessitate the adoption of IPC practices. In their review of the literature, Rice (2000) and Klein (2008) provide varying levels of evidence to support the implementation of interprofessional care. Despite the lack of strong empirical evidence demonstrating the effectiveness of IPC, there is an abundance of publications that support its implementation to enhance services. Evidently, the collaboration developed within IPC teams is correlated with enhanced clinical outcomes, continuity of care, decreased costs of providing care, improved job satisfaction, and the promotion of professional identity. Interprofessional care happens when teams comprised of various health care professionals engage in equal participation to aid health care decision making (Yeager, 2005). IPC occurs among and between healthcare providers, and the ultimate aim is to create empowering partnerships, teams, and organizations that are jointly responsible for services (McWilliam et al., 2003). HealthForceOntario, a provincial strategy to ensure high quality healthcare delivery, has recognized that IPC may compensate for some of the challenges faced by Ontario's healthcare system, as well as result in overall system improvement. On behalf of HealthForceOntario (2007), the Interprofessional Care Strategic Implementation Committee has endorsed IPC to increase access to care, improve outcomes for people with chronic diseases, reduce tension and conflict among caregivers, enhance use of clinical resources, aid the recruitment of caregivers, and decrease rates of staff turnover. The LHINs have been identified as enablers for IPC, and the CE LHIN is in the process of developing a strategic plan to implement an interdisciplinary team approach to care across agencies and across sectors in order to improve quality of care and to provide more efficient, effective healthcare delivery (CE LHIN, 2006).

Fundamentally, the recovery philosophy and IPC share many of the same basic concepts, which may facilitate their overall adoption into the workforce. Each require strong partnerships between the clinical team, the patient, family/caregivers, and the community; each require collaboration, participation, and effective communication; and each can provide enhanced quality of care and flexible services to meet the needs/goals of the patient. Recovery and IPC necessitate a patient-centred approach (Blickem & Priyadharshini, 2007; Schauer, Everett, & del Vecchio, 2007) which not only encourages patient participation and responsibility, but may help to reduce tension and conflict among clinicians as they engage in more meaningful, focused interactions. This will also impact patient safety as active engagement of all team members will help to reduce errors and protect the health and welfare of patients and staff at the Centre (Infante, 2006). At a system level, recovery principles have demonstrated improved clinical outcomes that will offer benefits to the patient, clinician, organization, and ultimately the healthcare system as a whole (Solomon & Stanhope, 2004). Although many articles pertaining to IPC discuss similar enhanced clinical outcomes, there is a lack of strong evidence to support these claims (Rice, 2000). The implementation of the recovery philosophy has resulted in better use of clinical resources and transitioning services, which will reduce costs and improve flow of patient care within and between organizations (Farkas et al., 2005). The literature indicates that IPC has a similar impact on patient flow and reduced clinical costs; however, these claims are not grounded in empirical research and offer limited or mixed support (Reid Ponte et al., 2007; Rice, 2000). Despite the lack of strong empirical support for IPC, there are many underlying similarities between the two philosophies that offer insight into the importance of collaboration and competence for organizational and system improvement. As a result, WMHC's strategic directive to embrace the recovery philosophy and IPC necessitates behaviour and value changes in frontline clinicians to support the practice of partnership on all levels: patient empowerment, teamwork and shared decision making (Schauer et al., 2007; McWilliam et al., 2003). This will translate into significant role changes and expectations as the workforce deviates from the traditional medical model hierarchy and adopts a more egalitarian philosophy. This change in practice is important for optimizing patient care; however, the significant shift in practice expectations also represents a barrier to successful implementation.

## Addressing Challenges to Implementation

It is anticipated that recovery and IPC components, values, and principles will help to guide WMHC's organizational transformation toward recovery-oriented services. As with any large scale change initiative, significant barriers exist. Challenges of implementing IPC are identified by Powell et al. (1999) and can also be applied to the adoption of the recovery philosophy as they share many of the same values and principles. Barriers are identified as (1) personal factors, (2) professional factors, and (3) organizational factors. The type of relationships formed with colleagues, the distribution of power between disciplines, and bureaucratic issues at an organizational level will impact the acceptance of recovery and IPC.

Communication, trust, competence, and confidence will have an impact on the way that clinicians interact with their patients and with each other. These personal factors and the concept of risk have important implications for recovery and IPC as it may be a significant barrier to embracing both philosophies. The recovery philosophy encourages risk and risk taking in order to promote a patient's personal growth and development. Patricia Deegan, an individual treated for schizophrenia, is an internationally renowned recovery advocate and calls all professionals to "...embrace the concept of the dignity of risk and the right to failure if they are to be supportive of us" (1996, p.97). This is contrary to the traditional treatment of individuals living with mental illness; historically the clinician was viewed as the "expert" and made decisions on behalf of the patient who was deemed incompetent as a result of their mental illness. Roberts & Wolfson (2004) discuss the concept of risk from the perspective of shifting from risk avoidance to risk-sharing in regard to medication practices, a contentious issue between the medical model and recovery approach. The medical model promotes compliance with medication as a life-long necessity to prevent symptoms and/or relapse. The recovery philosophy considers medication within the context of the patient experience, and advocates for shared decision making, choice and self-determination in regard to medication practices (Deegan & Drake, 2006). Allowing patients to make their own decisions and accepting the prospect of failure requires clinicians to provide unconditional support to individuals, and acknowledges that patients are entitled to make independent, informed choices. Roberts & Wolfson (2004) state "...risks can be taken within safe parameters and lessons learned from experience" (p.42). This approach will facilitate a partnership that unites the expertise of the clinician with the patient's experience of their illness, and negates issues of power and control. In a different context, the concept of risk threatens the successful adoption of IPC practices. Accountability issues have been raised as a concern in implementing IPC (Evettes, 1999). Bronstein (2003) offers further insight into regulation challenges of IPC as professionals share limited understanding of roles, expertise, and scope of practice which can result in tension, anxiety and conflict among care providers. IPC team members may also experience role confusion and harbor feelings of resentment when tasks or duties are shared among team members (McWilliam et al., 2003). This contributes to the reluctance to adopt IPC practices. Presently, Ontario does not allow for the flexibility required to foster interprofessional collaborative care as legislation is too rigid and focused on individual responsibility (Health Canada, 2007; Thornhill, Dault, & Clements, 2008). Consequently, clinicians who fear the potential liability and/or risks related to the negligence of colleagues will be reluctant to adopt a collaborative approach to care. As a result, individual values, skills, and perspectives will have a significant impact on the willingness to engage in change.

To illustrate challenges on a professional level, the adoption of the philosophy has in part been hampered by the tension between recovery and the medical model. Despite evidence from longitudinal research demonstrating that people can and do recover from long-term persistent mental illness (Harding, Brooks, Ashikaga, Strauss, & Breier, 1987; Harrison et al., 2001), the differences between the values and concepts of the medical model and recovery stand in significant opposition to one another. Numerous publications have debunked concerns and perceived limitations to the adoption of the recovery model, but reluctance to abandon the expert-driven model still exists (Davidson, O'Connell, Tondora, Styron, & Kangas, 2006; Mountain & Shah, 2008; Samele, Lawton-Smith, Warner & Mariathan, 2007). Similarly, the medical model remains a barrier to the implementation of interprofessional care. Locally, a recent Ontario Medical Association (OMA) Policy Paper on Interprofessional Care (Hanna, 2007) states that "physicians, having greater breadth of

training and larger scope of practice, should be the clinical lead in interprofessional teams” (p. 3), and further recommends that “Physicians should be compensated for their leadership and the indirect services they provide in interprofessional team settings” (p. 7). This type of professional elitism is apparent between all professional groups, as inflexibility, rigid role separation, tradition, and vested professional interest act as barriers to collaborative practice (Roberts & Priest, 1997). As a result of the tension created from entrenched power differentials, there is significant resistance to adopt a practice that calls for an inclusive approach.

At an organizational level, operational structure does not typically provide an optimal environment for collaboration or recovery-oriented care. Financial and budgetary decisions are often dependent on outcomes such as length of stay and readmission rates. Recovery-oriented services and measures require a shift in financial resources that support the enhancement of quality of life, self-empowerment, and hopefulness of patients (Sowers, 2005). These variables are much more difficult to define and measure as a result of their subjective nature. In order to embrace collaboration that supports both recovery and IPC, organizational structure must adopt a clear policy direction, performance criteria, and incentives that outline key determinants of collaboration yet allow for flexibility (Ginsburg & Tregunno, 2005). The importance of structure is reflected in effective leadership and commitment across all levels of the organization (Reide Ponte et al., 2007). At the heart of IPC, Ginsburg & Tregunno (2005) describe a type of shared leadership between frontline clinicians and management. This type of shared leadership can also be applied in the recovery context and extended to the patient, allowing individuals to take more of a leadership role when making decisions about their care. Evidently, creating a clinical infrastructure that fosters collaboration requires system changes and amendments to current policies and procedures to promote collaboration across all care providers.

Despite the many challenges on personal, professional, and organizational levels, recent attempts to bridge the gap between the recovery approach, IPC, and the medical model have begun. As a result of efforts to strengthen the recovery evidence base and establish the philosophy as a viable approach to care, new measures and outcomes are being generated and there is a movement to engage in quantitative research inquiries that formalize and operationalize recovery dimensions (Anthony, Rogers & Farkas, 2003). Attempts to find common ground between the two philosophical approaches have encouraged clinicians to connect symptoms with the specific meaning they have for the patient; to listen to individual patient stories and experiences instead of just taking a diagnostic history; and to reduce stigma and challenge clinicians’ assumptions about mental illness (Mountain & Shah, 2008). These developments are particularly relevant for WMHC. A significant challenge faced by the Centre is to abandon medical dominance and embrace a collaborative practice that addresses both the physical and mental health needs of individuals living with long-term, persistent mental illness. IPC models offer insight into the type of collaboration required to utilize effectively the clinical expertise of various disciplines to meet the client’s needs during their journey of recovery. Clearly, the redistribution of power and control, and the inclusive nature of recovery and IPC will result in a significant shift in values for all healthcare professionals as it will necessitate a change in the way they view their role, their patients, and their practice.

### Facilitating Change: Creating a Shift in Culture

Today’s healthcare system thinking has shifted from classic reductionism or top-down design, toward nonlinear dynamics or a complex systems theory (Burns, 2001; Suchman, 2001). This theory views the organization as a complex and adaptive system that continually interacts with several micro-systems thus evolving in response to multiple feedback loops (Plsek & Wilson, 2001). The complexity of implementing organizational change involves multiple variables that interact and impact each other (Sturmberg, 2007; Suchman, 2001). It is relatively easy to introduce new processes and procedures on a superficial level, but creating change that will impact ingrained values and beliefs is much more challenging and complex (Davies et al., 2000). Resistance to change in organizations is well documented, and many of the barriers to change have been identified in the literature. Senge et al. (1999) describe change as a disturbance in balance, and



states that individuals resist change to maintain status quo or comfort; others describe how change is frequently perceived as a loss (Folger & Skarlicki, 1999). Considering there are many theories that offer insight into behaviour change, WMHC's transformational change initiative must consider multiple factors that effect behaviour change.

In order to explain how behaviour change occurs among healthcare professionals, various theoretical perspectives have evolved. Grol & Grimshaw (2003) provide examples of how theoretical constructs translate to practice. For example, the cognitive theory offers an explanation of behaviour change in the context of receiving knowledge and information; adult learning theories attribute change to experience, reflection, and discussion with colleagues; behavioural theories contend that performance is shaped by feedback, incentives, modeling, and reinforcement; and organizational theories explain change within a system, process, and cultural context. Despite investigations that attempt to identify standardized strategies that change or modify clinician behaviour, specific knowledge translation tactics remain elusive (Perkins et al., 2007). Deane, Crowe, King, Kavanagh & Oades (2006) have investigated the failure of transfer of training related to recovery oriented practice, and found that despite policy implementation, support from management, and staff training, there were minimal behaviour changes in clinicians. In their 2006 publication, Crowe, Deane, Oades, Caputi & Morland discuss the friction between the recovery philosophy and the value system that differentiates recovery-oriented care from traditional care models; they conclude that staff attitude can be a barrier (or in some cases a facilitator) to adopting implementation. Staff attitude and perspectives are important considerations in developing strategic change initiatives as both represent the culture of the organization. They can also be applied when attempting to understand barriers to change at an individual, group, or systems level. To establish a change management process, it is apparent that a baseline measure of values, attitudes, and beliefs must be conducted.

A critical factor in any change management process is to determine the organizational culture and readiness for change (Jones & Redman, 2000). In describing the term organizational culture, Scott, Mannion, Davies, & Marshall (2003) offer the following description:

It denotes a wide range of social phenomena, including an organization's customary dress, language, behavior, beliefs, values, assumptions, symbols of status and authority, myths, ceremonies and rituals, and modes of deference and subversion; all of which help to define an organization's character and norms (p. 925)

A post divestment cultural assessment survey has indicated that the majority of employees at the WMHC exhibit significant concern about pay; lack of respectful treatment; need to improve patient focus; tension between union/management relations; lack of adequate staffing; decreased morale; and inadequate leadership (HayGroup, 2007). In order to devise a change management strategy additional workforce assessments were completed. These assessments confirm that the current environmental culture at WMHC resists change initiatives, that frontline staff engage in bullying tactics, that there is a lack of communication throughout the organization, and that employees take minimal ownership for initiatives and have a "why bother" attitude. (Deloitte, 2008). Many of the factors identified by HayGroup and Deloitte are not unique to the WMHC organizational culture and are well documented in the literature. Sovie (1993) describes dysfunctional hospital cultures as organizations that engage in turf battles, do not recognize staff accomplishments, have limited concern about employee satisfaction, and do not regularly measure quality of service. Perceived power imbalances, dissatisfaction, frustration, internal competition, organizational change, and changes in the composition of the work group are other variables that contribute to dysfunction in organizations (Liefoghe & Mackenzie Davey, 2001; Salin, 2003).

Many of the predominant themes that emerged from the cultural assessments completed at WMHC can be related to theoretical constructs of bullying. Bullying in healthcare is a significant issue resulting from organizational structure and power imbalances among/ between clinicians and/or management and has been identified as a key factor in shaping organizational culture (Bate, 2000). Absenteeism, high staff turnover,

decreased morale, loss in productivity, and a depersonalized organization, are behaviours that have been identified as indicators of workplace bullying specifically in healthcare (Hutchinson, Vickers, Jackson & Wilkes, 2006). Turney (2003) provides evidence to support both vertical and horizontal workplace bullying in the medical profession. She describes workplace bullying that occurs between professionals on the same level, and bullying caused by power imbalances created by status attributed to certain professions. Potentially, the shifting power among and between clinicians working within an IPC team could initially heighten tensions and increase animosity among the staff at WMHC, an important factor to consider when developing a strategic implementation plan. Hutchinson et al. (2006) argue that bullying can become normalized within an organization and is strategically used to maintain order. This concept needs to be considered when implementing change initiatives as the “push back” from staff may result in rejection of the recovery and IPC philosophies as it represents such a drastic change from current practice. Many of the behaviours and values currently held by staff are not reflective of those required for the successful adoption of the values inherent in the recovery philosophy and IPC. Clearly, the cultural context at WMHC will have a significant impact on the successful implementation of The Shared Journey project. As a result of organizational culture similarities, it is anticipated that the Baycrest strategy will provide insight into successful techniques that bring about significant organizational culture change at WMHC.

### Organizational Readiness and Implementation Strategies

As discussed earlier, adoption of the recovery philosophy extends well beyond written policy statements. Similar to any large scale change initiative, preparation and process are critical success factors for implementing the recovery philosophy and IPC initiatives. Organizational change literature has established that workplace culture, leadership and motivation are critical elements for any change process. However recent evidence has also correlated the following variables with successful change initiatives: the duration of the project and benchmarking for success, the integrity of team members, staff and leadership commitment, and the amount of effort the change demands from staff (Sirkin, Keenan, & Jackson, 2006). This emphasizes the importance of planning in order to embark on a successful organizational change initiative. Grol & Grimshaw (2003) recommend proper preparation to engage in a change process involving patient care. Key steps include involving the relevant people; developing a proposal for change that is evidence based, and feasible; studying the main difficulties in achieving the change; and selecting a set of strategies and measures at different levels (individual, team, and organization) that are linked to identified problems. The importance of defining indicators for measurement of success and monitor progress continuously or at regular intervals is emphasized.

Organizational change management strategies are critical considerations; however, approaches specifically related to the recovery and IPC systems issues must also be considered. Farkas, Ashcroft, & Anthony (2008) offer specific strategies to facilitate the introduction of the recovery philosophy within organizations. They recommend enabling a culture of recovery through the implementation of values based practice, obtaining commitment from staff and administrators, and building capacity through staff skills training and knowledge development. Anthony & Ashcroft (2008) offer strategies for overcoming resistance to the adoption of recovery, including encouraging all clinicians to participate in planning for recovery, and integrating trained peer support workers to work alongside staff to represent examples of hope and recovery. New developments are emerging to address the challenges related to transfer of training and include an emphasis on values-based interventions for clinicians (Crowe, Couley, Diaz, & Humphries, 2007; Oades, Crowe, & Deane, 2007). Outcomes from their preliminary research should be interpreted with caution as the evaluative tools used by Crowe et al. (2006) are subject to sources of error, including bias in responding and measurement bias as clinicians are likely to provide socially desirable answers and may not have an accurate perception of the recovery-oriented services they provide. The psychometrics of each proposed measure, the Collaborative Recovery Knowledge Scale and the Staff Attitudes to Recovery Scale, are compared with the Recovery Attitudes Questionnaire (RAQ-7). However, the RAQ-7 does not establish strong reliability as Chronbach's alpha coefficients ranged from .64 to .70, the low end of acceptable limits for research (Streiner & Norman,

2003). Each measure establishes face and content validity but fails to report on longitudinal validity, a key indicator that changes in behaviour have been adapted over time. This emerging research is encouraging; however, it reinforces the need for stronger evaluative measurement tools to demonstrate transfer of training. Clearly, disseminating the best methods to implement change, monitor, and evaluate effectiveness is important for the success of the Shared Journey Project.

Systems structures must be adapted to support a new approach to collaboration and reinforce change efforts. The new processes may include implementing new policies, procedures, and strategies that recognize and reward partnership efforts, and performance appraisals that recognize partnership-building efforts (McWilliam et al, 2003). Strategies for implementing IPC and expanding collaboration within WMHC include: creating opportunity for interprofessional education, partnerships, and relationship building (Bronstein, 2003); developing routine processes for feedback, negotiation, and conflict management; and providing opportunities for informal relationship building, encouraging a spirit of fun, and inviting participation (Gerardi & Fontaine, 2007). Creating and sustaining a change in practice will require strong leadership and a highly structured, organized approach to implementation (Barrier, Anson, Ording, & Rogers, 2002). Clearly, implementation strategies must also be sensitive to the tensions between recovery and traditional pathological models if change efforts are to be successful. The shared values and underlying philosophical approach to recovery and IPC will act as enablers in their implementation; each approach reinforces the values and beliefs of the other.

### Implications for Rehabilitation Practitioners

The evolutionary nature of healthcare will continue to have a significant impact on the rehabilitation practitioner. In Ontario, healthcare system changes coupled with mental health reform will drastically change the demands and expectations placed on clinicians. With the implementation of recovery and IPC the rehabilitation practitioner will engage in a collaborative process with team members and patients within a system that promotes and encourages all health disciplines to share their expertise. Interactions with patients will transform from an “expert” clinician approach to a partnership that includes the patient as an equal participant in information sharing and decision making. The rehabilitation practitioner will adapt to new organizational structures, changes to professional autonomy, and new approaches to teamwork (Ginsburg & Tregunno, 2005). In order to engage effectively in IPC, the rehabilitation practitioner must understand their full scope of practice and be competent in their skill set (McCallin, 2006). The emphasis on teamwork and team collaboration will require interpersonal skills, effective communication, and ongoing reflective practice (Barry, 2007). The rehabilitation practitioner will engage in shared leadership practices with their colleagues, and extend shared leadership with their patients. Assessments and interventions will be conducted from a strengths-based perspective ensuring client centredness and effective use of clients’ personal resources. Interventions will need to be conveyed in a manner that is easily understandable for patients and colleagues to ensure continuity of care and follow-through. Documentation will encompass client’s strengths and resources instead of focusing on symptoms and pathology. Clinical records will also become a forum for all healthcare providers to “contribute their personal and professional knowledge of the client on a regular basis” and become “...an evolving collection of information about the client’s holistic health status” (McWilliam et al., 2003, p.370). Patient care will be provided by all disciplines working from, and contributing to, the same plan of care. To support this type of collaboration from a theoretical perspective, new models of IPC are being developed (Bronstein, 2003; McWilliam et al., 2003). The rehabilitation practitioner must show “respect for other disciplines, a willingness to share information and listen to others’ opinions, and tolerate disagreement” (Reid Ponte et al., 2007). As a result recovery and IPC will support the LHINs mandate and mental health reform in Ontario, while enhancing the role of the rehabilitation practitioner by encouraging true collaboration.

Not only will clinical practice be transformed, but the way that clinicians study and train will also change. New approaches to interprofessional education have been incorporated into academic training, and initiatives

for continuing IPC education have increased in recent years (Barr, 1998; Roberts & Priest, 1997). A review conducted by the Cochrane Collaboration has found a lack of strong evidence supporting the effectiveness of current methods of inter-professional education; therefore, new methods of teaching and instruction coupled with more rigorous studies will also have an impact on the rehabilitation practitioner (Zwarenstein et al., 2007). Collaboration among professionals will be reflected in research initiatives as the integration of different disciplinary perspectives will add richness and depth to our inquiries (McCallin, 2006). Recovery research will bring professionals together in an approach that expands traditional notions of services, outcome measures, and standards of evidence (Solomon & Stanhope, 2004). Best practice guidelines will be enhanced as contributions across disciplines will promote mutual understanding and better partnering (McWilliam et al., 2003).

In order to promote IPC, Health Canada (2007) has called for legislative reform to address the current practice of assessing negligence on the level of the individual, and to develop a framework to better support IPC and collaboration. This will provide opportunity for rehabilitation practitioners to participate in a process that will restructure regulatory policies and legislation, thus shaping the future of their practice. As a result of recovery and IPC, the rehabilitation practitioner will have to engage in reflective practice and maintain ongoing assessment of values, both personal and professional, in order to provide optimal care. The rehabilitation practitioner will experience large-scale system changes and will have opportunity to engage in a more efficient and effective process when delivering healthcare to Ontarians.

## Conclusion

Undoubtedly, we live in an age of continuous quality improvement and healthcare system advancement. Ontario's initiative to strengthen the delivery of mental health services can employ the shared values and philosophies of recovery and IPC to provide effective, efficient services in the future. In order to improve frontline clinical care, WMHC will need to address organizational culture issues and engage in its own recovery process prior to facilitating the recovery of individual patients. A successful change initiative must assess workforce readiness to embrace the recovery philosophy, a comprehensive change management strategy, and a long-term sustainability plan that will act as a catalyst for system improvement. Future research is needed to better understand barriers when translating knowledge from policies and procedures to behavioural changes in the frontline staff. Strategic initiatives that help to ensure healthcare organizations are ready and able to sustain changes must also be developed. The shared values and beliefs introduced by recovery and IPC will facilitate the development of newer ways of thinking, and may contribute to yet another paradigm shift in our ongoing efforts for system improvement in Ontario.

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# Healing Of The Soul: The Role Of Spirituality In Recovery From Mental Illness

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## Abstract:

**Topic.** Experience with deinstitutionalisation and the consumer movement has supported the claim that recovery from mental illness, in the sense of being able to live a rewarding life, is possible. However, the benefits of a holistic approach to recovery, including the spiritual, have been largely ignored.

**Methods.** The study is based on a phenomenological qualitative methodology. It explores what recovery means to six individuals recovering from a mental illness. Three men and three women were interviewed three times each, with the information transcribed and analysed using Colaizzi's (1973) framework.

**Findings.** The participants identified holistic treatment strategies as essential to the recovery process. For most, the spiritual aspects of recovery play a large part in a very personal and unique transformation.

**Conclusions.** Mental health workers need to be aware that spirituality can be a significant component in recovery from mental illness and be open to exploring spiritual issues with clients.

**Keywords:** Mental health; recovery; spirituality.

## Introduction

One in five people in Australia suffers serious mental illness at some stage in life (Australian Bureau of Statistics 2001) and it has been estimated that during this century depression will account for more hospital beds than any other illness. A medical diagnosis of mental illness often results in depersonalised labeling and furthers stigmatisation by society. The 21st century has seen an insurgence in the field of mental health care with the consumer movement, involving not only consumers but also sympathetic workers, pushing the boundaries of awareness and understanding of the recovery process. The term 'recovery' does not necessarily correlate with the word 'cure'. Patricia Deegan, (cited in Watkins, 1996:109) states that,

Our recovery is marked by an ever-deepening acceptance of our limitations. But now, rather than being an occasion for despair, we find that our personal limitations are the ground from which spring our unique possibilities. This is the paradox of recovery, i.e. that in accepting what we cannot do or be we begin to discover who we can be and what we can do.

Researchers are taking great strides towards understanding recovery, but there still remains the need to further investigate and define this concept (Yanos, Primavera et al. 2001). Gene Deegan (2003), for example, more specifically talks about recovery as a unique and complex path with recurring themes such as reclaiming hope and a positive self identity, not labeling oneself, managing symptoms, having good support systems and finding meaning and purpose in life.

Although post-war studies influenced the mental health movement by generating interest in community care, it was the social and political 'revolution' of the 1960s that brought about a shift from treatment in large, bureaucratic, and hierarchical institutions, to community care programs. The change was due in part to the use of psychotherapy, but more to the advent of greatly improved anti-psychotic medication. During this period, the notion of anti-psychiatry emerged which, according to Goffman (1961), questioned the existence of institutions as a place and means of treatment for the mentally ill and instead looked in depth at the actual experience of psychosis. Szasz (1987) challenged mental illness as not a verifiable disease but simply legal fiction, a euphemism for problems in day-to-day living. It was argued that institutionalisation, aside from the high cost involved, also exacerbated such negative symptoms as social withdrawal, poverty of speech and underactivity as well as loss of dignity, self-esteem and self-confidence (Watkins 1996). The antipsychiatrists were sympathetic to the patient's suffering and believed that psychosis, if left to evolve, could heal and transform the individual into an enlightened soul. This belief had its limitations, however, and for many suffering mental illness, medication was the only relief from distressing symptoms and recovery, by any definition, was not seen as part of their future.

### Mental Illness and Scientific Understanding

The Medieval Christian Church, which promoted a fearful and dogmatic belief in the power of God and the wrath towards those who sin, became less influential in the era of the domination of intellectual thought. New

theories based on reason and the material world became the predominant perspective for most philosophers. The Age of Enlightenment, during the eighteenth century, saw the rise of empiricism, the foundation of a new scientific and technological age (Kramnick 1995).

The central dogma of the scientific world was Naturalism. This belief, that there is no “God” or supernatural causes, enabled scientists to explain the happenings of the Universe as natural. With this theory there was no room for mystical or religious explanations of any kind. Fundamentally it was believed that everything had a natural cause, nothing was left to chance. Furthermore, everything could be reduced to smaller parts and man and the universe worked like a machine. Descartes believed, for example, that the body was separate from the mind, which was the seat of the soul (Hart 1985). Matter was the only reality and whatever existed was physical. Knowledge was limited to observable evidence and only sense experience could be regarded as the truth. Scientists were therefore regarded as objective observers who could verify facts and thus understand reality. Although empiricism can lead to an explanation of the universe, it leaves no room for spiritual experiences that are often invisible and private and therefore cannot be empirically observed or replicated.

The influence of these scientific beliefs on medicine has generally remained steadfast over the last hundred years with the biomedical model dominating the health care system. Within the field of psychiatry, the medical model encourages the belief that a physiological problem, that is, a chemical imbalance in the brain, can explain why mental illness occurs. As a result, mental illness can be diagnosed according to certain symptoms and the appropriate medication prescribed (Turner, 1987: 214).

Both Western and Eastern world religions oppose the reductionist belief systems of the scientific world. These religions not only believe that there is a Supreme Being or Beings, but they also hold that we require this spiritual belief for our optimum fulfillment as human beings. Some writers would now talk about spirituality more broadly. Dudley (2006:60) says “Spirituality, recognized as central to mental health from ancient times, has remained so in many non-Western and indigenous traditions, while this knowledge has been substantially lost in the West in recent centuries. Modern Western psychiatry is a secular discipline that applies scientific methodologies to clinical questions”. Whilst relatively few psychologists or psychiatrists have integrated a spiritual perspective into their work, Rumbold (2002) suggests that “Spirituality is an emerging theme in the professional and academic literatures of business, education, and healthcare, as well as in the curricula of training institutions”.

Certainly, there has been a continuing increase in interest in the place of spirituality in many professions including education (Fisher, 2007), nursing (Johns, 2005), pastoral care (Lartey, 2003) and social work (Gale et al, 2006). Speck (2005) points out that one of the complexities of working in this are it the many definitions of spirituality used. Tacey, (2003:38) talks about spirituality as the new umbrella term which “refers to our relationship with the sacredness of life, nature and the universe, and this relationship is no longer felt to be confined to formal devotional practice or to institutional places of workshop”. He sees religion as part of this broad spiritual umbrella: some people continue to participate in religious traditions using particular symbols and rituals that are meaningful for them. For others, Swinton (2001:20), says “Spirituality is the outward expression of the inner workings of the human spirit.....intrapersonal in that it refers to the quest for inner connectivity...interpersonal in that it refers to the relationships between people and within communities...transpersonal in so far as it reaches beyond self and others into the transcendent realms of experience”. Spirituality in this sense might be expressed through meditation or prayer, as part of a religious tradition, but equally through valuing the spiritual in daily life through experiencing nature or music, for example. Bouma (2005:xiv) suggests that what has changed is “the religious and spiritual have moved out from the control of both the state and such formal organisations as the church. No longer strictly controlled, the forms taken by the religious and spiritual become increasingly varied.”

The aim of this paper is to discuss the role of spirituality in the process of recovery from mental illness from the perspective of consumers who have suffered and recovered from mental illness. A broad understanding of spirituality was used which allowed the participants to define spirituality for themselves. It demonstrates that

recovery from mental illness often incorporates a strong spiritual component and argues that mental health workers who ignore this are working within a limited framework that discourages an holistic approach to management of mental illness. It also demonstrates that what spirituality is will vary considerably for each individual: for some including connection to a religious tradition for others a variety of expressions of the human spirit.

## Methodology

The study was based on a qualitative phenomenological research design. Through the exploration of human feelings, attitudes and experiences, as described by a small number of participants, this study was an investigative journey that reached into the personal realm of mental illness and discovered a deeper understanding of holistic well being and overall recovery.

### The Participants

Six participants, (three men and three women), were selected for their extensive experience with mental illness and their recovery process. They were contacted through their case managers, who made the details of the project available to appropriate clients, who could then notify the case manager if they wished to participate. Three suffered from bi-polar disorder, one from schizophrenia, one from atypical psychosis and one from a varying number of different diagnoses. Each participant had been involved with psychiatric services over a period of a decade or longer. All six participants had, with varying degrees of success, traversed the hazardous highs and lows of mental illness on their very personal journey of recovery.

Their ages ranged from 31 to 58 years and they resided in a large regional area in Australia. <It should be noted that three participants relapsed during the duration of the study and were hospitalized for short lengths of time. Due to this, participants did not complete the third and final round of interviews until they felt emotionally stable and able to cope with requirements of the study. Each was asked whether they wanted to continue with the interviews and all were positive. The relapse was not an unusual situation given the unpredictable nature of mental illness. The participants agreed, however, that although they suffered some setback, their overall recovery was still positive and they were moving forward with their lives.

### Data Collection

The use of semi-structured, in-depth interviews enabled the collection of rich, perceptive and sensitive data. Each participant was interviewed three times, each interview focusing on a different aspect of recovery and culminating in a subjective description of their personal understanding of achieving recovery from mental illness. Having three interviews allowed the participants time to reflect on previous interviews and to deepen and extend their responses if they so wished. The interviews were conducted in the participant's own home, in the interviewer's home or in a private office at the university and lasted for one to two hours.

### Data Analysis

Interviews were transcribed verbatim and analysed according to the procedural steps described by Colaizzi (1978). Data analysis began with the scrutiny of the descriptions contained in the transcribed data. Significant statements, relevant to the phenomenon, were extracted from the main body of the data. This gathering of statements was the first requirement of the analysis procedure described by Colaizzi. These were then grouped into aggregate areas of meaning and highlighted as such. Each meaning was further reflected upon and a group of themes emerged. An exhaustive description of the investigated topic was extracted from the results so far, and the fundamental structure of recovery was articulated. Once this analysis was complete, the six interviewees were presented with the themes for further discussion and any new information was worked into the final product of the research. <A concept map assisted in visualizing and developing the themes that resulted from the research. By working on an intuitive level and continually checking, the data was pulled apart and scrutinized to find the meaning behind the facts. This interrogation of the data started by generalizing the facts into meanings then by working down towards a specific theme for each group of

meanings, a definition of the phenomenon, in this case ‘recovery’, was elicited.

### Reliability, Validity and Limitations of the Research Method

Prior to the interview, a practising psychiatrist was asked to check the structure of the interviews and make recommendations that would enhance the overall process of the research. Before the third interview took place, the general themes that had emerged in prior interviews were checked with the interviewees and with research supervisors. The final round of interviews included questions based on the findings so far and the emergent themes. These were used to validate the previously obtained data by comparing the interviewees’ final understanding with their previously expressed perceptions. < Due to the nature of the methodology used, this research is limited in its application to the general community. This research is qualitative rather than quantitative and therefore reliability and validity are demonstrated through the richness of the data and the processes used to increase trustworthiness.

## Findings

Participants explored a number of themes, including the journey of recovery, physical and material losses and gains, relationships with family, friends and health workers and self-help strategies for recovery. This paper reports on one of these themes – the reflection of the participants on the role of spirituality in their recovery process.

### Personal concepts of spirituality

All participants reported a degree of faith and a belief in a higher or Supreme Being, most often recognised as God. Each discussed their own personal concept of spirituality and described God as all loving, powerful, forgiving and compassionate. Participants ranged in their belief from practising and non-practising Christianity to a non-religious but personal spirituality. In all cases this spirituality was perceived as a positive aspect of their current life, even though spiritual experiences related to their religious upbringing were, for the most part, negative. Some even held that prior religious experiences were at least partly responsible for their mental illness. These views were in clear contrast with their current understanding of, and affinity with, their spirituality. Every participant agreed that they had developed a self-affirming, significant personal belief in spirituality that provided hope and a positive outcome from their suffering. Some attributed their recovery to heightened spiritual awareness:

In the second psychosis I actually gained through the help of my father...and his beliefs, I actually gained a sort of private spiritual belief of my own.

It’s very strong [spiritual awareness]...I guess I could even say that without that I probably would still be quite unwell.

### Relationship to religious experience

Several participants had had previous negative experience of religion, particularly in relation to making judgements about what behaviour was seen as immoral or leading to ‘guilt and sin’. Two felt their religion had played a part in their illness.

However, unlike their earlier experiences with religion, participants regarded their spiritual beliefs as now being free from guilt, shame, sin, judgment, and the church:

I sort of gained this belief of a higher being as being God, even if it was a sort of a light in the sky as appeared, but someone up there...space, cosmos...sort of looking out for us and who loved us as his children but there wasn’t a guilt thing and it wasn’t a church thing, it was just a belief of a higher being.

Closely linked with the idea of spirituality was the notion of the soul and its relationship with mental illness. Some described the soul as an earthly connection; the body being the tool through which soul and spirit were connected. One participant explained:

... your body's an earthly sort of a tool and that's your earthly connection to the soul... your body's your connection to the earth as an animal or a human being or a natural phenomenon...the body and soul are fairly integrated into the one being and so rather than being sort of separate, especially on earth anyway.

Another described it similarly:

I think the soul is more of your carnal nature, like your earthly sort of nature.

Other participants talked about the soul as being a measure of goodness, the very being or inner self and the emotional connection to the spiritual side of life:

It's something within...something that can be if the person wants to be conscious of it, develop it and do good with it.

◇In relation to mental illness, participants saw the soul as being damaged by the emotional turmoil that accompanies psychosis. They felt that the soul is closely linked with spirit, mind and body and those who experience its pain when damaged understand it to be the very essence of being. However, participants also described mental illness as a learning process from which they emerge a better person. They had attained a 'good' soul through psychological and spiritual healing and, as a result, had developed a strengthened understanding of themselves and others.

### Spirituality and developing sense of recovery

After having experienced the acute stages of their illness, participants often began the journey of recovery with renewed hope and determination for a brighter future. During this period, they discovered new levels of compassion, understanding and empathy and were able to use it to benefit others who suffered similarly. Participants talked about their true personality or self as emerging from the ruins of their mental illness; however, as one participant put it, "it came at a price":

I have grown as a person...I am a more compassionate person, a more understanding person...but without sounding too bitter and twisted...my God it came at a price...it's gonna be hanging over me until the day I die.

Perhaps the real transformation and healing of the soul occurs with the belief that life ultimately turns out for the better and hope and happiness are achievable regardless of the past. This was expressed by one participant who said:

My character now gives hope to others, hope for them to start to create a vision and purpose and a quality of life...sometimes I pinch myself and think how come I'm so happy? ... I'm grateful...everyday I thank God that I'm alive.

Perhaps the most positive aspect of spiritual awareness was that, during the dark hours of mental illness, for those participants with belief in a higher power, felt given the necessary hope that they could come through the suffering and achieve recovery:

It has helped me through just having that spiritual belief in God, mainly like God as a really loving, caring father, that's helped me get through some of my episodes of mania particularly or depression.



I find that at my lowest points during an illness...I still have that sense that there's some higher power that's going to get me through it and I still bring that a bit into recovery.

For these participants, the hope that a better quality of life exists and that people suffering mental illness can achieve this, seems linked with a positive belief system and an ever increasing spiritual awareness.

### What supported spirituality

Various creative and recreational strategies provided spiritual components that participants identified as being important to recovery. For some, this was being in touch with nature:

I think it's being in touch (with nature), I mean there's never a day goes by without I'm sort of struck by the beauty of the land and that sort of feeling and oneness.

◊ Quiet time when I'm walking by myself...the nature thing, that's why I like living here, the nature thing helps. ◊ One participant found singing at church to be uplifting and peaceful:

Well now I attend church and I find I am singing at the church now and finding the words in those songs are quite uplifting, so when I'm practising I find that that sort of gives me that bit of peace.

◊ An important practical aspect of every participant's faith was the act of prayer or meditation which was used to express gratitude and to make supplication on behalf of self or others. One participant described use of praying and the scriptures to help relieve them of symptoms and prevent the return to old habits: I don't have that restlessness anymore, it gives me a peace.

## Discussion

For most participants in this study, the experience of religion in their upbringing had been, overall, a negative one. The pain, guilt and oppression caused by some organized religions can actually deepen and complicate the need for recovery (Fallot, 1998). Instead of providing spiritual growth and expression, they can simply be repressive and limiting in their understanding and outlook on life (Fry, 1998; O'Reilly 2004). ◊ For some participants their experience led to a preoccupation or obsession with their beliefs that they felt may have ultimately caused delusional thoughts and irrational behavior (Sullivan, 1998). There is some debate in the literature surrounding the possibility that some individuals may suffer a form of spiritual distress rather than the mental illness with which they are diagnosed. The person may question their religious faith, resulting in spiritual pain, alienation, anxiety, guilt, anger, loss and despair. Spiritual crisis may be similar to an existential crisis where the belief and value system of an individual are questioned (Thompson, 2002).

Although participants had experienced the pain, guilt and shame of dogmatic religious belief, they also came to understand a newfound positive spiritual awareness that transcended the negative impact of mental illness. "It is not necessary to hold formal religious beliefs or engage in religious practices, or belong to an established faith tradition to experience the spiritual dimension (Culliford and Powell, 2005:1). Spirituality was, to the participants, a source of hope, inspiration, love, joy, courage, comfort and guiding values or a moral code by which to live a complete and meaningful life; it also allowed them to ascribe meaning to their experience of mental illness. Galanter (1997) defines spirituality as a search for existential or transcendent meaning. Participants believed that the occurrence of a mental illness has a reason and poses a lesson in life, allows belief in a higher being and influences the way in which recovery is approached. The concept of soul was important to participants although they suggested it is difficult, yet important, to understand a definition of soul, particularly in practical terms. It can be explained as that which evokes thought, memory, emotion, desire and action or simply self-consciousness or personal identity. Participants felt that the soul was related to personal qualities such as compassion, understanding and insight, and that life experience such as mental illness, was a learning process from which one emerged a better person. The soul may be damaged when

feelings are disregarded and important truths ignored, leaving a trail of pathological problems that are eventually vented through the symptoms of mental illness (Tacey, 2006). A soulful person is perhaps in touch with their feelings in a genuine day-to-day reality (Moore, 1992). Thus healing of the soul is directly related to recovery and ongoing mental health.

The process of healing the soul eventually occurred when participants took responsibility for their illness and began to understand the depth and reasons for their despair. “Some view it as a journey forward; the emerging self is being both discovered and created along the way, incorporating many struggles as well as achievements in its composition” (Fallot, 1998: 41).

It is suggested by some authors that life with all its hardships, is simply a means of developing the soul, and that through these experiences we grow mentally and emotionally. Barnum (1996: 66) talks about individual life on earth:

“It is certainly interesting to contemplate whether, if all its traumas and tragedies were removed, earth would be an easier, but less efficient, learning environment for soul growth”.

Participants in this study agreed that through the experience of mental illness they were transformed into more compassionate, caring and soulful beings. On the one hand mental illness can be disruptive, damaging and disabling, whilst on the other it can be purposeful, non-judgmental and mindful. Mental illness can teach people to live in the present, accept life’s challenges with dignity and maturity, and grow through hardship. Participants agreed that it teaches people not to take their mental health, happiness or life for granted. Above all it teaches individuals that life is all about how you think, feel and react to stressful situations and that with regular positive affirmations and an optimistic yet realistic outlook on life, circumstances can improve and life be worth living.

In the opinion of the participants, spirituality had a direct influence and positive impact on recovery from mental illness, giving them a sense of peace, fulfillment, value and particularly hope similar to that described by Thompson (2002). They suggested that therapeutic relationships between the patient and mental health practitioner can aid recovery or healing of the soul through a spiritual connection.

The attributes of spiritual relationships nourish the core of one’s being, which is the inner self or soul. Spiritual relationships can be a source of love and foster the characteristics of inner strength, peace, a sense of meaning and purpose, self- reflection and interconnectedness (Fry, 1997: 30).

Where mental health workers do provide spiritual care, it was the quality of interpersonal care such as the expression of love and compassion towards patients that mattered most (Greasley et al 2001). For example, the Israeli Psychiatric Nursing Program which is based on relapse, recovery and rehabilitation includes addressing the patient’s environmental factors, spiritual attitudes and behaviours and interpersonal relationships (Roe et al, 2004). However, this aspect of recovery is rarely addressed by mental health workers. In fact, the limits imposed on health care through the materialistic, mechanistic viewpoints of Western medicine and culture, have resulted in an increasing number of people turning their interest towards Eastern medicine and mysticism to gain a deeper understanding of life and an holistic belief in the interconnectedness of the mind, body and spirit (Miller, 1990). Ideally, participants suggested they would be able to explore these issues with their workers.

## Conclusion

Spirituality was described by participants in the reported study as providing strength through adversity, a

moral code by which to live, and the desire to fill unhealthy voids with positive self-love and a new personal concept. Personal faith also provided hope for the future and strength to get through the day. It helped resolve fear and anger and promoted forgiveness. From the results of this study, it may be inferred that participants consider a personal concept of spirituality is indeed important to recovery: gaining and maintaining mental health and a more positive lifestyle. The message for workers in the mental health system is that a failure to acknowledge spiritual issues in assisting clients to manage their mental illness may impact negatively on the clients' recovery.

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# The Validity of Occupational Performance Measurement in Psychosocial Occupational Therapy: A Meta-Analysis using the Validity Generalization Method

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## Abstract

The purpose of this study was to determine an estimate of the mean validity and generalizability from research to clinical settings of occupational performance measurement scores through a meta-analysis of findings from 19 studies. We used the validity generalization (VG) method developed by Hunter and Schmidt (2004). Our analysis indicated that the mean weighted validity coefficients were small according to interpretation guidelines outlined by Cohen (1988). Scores based on self-report assessments had the highest mean validity. When variance of the coefficients was corrected for attenuation by sampling error and variability of the test criterion measurement reliability, less than 75% (suggested by Hunter and Schmidt to be the decision rule) was explained. This suggested that the validity of the instruments investigated in the 19 studies could not be transferred from research to clinical settings without need for further validation. Further meta-analysis is indicated for more definite conclusions to be reached.

**Key Words:** Occupational Performance, Assessment, Validity

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## Introduction

In recent times, evidence-based practice has been advocated as a way of providing effective and efficient occupational therapy services (American Occupational Therapy Foundation [AOTF], 2007; Canadian Association of Occupational Therapists [CAOT], 2007; Coster, Gillette, Law et al., 2004; Law, Baum, &

Dunn, 2005). The most preferred type of evidence in medical disciplines is that derived from a meta-analysis of randomized controlled trials (Coster et al.; Depoy & Gitlin, 2005; Trombly & Ma, 2002). This is because a synthesis of research decreases the demand on therapists to retrieve and evaluate individual studies (Bennet & Townsend, 2006).

Polatajko (2006) suggested that there was a lack of enough research evidence available for synthesis in meta-analysis to support occupational therapy interventions. She argued that for that reason, there was not enough data to support evidence-based practice in occupational therapy. This could be due to limited research history and infrastructure in the profession (Ilott 2004). Before enough evidence can be accumulated for summary and synthesis in order to support practice, data have to be adduced using valid and reliable research instruments. Therefore, the first concern should be whether we have valid instruments to produce needed evidence.

In this paper, it is argued that evidence relevant to occupational therapy must be related to occupational performance, as defined by occupational therapists and occupational scientists. Therefore, the issue at hand is whether or not we have valid instruments to measure occupational performance. Having such instruments would provide a starting point for accumulation of the appropriate type of evidence to support evidence-based occupational therapy practice.

The purpose of this study was to investigate: (1) the robustness of mean validity coefficients of various types of occupational performance measurement scores after correction for sampling error and variability of the test criterion measurement reliability; and (2) whether the validity of the occupational performance scores could be generalized from research to clinical settings. Following were the specific questions guiding this inquiry: (1) What were the mean weighted validity coefficients of the various types of occupational performance measurement scores after correction for sampling error and variability in test criterion reliabilities (by test criterion was meant the occupational performance indicators that were observed during measurement)? (2) Could the validity coefficients of occupational performance scores be generalized from research to clinical settings without need for further validation? In other words, if a therapist chose an occupational performance measurement instrument with documented validity, could it be assumed that such validity would hold in the clinical setting where he/she intended to use the instrument without need for further validation research? Answering the above questions would give the therapist confidence in defending h/her choice of occupational performance assessment instruments to clients, payers for occupational therapy services, the public, etc.

## Research Methods

The Validity generalization (VG) method was developed by Schmidt and Hunter (1977) and recently updated by Hunter and Schmidt (2004). It is a type of meta-analysis aimed at determining the overall validity of measurement scores for a given phenomenon, as well as whether such validity can be generalized from the research setting to other situations. This type of study tests the situation-specificity hypothesis (Callender & Osburn, 1980; Hunter & Schmidt, 2004; Pearlman, Schmidt, & Hunter 1980; Schmidt & Raju, 2007; Schmidt, Law, Hunter et al., 1993; Schmidt & Hunter 1977). The hypothesis, which was originally proposed by Schmidt and Hunter, was re-stated for the purpose of this study as follows: Occupational performance scores observed in assessments vary from situation to situation due to local modifiers [also known as “random effects” (Brannick & Hall, 2001, p. 1)]. Therefore, they cannot be generalized to situations other than where the validation study was conducted without requiring further research.

According to Schmidt and Hunter (1977), the situation-specificity hypothesis was in the past considered to be self-evident in personnel psychology (the field for which VG procedures were originally developed). It originated from the empirical observation that “considerable variability is observed from study to study in raw validity coefficients even when jobs (types of occupations in our study) and tests studied appear to be similar or essentially identical...” (Pearlman, Schmidt, & Hunter, 1980, p. 373). This meant that the validity of personnel selection methods could not be assumed for practical use even though past studies had indicated



that they were valid. It also meant that general principles about personnel selection could not be developed because, “the inability to generalize validities makes it impossible to develop the general principles and theories that are necessary to take the field (personnel psychology) beyond a mere technology to the status of a science” (p. 374).

The same can be said of occupational performance. It can be argued that even when occupational performance measurement instruments have been proven valid, their validity only pertains to the research setting. A therapist cannot assume that such instruments are valid in a variety of clinical situations. The assumption that validity cannot be generalized would mean that general principles about occupational performance measurement cannot be developed. In order for therapists to have complete confidence in the validity of their occupational performance instruments, and in order to embark on the process of developing general principles about occupational performance measurement, the situation-specificity hypothesis of occupational performance measurement has to be proven null, hence, the need for VG research.

In general, the VG method used in this study consisted of the following steps: 1) computation of an estimate of observed variance of occupational performance score validity coefficients for studies included in the analysis; 2) computation of an estimate of variance of occupational performance score validity coefficients attributable to statistical artifacts such as sampling error, differences in criterion reliability, differences in test reliability, reliability criterion contamination, computational and typographical errors, range restriction, etc. In the present study, due to limited information (such as lack of: independent variable reliability coefficients; range restriction data; etc.) provided in the studies that constituted our sample, we could not do a complete meta-analysis. Instead, we used Hunter and Schmidt’s (2004) “bare-bones” (p. 134) procedures to correct observed variability for variance due to differences among studies in sampling error and variability in test criterion reliability; 3) subtraction of variance due to statistical artifacts from observed variance; 4) division of the variance due to artifacts by observed variance; 5) Using the 75% decision rule suggested by Schmidt and Hunter (1977) and Hunter and Schmidt (2004) to accept or reject situation-specificity hypothesis based on how much of the observed variance could be accounted for by statistical artifacts; (6) Determining the robustness of the validity of occupational performance measurement by computing pre-attenuated (corrected) mean weighted validity coefficients and their standard deviations.

We used the following formulas provided in the procedures described by Hunter and Schmidt:

$$V_{obs} = \frac{\sum [N_i(r_i - r_m)^2]}{\sum N_i} \quad (1)$$

where  $V_{obs}$  = the observed variance of occupational performance score validity coefficients;  $N_i$  = the sample size associated with the  $i$ th validity coefficient;  $r_i$  = the  $i$ th validity coefficient;  $r_m$  = the weighted mean of the validity coefficients; and  $\sum N_i$  = the overall sample size associated with the validity coefficients across all studies included in the analysis.

The uncorrected weighted mean validity coefficients were calculated using the following equation:

$$r_m = \frac{\sum [N_i r_i]}{\sum N_i} \quad (2)$$

where  $r_m$  = uncorrected weighted mean validity coefficient;  $N_i$  = the sample size associated with the  $i$ th validity coefficient;  $r_i$  = the  $i$ th validity coefficient; and  $\sum N_i$  = the overall sample size associated with validity coefficients across studies included in the analysis.

The attenuating factor for criterion reliability measurement error for each reliability coefficient was calculated using the equation:

$$a = \sqrt{r_i} \quad (3)$$

where  $a$  = attenuating factor,  $r_i$  = the  $i$ th validity coefficient.

The mean attenuation factor for criterion reliability measurement errors was calculated using the equation:

$$a_m = \sum[\sqrt{r_i}] / n \quad (4)$$

where  $a_m$  = mean attenuating factor;  $r_i$  = the  $i$ th reported validity coefficient; and  $n$  = number of validity coefficients in the analysis.

The pre-attenuated (corrected) mean weighted validity coefficients were calculated using the equation:

$$P = r_m / a_m \quad (5)$$

where  $P$  = corrected weighted mean validity coefficient (an estimate of the true population validity coefficient);  $r_m$  = uncorrected mean weighted validity coefficient; and  $a_m$  = mean attenuating factor.

The variability of test criterion reliability attenuation factors was computed using the following equation:

$$SDa^2 = \sum(a - a_m)^2 / n - 1 \quad (6)$$

where  $SDa^2$  = Variance of attenuating factors.

The sum of squared coefficients of the test criterion reliability variation was computed using the equation:

$$V = SDa^2 / a_m^2 \quad (7)$$

Variance of reported validity coefficients due to variability in test criterion reliability was computed using the equation:

$$S^2 = P^2 a_m^2 V \quad (8)$$

The estimated variance due to sample size was calculated using the following equation:

$$V_s = (1 - r_m^2)^2 / N_m - 1 \quad (9)$$

where  $V_s$  = estimated variance due to sample size;  $r_m$  = uncorrected weighted mean validity coefficient; and  $N_m$  = the mean sample size for all the 19 studies included in our analysis.

Residual variability was calculated by subtracting combined variance due to sampling error and variability in test criterion measurement from the observed variance thus:

$$V_{Res} = V_{Obs} - V_s - S^2 \quad (10)$$

where  $V_{Res}$  = true or residual variance;  $V_{Obs}$  = Observed variance;  $V_s$  = Variance due to sampling error;  $S^2$  = Variance due to study differences in test criterion measurement reliability. The percentage of variance accounted for by a combination of sampling error and variability in test criterion measurement reliability was obtained using the equation:

$$(V_s + S^2) / V_{Obs} \quad (11)$$

Finally, the pre-attenuated (corrected) residual variance was computed using the equation:

$$V(P) = [V_{Obs} - V_s - S^2] / a_m^2 \quad (12)$$

where  $V(P)$  = Corrected residual variance. The corrected standard deviation ( $SD(P)$ ) was the square-root of the corrected residual variance ( $V(P)$ ).

The above description of the procedures and the results of our study were emailed to Dr. Schmidt, the leading author of the VG method. His feedback indicated that our findings were generally correct [Schmidt, personal communication, January 17, 2008]. In order to ensure generalizability of occupational performance score validity coefficients in the event that the situation-specificity hypothesis was rejected, we developed criteria for inclusion of studies in our analysis based on a consistent definition of occupational performance. Such criteria included that the following categories of occupational performance be measured in the validation study under consideration:

Self-maintenance (Basic ADLs such as dressing, bathing, toileting, and obtaining nutrition; and Instrumental Activities of Daily Living such as community mobility, shopping for clothes and other items, and shopping for groceries)

Productivity (unpaid work such as home management and care for family members; paid work; volunteering, etc.)

Leisure (both quiet and active recreation)

Education

Play (sports and child play)

Social participation (including community participation, family related occupations, and peer related occupations) (American Occupational Therapy Association [AOTA], 2002; Baum & Christiansen, 2005; Law et al., 2002)

The above listed criteria were derived from the new occupational therapy paradigm which emphasizes occupation-based, client-centered, and collaborative approach to intervention as central components of authentic occupational therapy practice (Ikiugu, 2007; Kielhofner, 2004; Law et al., 2002).

Occupational performance measurement scores reported in the studies included self-reported ratings of performance, observed performance (either by a therapist or by other people), interview-based assessment of performance, or a combination of any or all of the above (see discussion on “data coding” discussed below). Also, Schmidt et al. (1993) demonstrated that non-Pearson validity coefficients tended to over-estimate artifactual variance and therefore to under-estimate true variance. They recommended exclusion of such coefficients from the VG analysis. Therefore, Spearman rho, Cronbach’s alpha, Intraclass Correlation Coefficients (ICC), etc. were not included in our sample. The studies retrieved for our analysis investigated; convergent, divergent, criterion referenced, and predictive validities of occupational performance.

### Study Sample

In VG research, individual studies constitute “the study subjects”. Such studies were identified by reviewing a book that we found in our literature search devoted to a discussion of occupational performance measurement in occupational therapy and occupational science (Law, Baum, & Dunn, 2005). We identified studies discussed in the book in which validity of occupational performance measurement scores had been investigated and requested the articles through the inter-library loan. One study was reported in a Master’s degree thesis which we also acquired through the interlibrary loan.

In addition, we searched a variety of electronic databases for relevant studies published between 1977 and 2007 (a 30 year span). Later, we updated the search to include studies published in 2008. Key phrases used in the search included “occupational and performance”, “occupational, performance, and measurement”, and “validity, occupational performance, and measurement instruments”. The databases searched included the

EBSCO Mega FILE; Ovid (Cochrane database of systemic reviews, All EBM reviews); Cochrane, DSR, ACP, DARE & CCTR; Health and Psychosocial Instruments, Ovid Medline In-Process and other non-indexed citations and Ovid Medline 1950 to present; CINAHL; PsycINFO; and OT Search. The history and outcome of the search are reported in table 1.

Table 1  
*Obtaining the Data Sample: Search History and Outcome*

Key phrase	Databases Searched and Number of Hits Realized				
	<u>OT Search</u>	<u>EBSCO Mega FILE</u>	<u>Ovid</u>	<u>PsycINFO</u>	<u>Total</u>
Occupational Performance	940	134	1285	266	2625
Occupational Performance Measurement	28	2	21	2	53
Validity of Occupational Performance Measures	25	0	2	0	27

As can be seen in table 1, the key words “occupational and performance” resulted in 2625 hits. When the scope was narrowed using the key words “occupational, performance, and measurement instruments”, the number of hits was reduced to 53. The terms: “validity, occupational performance, and measurement instruments” yielded 27 studies. Thus, 80 studies were found to be closely related to the purpose of our study (i.e., measurement of occupational performance). The abstract for each of the identified studies was reviewed to determine its specific relevance to our objective of determining the robustness and generalizability of the validity of occupational performance measurement scores. In all, 75 studies were retrieved and downloaded but only 25 of them were found to be relevant to our investigation. The 75 studies were downloaded online, copied from the bound Journal collection in the University of South Dakota (USD) library, or acquired through interlibrary loan.

When studies in which the validity estimate coefficients were non-Pearson were removed, only 14 studies remained. A later search for studies published between the years 2006 and 2008 revealed 5 more studies in which validity of occupational performance measurement using Pearson type validity estimates was investigated. Therefore, a total of 19 studies were included in our analysis. The studies are indicated in the reference list by asterisks (\*). The instruments that were the subject of the studies were: Occupational Performance Calculation Guide (OPCG); All about me; Canadian Occupational Performance Measure (COPM); Functional Behavior Profile (FBP); World Health Organization Disability Assessment Schedule (WHO-DAS); Late Life Function and Disability Instrument (LLFDI); Barthel Index; Vineland Adaptive Behavior Scales (VABS); Assessment of Occupational Functioning (AOF); Functional Independence Measure (FIM); Assessment of Motor and Process Skills (AMPS); Occupational Abilities and Performance Scale (OAPS); Executive Function Performance Test (EFPT); 3-Day Physical Activity Recall Questionnaire (3dPAR); and the Activity Card Sort – Hong Kong version (ACS-HK).

### Data Coding

Data from the studies were categorized as follows:

Observation-based occupational performance – Data based on measurement of occupational performance by observation using instruments such as the Assessment of Motor and Process Skills (AMPS), Functional Independence Measure (FIM), etc.;

Interview-based occupational performance – Data based on measurement of occupational performance using interview based instruments such as the Canadian Occupational Performance Measure (COPM);

Self report-based occupational performance – Data based on clients rating of their perceived occupational performance using instruments such as the Role Checklist;

Combined Measures – Data based on measurement of occupational performance using instruments that combine observation, interview, and self-rating.

## Procedure

We read the articles retrieved from our search as explained above. We created a matrix in which we outlined the data as follows: study author; instruments that were the subject of the study; type of occupational performance scores gathered using the instrument (observation-based, interview-based, or self-report); type of occupational performance variable measured (e.g., productivity, leisure, play, etc.); type of validation study (convergent, divergent, criterion-referenced, or predictive); sample size (n), and validity estimate coefficient (r). We entered the validity data (study sample sizes and validity coefficients) as laid out in our data matrix into a Microsoft Office 2007 Excel Spreadsheet. Each of the researchers checked the entries at least twice in order to ensure accuracy.

## Data Analysis

Based on equations 1 through 12 as explained above, we used the Excel spreadsheet to calculate the uncorrected weighted mean occupational performance validity coefficient for each occupational performance category, weighted mean validity coefficients corrected for attenuation by variability in the test criterion reliability, estimated observed variability of the coefficients, variability attributable to sampling error and variance in test criterion measurement reliability, residual variability, and percentage of observed variability explained by the two statistical artifacts whose attenuation was corrected in the analysis. We also computed credibility intervals of corrected weighted mean validity coefficients at 95% level ( $SD = 1.96$ ) using the formula:  $CI = \text{Corrected weighted mean validity coefficient} \pm 1.96 \times SD(P)$ , where CI=Credibility Interval, and 1.96=the critical value of the standard deviation at 95% confidence level (see Hunter & Schmidt, 2004 for explanation). ◇

## Findings

The findings of our data analysis are shown in Table 2.

Table 2

*Validity Generalization Meta-Analysis Results for Various types of Occupational Performance Measurement Scores (n=19)*

Type of OP Measure	Total N	Mean N	No. of rs	$r_m$	$a_m$	$p$	Observed Variance	$V_s+S^2$	% of Variance Acct.	Corrected Residual Variance ( $V_{(p)}$ )
All Studies Combined	40837	91.98	444	.065	.676	.096	.259	.011	4	.544
Interview-Based (n=9)	36724	122.01	301	.060	.698	.086	.265	.008	3	.526
Observation-Based (n=6)	2455	45.46	54	.021	.531	.04	.204	.023	11	.643
Self Report-Based (n=4)	1658	18.63	89	.228	.637	.358	.193	.055	29	.34

Key: n=Number of studies in the analysis; N = Sample size;  $r$ =Reported occupational performance score validity coefficient;  $r_m$ =Uncorrected weighted mean occupational performance score validity coefficient;  $a_m$  = Mean attenuation factor for test criterion reliability (test criterion = occupational performance);  $p$  = pre-attenuation or corrected mean weighted validity coefficient;  $V_s+S^2$  = Combined variance due to sampling error and variability in test criterion measurement reliability; % of variance acct. = Percentage of occupational performance score validity coefficient variance accounted for by sampling error and test criterion reliability differences among studies;  $V_{(p)}$  = Corrected or pre-attenuated residual variance of validity coefficients;  $SD_{(p)}$  = Corrected or pre-attenuated standard deviation of validity coefficients; and CI =Credibility Interval (at 95% =  $p \pm 1.96SD_{(p)}$ ).

## Robustness of the Corrected Weighted Mean Validity Coefficients of Occupational Performance Scores

### All studies combined

The mean weighted  $r$  for all the 19 studies was .065. The pre-attenuated mean validity coefficient ( $P$ ) was .096. According to guidelines by Cohen (1988) and Kraemer, Morgan, Leech, Gliner et al. (2003), this constituted small (low) validity of occupational performance measurement assessments in comparison with typical instruments used in social science research.

### Interview-based scores

As can be seen in table 2, the mean weighted  $r$  for interview-based occupational performance measurement was .06 ( $P=.086$ ). According to Cohen and Kraemer et al., this coefficient similarly constituted low validity.

### Observation-based scores

The weighted mean  $r$  for observation-based occupational performance measurement scores was .021 ( $P=.04$ ).

Again, this coefficient indicated low validity for this category of occupational performance measurement scores in comparison to typical instruments used in social science research.

### Self report-based scores

The corrected mean weighted  $r$  for self report-based occupational performance scores was .23 ( $P=.36$ ). This coefficient, according to Cohen and Kraemer et al., was still low but it was close to medium validity ( $r=.30$ ) in comparison with typical instruments used in social science research. The pre-attenuated validity coefficient ( $P$ ) was clearly in the medium validity range.

## Generalizability of Validity Coefficients of Occupational Performance Scores

### Overall generalizability

The residual overall variability of occupational performance validity coefficients after correction for attenuation by sampling error and variability of test criterion measurement reliability was .544, and about 4% of observed variance was explained by the two statistical artifacts. Based on the 75% decision rule, the situation-specificity hypothesis could not be rejected. This wide variability of validity coefficients was apparent in the CI whose pre-attenuated validity coefficient values ranged between  $P=-1.40$  and 1.49 [variability by more than one Standard deviation at .05 confidence level (1.96)].

### Interview-based scores

The residual variability of interview based validity coefficients was .526. About 3 % of observed variance was explained by the artifacts. Again, based on the 75% decision rule, situation-specificity hypothesis could not be rejected for interview-based occupational performance measurement score validity. The CI of interview-based occupational performance pre-attenuated validity coefficients ranged between  $P=-1.38$  and 1.46.

### Observation-based scores

The corrected residual variability of the observation-based occupational performance scores was .643. About 11 % of the observed variance was attributable to sampling error and variability in test criterion measurement reliability. Therefore, the situation-specificity hypothesis could not be rejected, and as can be seen in table 3, the credibility interval was remarkably large ( $P=-1.56$  to 1.59).

### Self report-based Scores

The corrected residual variability for self report-based occupational performance score validity coefficients was .34 (the lowest variability among all occupational performance measurement instruments in our sample). About 29% of the observed variance was attributable to the sampling error and variability in test criterion measurement reliability, again leading to failure to reject the situation-specificity hypothesis.

## Discussion

Validity Generalization analysis results in two mean validity coefficients: one attenuated (or modified) by statistical artifacts (in our case sample size and variability of test criterion reliability); and the other a pre-attenuated coefficient. Our interpretation of those mean coefficients was based on Cohen's (1988) guidelines for determining the effect sizes and their importance. In applying Cohen's notion of effect sizes, we can think of the effect of an assessment in terms of its ability to detect the indicators of occupational performance as defined in this study. In other words, it is a reference to the effectiveness of an assessment in detecting and measuring occupational performance as we have defined it. Cohen suggested that the effect sizes in social sciences were generally small in comparison to other disciplines because of attenuation of validity of the

measures used and the subtlety of the variables involved. Consequently, he defined effect sizes ( $d$ ) as follows: small ( $d=.20$ ;  $r=.10$ ); medium ( $d=.50$ ;  $r=.30$ ); and large ( $d=.80$ ;  $r=.50$ ).

Based on the above criteria, our analysis indicated that the weighted mean occupational performance score validity coefficients for all the 19 studies combined, interview-based, and observation-based occupational performance scores were small ( $r=.065$ ,  $.060$ , and  $.021$  respectively). The weighted mean validity coefficient for self-report based scores was small but approached the medium range ( $r=.23$ ). However, Cohen's interpretation criteria do not take into account the confounding effect of the sample size or the statistical significance. Of course, we need to remember that as Valentine and Cooper (2003) argued, statistical significance is not the best measure of effect size because it does not provide information about "practical significance or relative impact of the effect size" (p. 1, emphasis original).

Pearson and Hartley (1962) provided guidelines for interpretation of the statistical significance of  $r$  based on a chosen power level and  $p$  value. Based on Pearson and Hartley's guidelines, the pre-attenuated validity coefficients ( $P$ ) at .80 power level and  $p=.05$  can be interpreted as follows: Overall, the mean pre-attenuated validity coefficient ( $P=.096$ ) with a mean sample size of  $N=.91.98$  was not statistically significant. The  $p$  value would need to be at least .196 in order for  $P$  to be significant for that mean sample size. Using the same criteria, the pre-attenuated interview-, observation-, and self-report-based validity coefficients were similarly not statistically significant [mean  $N=122.01$ ,  $p=.086$  (critical value=.196); mean  $N=45.46$ ,  $p=.04$  (critical value=.444); and mean  $N=18.63$ ,  $p=.36$  (critical value=.632 respectively)]. Therefore, our analysis indicated that the mean weighted validity coefficients of occupational performance measurement instruments for the studies in our sample were not statistically significant. They were all small in comparison with validity of assessments used in social science research.

Our search of literature did not reveal other occupational performance validity generalization studies with which we could compare our findings. Ottenbacher, Hsu, Granger, and Fielder (1996) completed a meta-analytic study in which they found  $r$ s ranging between .84 and .92. However, they did not use the VG method. Rather, they converted reliability coefficients into Fisher  $z$  scores for comparison across studies and then converted them back to reliability coefficients for interpretation. They did not weight their observed  $r$ s with sample sizes or correct the mean  $r$ s for attenuation by variability in the test criterion reliability. Therefore, their findings were not comparable to ours.

The mean weighted  $r$ s in the present study were comparable to those found in other Validity Generalization studies in social science research such as Hackett (1989) who found mean weighted coefficients ranging between -.04 and -.17; and Pearlman, Schmidt, and Hunter (1980) who found mean weighted  $r$ s ranging between .07 and .26. Our findings were therefore consistent with Cohen's assertion alluded to earlier that: "Many effects sought in personality, social, and clinical-psychological research (to which occupational performance may be categorized) are likely to be small...because of the attenuation in validity of the measures employed and the subtlety of the issue frequently involved" (Cohen, 1988, p. 13). Therefore, occupational therapists and scientists should not be alarmed by the small mean validity coefficients of occupational performance measurement instruments found in our analysis. Our findings indicated that the mean validity of the instruments compared well with that of other instruments used in social science research to measure phenomena that are as elusive as occupational performance.

The mean weighted validity coefficient for self-report-based occupational performance scores was the highest in our analysis ( $r=.23$ ,  $P=.34$ ). This finding suggested that among the occupational performance measurement assessments used in occupational therapy, those that were based on self-report of occupational performance, such as the Assessment of Occupational Functioning (AOF) and the 3-Day Physical Activity Recall Questionnaire (3dPAR) were the most valid. Given the few studies in this category in our sample ( $n=4$ ), this finding was interesting. It denoted possibility of high mean validity coefficients for such assessments in future VG research when more studies become available. This finding could be particularly important in light of the current occupation therapy paradigm which emphasizes client-centeredness in



therapeutic discourse. It means that use of instruments that require clients to identify their own occupational performance priorities, consistent with the client-centered focus of the professional paradigm, may be the most valid approach to occupational performance assessment.

In general, more VG research is indicated as more studies become available so that more conclusive findings may be realized. In addition, the reader should note that our findings are very limited because we could only include Pearson type validity coefficients in our analysis. If the entire range of coefficients were included, it is possible that the mean validities could be different. One of the most important findings in our study was that none of the occupational performance score validity estimate coefficients were found to be generalizable using the 75% decision rule proposed by Schmidt and Hunter (1977) and Hunter and Schmidt (2004) after correction for variability due to statistical artifacts. Self report-based occupational performance scores were the most generalizable with 29% of observed variance being attributed to sampling error and variability in test criterion measurement reliability. Interview-based occupational performance validity coefficients were the least generalizable with the two statistical artifacts accounting for only 3% of observed variance.

This lack of generalizability would suggest that therapists cannot automatically assume validity of occupational performance assessments (note that this statement applies only to Pearson validity estimate coefficients) even if such instruments have been proven valid in prior research. However, it is important to remember that only variance due to sampling error and test criterion measurement reliability variability was accounted for. The studies included in our analysis did not provide enough information to allow us do a complete meta-analysis in which all attenuating factors would have been modulated. Therefore, more validation studies were indicated in order to determine conclusively the generalizability of validity of occupational performance measurement instruments in the clinical situations where therapists need to use them.

Furthermore, it may be clinically useful to bear in mind that according to our findings, self report-based occupational performance scores had the most robust mean validity coefficient and the highest generalizability from research to clinical settings even with our limited meta-analysis results where many attenuating factors were not accounted for. This finding was encouraging because it indicated that assessment instruments that were the most consistent with the occupational therapy paradigm had the greatest promise of being found to be valid and transferable to clinical situations in future VG analysis involving more studies. However, our findings were not conclusive. In the end, until further analysis is completed to reach more definitive conclusions about occupational performance score validity generalization, therapists and scientists need to review available validity research for instruments that they want to use in practice and make their decisions based on clinical expertise and specific circumstances of practice.

It has also been suggested in literature that the percentage of observed variance attributable to statistical artifacts may not be a good way of making decisions about VG. Rather, it is “The actual amount of observed variance” that is important (McDaniel, Hirsh, Schmidt, et al 1986, p. 144). Even Hunter and Schmidt (2004) suggested that the 75% rule has been misinterpreted. It is not a means of statistically testing for chance fluctuations in sampling error. In situations such as our study where the number of studies in the meta-analysis was small, the value of observed variance could be significantly larger than may be accounted for by sampling error alone. In that sense, the relatively small variance (.193) of self report-based validity coefficients is of interest because it means that the validity of such instruments could conceivably be generalizable. However, there is no meaningful way other than the 75% rule of determining an absolute value of observed variance that would be considered small enough to allow generalizability.

Based on our findings, it may be beneficial to replicate this study and include published and un-published studies in order to determine if generalizability of occupational performance score validity coefficients is really a problem or whether our findings are due to limitation of the types of studies included in the analysis. In addition, an investigation of modifiers that increase variability of validity coefficients from situation to situation may be beneficial.

### Limitations and Recommendations

One of the limitations of this study may be the small number of studies included in the meta-analysis (only 19 studies). However, further literature review indicated that this was typical of Validity Generalization research. In his review, Hackett (1989) found that the number of studies included in a variety of meta-analyses ranged between 20 and 31, and the number of correlations between 106 and 707. Therefore, it was typical to have a small number of studies in a meta-analysis, perhaps due to stringent inclusion criteria necessary in order to ensure commonality of characteristics that make generalizability possible.

A more significant limitation was the fact that only published studies were included in our analysis. This could have tended to exclude methodologically poor studies, such as those with inadequate power due to small sample sizes, failing to take into account the broad spectrum of validation research and therefore skewing the findings (Schmidt & Hunter, 1977). That is why many VG investigators tend to seek to identify both published and unpublished studies for inclusion in their meta-analysis (Pearlman, Schmidt, & Hunter, 1980).

The strength of this study was the fact that occupational performance measurement was stringently defined consistent with the current occupational therapy paradigm. Therefore, rejection of the situation-specificity hypothesis would have meant that a therapist only needed to analyze the clinical situation where he/she intended to use an instrument and if the circumstances of clinical practice were similar to the validation research situation, and if the assessment instrument measured occupational performance as defined in this study, he/she could use the instrument with assurance of validity without need for further validation.

It is recommended that this study be replicated and an attempt be made to include non-published studies in the replication. Also, in future studies, attempts to convert non-Pearson type validity coefficients to forms analyzable using the VG method should be made in order to make the meta-analysis more inclusive and complete. In addition, situation-specific modifiers that increase variability of validity coefficients and therefore make their generalizability difficult should be investigated. One way to do that may be to find out the common characteristics of occupational performance measurement instruments and to complete separate meta-analyses of groups of assessments based on those characteristics. That would reveal groups in which variances of validity coefficients differ significantly, allowing us to draw conclusions about attenuating factors that are the most important in occupational performance measurement. Finally, the present meta-analysis should be regularly up-dated using the methods proposed by Schmidt and Raju (2007) as new validation studies become available.

## Conclusion

In this study, a meta-analysis was completed using Hunter and Schmidt's (2004) methods in order to determine the robustness of the mean validity coefficients of occupational performance scores and generalizability of those coefficients from research to clinical situations. Our analysis revealed that the mean weighted validity coefficients of self report-based occupational performance measurement scores were the most robust suggesting that self report-based occupational performance measurement instruments were the most valid. After correction of observed variance by subtracting variability due to sampling error and variability of the test criterion measurement reliability, too much residual variance was un-explained based on the 75% decision rule. Therefore, situation-specificity was not rejected and generalizability of the validity of occupational performance measurement scores could not be justified. It is important to bear in mind that many attenuating factors that could have explained such variance were not accounted for because of limited information provided in the studies included in our sample. Because of that limitation, definite conclusions could not be drawn. Future research should investigate situation modifiers that increase variability of validity coefficients making them un-generalizable.

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- \*Studies constituting the sample that we analyzed.

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# A Study of Socio Cultural Perspectives of Care Givers in Burden Coping Behaviour in Bipolar Disorder and Schizophrenia Cases

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## Abstract

Qualitative dimension of care giving and burden coping strategy was assessed by doing Focus Group Discussion (FGD) and appropriate educational intervention were designed thereafter to help improve quality of coping strategy and reduce the burden of the care givers. Ten FGDs and twenty two intervention sessions brought out, how efficaciously “therapy management group”, in this case the care givers (the spouses /children /parents ) evolved in the process of care giving and had positive bearing as well. The process of intervention in particular was done in the presence of the patients. The patients

were very much aware of the activities (at the cognitive level) going on during the intervention session. However, they were not part of the FGD as the principle of FGD does not allow non homogeneity of the group. It was evident from the study that the sessions had positive impact for coping behaviour and increased confidence.

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## Introduction

Mental health problem in India mostly remains unnoticed due to various reasons i.e. either not considered as a problem needing attention or some times it is ignored as no one in the family has time to think or discuss about the mentally challenged person or the issue of mental ailment. The situation gets further aggravated by lack of adequate medical or health facility to treat the case right earnest.

Vagaries of care givers was observed quite commonly among the patients of mental disorder i.e. Bipolar Disorder and schizophrenia visiting to Institute of Human Behavior and Allied Sciences (IHBAS). Delhi. The study was carried out by a team of psychiatrist, social and behavioral scientist to look into various qualitative dimensions of quality of life of caregivers and their way of dealing with patients. And suggestions were also given by the team to care givers during the sessions of burden coping, care giver and research team for betterment of the problem.

Earlier bipolar affective disorder (manic depressive psychosis) with its episodic course was considered to have a better prognosis than schizophrenia, which often tends to have a chronic course, research in the last few years has shown that the bipolar affective disorder is also an equally disabling illness. Both the illness find a place in the list of most disabling illness for the most productive age group of 15-44 (World Health Report, 2001). Until 1950s, a large number of these patients used to be confined to the walls of the mental hospitals (asylums). With the advances in the psychopharmacology and growing emphasis on outpatient treatment in psychiatry, most patients with these disorders are being looked after by their families. In India unlike in the West, the families have always remained the major source of care for the mentally ill even in the past, since there was never adequate number of mental hospital beds for these patients in our country.

Chronic illness of a family member is an objective stressor that results into strain for the caregiver or relative because of the difficult tasks of care of patient (Schene, 1990). This is likely to affect both physical and mental health of the caregiver, which depends upon the characteristics of the patient, the relative, their relationship and their environment (Brown & Birstwistle, 1998). Unlike in the West, the traditional joint family system in India acts as a buffer against various kinds of stresses. However, due to rapid urbanization and industrialization, the joint family is breaking. The nuclear families are more vulnerable to stresses and are less equipped to handle mentally ill members (Kapoor, 1992; Sethi & Manchanda, 1978).

In order to understand caregivers plight, it is necessary to comprehend certain key components essential in maintenance of social interaction and inter personal operation among caregivers and the mentally challenged, as well as the challenged vis a vis the family. Besides, one also needs to understand the dynamic equilibrium that maintains the bond between the patients and the persons beyond family, be it relatives or community he lives in. Caregivers need to “cope” with “burden of both types, objective and subjective stress. Coping is a process by which the care giver not only eases out the hardship of care giving but also improves the psychiatric patients in many ways to bring him back to terms with the out world, world beyond the mentally challenged and the care giver.

The term ‘burden’ is a common English word, which has become quite popular in psychiatry with de-institutionalization. There are some minor differences in the way; the term has been defined by different investigators. According to Platt (1985), “burden refers to the presence of problems difficulties or adverse events that affect the lives of psychiatric patients.”



Similarly, ‘Coping’, in general, refers to a person’s cognitive and behavioural response to a stressful situation. Lazarus and Folkman (1985) have defined coping as “coping refers to the constantly changing thoughts and behaviours that people use in order to manage stressful situations. “Ways of both patients and relatives, and depend on relatives’ appraisal of their patients’ situation.

India with a population of more than one billion is home of one sixth of the world’s mentally ill. The prevalence rate of schizophrenia as reported in different studies from India range from is 0.7- 5.5/1000 and that for bipolar affective disorder (manic- depressive psychosis) range from 0.7- 15.0/1000 (Reddy & Chandrashekar, 1998). Families are the main caregivers for patients suffering from psychiatric illness. Severe mental illness like schizophrenia, bipolar affective disorder and depression is one of the major cause of concern from many Indian homes. The problem of burden on the caregivers of the patients with severe mental disorders is enormous. Coping strategy of the care giver is highly important factor which not only determines his or her way of socio-cultural and economic life but also has bearing on course of illness improvement. Thus, burden and coping strategies in caregivers of psychiatric patients has been an important area of research attracting the psychiatrists and social scientists in last few decades.

In one of the studies carried out by Fadden et al (1987a, b) impact of functional psychiatric illness on the patients’ family, found that the family members had to bear a lot of burden because of patients’ illness. Many patients caused moderate to severe hardship to their relatives such as social embarrassment, inconvenience, and disturbed behaviour, which frightened the family. High rates of divorce and separation in marriages were reported where the patient is mentally ill. Wives believed mental illness to be a stigma in the society. Family of schizophrenic patient experienced financial burden in taking care of the patient. Wives experienced anxiety, guilt and feeling of rejection towards their husbands because of illness. Burden increased with increase in the duration of illness. Problems also arose with neighbours

Indian Studies on BAD and schizophrenia burden coping Strategies

In a one of the studies, Pai and Kapoor (1983) evaluated the impact of home care treatment for schizophrenia patients in terms of outcome. The results revealed better clinical outcome, better social functioning and significant reduction of burden on the family, compared to the patients who were hospitalized and followed up on outpatient basis.

In another Indian study, reported from Jaipur in North India, Gautam and Nijhawan (1984) compared the experience of burden on the relatives with chronic schizophrenia with relatives of patients suffering from chronic lung disease. It was found that the relatives with schizophrenia experienced severe burden than those of patients with chronic lung disease. Further relatives of male schizophrenics experienced increased financial burden.

Differences in perception of burden between rural and urban background have also been examined. Ranga Rao (1988), in a study from Bangalore, assessed burden of relatives of patients suffering from schizophrenia who hailed from rural and urban background using Family Burden Scale (Ranga Rao, 1988). Relatives of urban patients experienced more burden than their rural counterparts. However, somewhat different results were found in another study from the same centre. Ali and Bhatti (1988) examined the relationship between social support system and family burden in chronic schizophrenia in comparable rural and urban samples. Thirty patients each from rural and urban areas were selected. The study used Alan Vax Social Support appraisal Scale and family Burden Scale of Pai & Kapoor (1981). It was found that families experienced equal burden irrespective of the setting.

Gopinath and Chaturvedi (1992) systematically evaluated the impact of behaviour of the Patient at home in 62 relatives using the Scale for Assessment of Family Distress. It was found that inactivity, slowness, poor self care inability to participate in household activities were perceived as most distressful. Interestingly,

aggressive or psychotic behaviour was not perceived as distressful by relatives. However, young and educated relatives reported distress more often.

In a comparative study on relatives of long term psychiatric patients (schizophrenia and bipolar affective disorder) from Kolkata, Roychaudhuri et al (1995) assessed the subjective and objective burdens of 54 caregivers of schizophrenia and bipolar affective disorder patients. Results showed that caregivers of schizophrenia patients showed increased severity of burden as compared to bipolar affective disorder patients.

In a recent Indian study from Pondichery, Chanrasekran et al (2002) evaluated the coping styles adopted by the relatives of schizophrenic patients. Forty four patients (twenty men and twenty four women) and same number of relatives were included in the study. Seventy one per cent of the relatives used resignation strategies, 79% failed to maintain social contacts, and 60% did not seek information about the illness. Only one third of the relatives ever attempted active social involvement of the patients, coercion and avoidance strategies.

Most of the work on burden and coping in caregivers of psychiatric patients has been undertaken in patients of schizophrenia, though there are some studies on affective disorders. Some studies have reported higher burden in caregiver of patients with schizophrenia than in those of affective disorders, while others have found equivalent severity. Studies done in India are of cross sectional nature and mostly studied one or two parameters. Present study assessed burden and coping strategies in a group of caregivers of patients with schizophrenia and bipolar affective disorder in a prospective design using both qualitative and quantitative (though the findings of quantitative component of the study has been discussed in other communication) techniques. In the present communication, qualitative dimensions of care giver patient relationship, coping of burden by care giver and various subtle nuances adopted as strategy to deal with the issue of coping of burden while giving care to patients as well as ways and means to defend self esteem under stressful situation.

## Methods:

### Qualitative Assessment:

Ten Focus Group Discussions (FGDs) were conducted to gain different perception and domains of care giving of the family members with psychiatric disorders. Focus group discussions helps to explore the critical perception and values of the care givers and helps understand the collective consciousness of the group in question (care givers) in regard to skilful patient handling, Values and meanings attributed to a certain social phenomenon is a strong marker to understand finer details in care giving and care givers rite de passage as well as patients reaction to the discussion

The care givers were told that they will be part of a study where by the researcher (comprising of treating physicians, psychologists and social scientist) will be able to conduct a study to know about the amount and type of burden they face to cope the stress in care giving of the patients. The caregivers were initially reluctant as they were not able to comprehend that why they would be interviewed or take part in focus group discussion. Their feeling was that the patient should be subject of study but not they. Explanation in detail by the researchers regarding aims, objectives and purpose of the study, they agreed to sign/ put thumb impression on the consent form. And for the academic sessions they also signed the consent form on behalf of their patient. It was promised to the care givers that confidentiality of all sorts will be maintained the care givers were ready to come forward for the study.

Though the participants were not initially keen to be part of FGD. Albeit, they were under strain of both psycho social as well as physical in nature, not only they had to negotiate with severely depressed psychiatric patients but also had to carry out their own day to day activities and responsibilities. The purpose of FGDs and benefits thereof to the care givers and the patients by being a part of FGD was well explained by the research team, though the FGDs were time consuming but the care givers realized the importance of the

discussion very quickly and were anxious to be part of the same.

Ten sessions of Focus Group Discussions (FGDs) were conducted with the caregivers to make qualitative assessment of burden and coping strategies of the caregivers. Each of the sessions comprised of different batch of care givers. The session lasted about one hour and was conducted under the supervision of a medical anthropologist. Audio recording was done and notes were also taken for the sessions. And all necessary precautions were taken to carry out the session successfully. Each FGD session was attended by 10 caregivers. Care givers were considered as homogeneous group so far as care giving was concerned (the research team had before hand knowledge regarding the care givers, as they were frequenting to the institution for treatment of the mentally challenged dependents). Although, most of the caregivers interviewed were in the age group of 40s or 50s. And the participants were from economically lower-middle class background. Most of the families (involved in FGD) were earning on average Indian Rupees 4500-5000 per month (USD 100-110). All the caregivers were in the care giving role for a minimum of 2 years period. The length of care giving ranged from 2 years to 38 years, however, average period being about 10 to 15 years.

## Findings of Focus Group Discussions (FGDs)

Focus group discussions were primarily conducted to elicit the nature of burden, coping strategies and problems faced by the caregivers in day to day interaction with the patients and how they found out solutions to such problems.

Non considerate, a-sympathetic attitude towards patients; care givers dilemma

Many of the interviewees opined about their sense of isolation from the rest of the society. Father of a young patient said, "People stop coming to the house. Even close relatives are reluctant to come."

A father of a young unmarried schizophrenic female said, "We have to hide the disease because she is unmarried and if we tell anyone, we will face difficulty in finding a suitable match for her." "Sometimes, I am not able to share my feelings and tension with anybody because of her illness"

But, some of the caregivers were also optimistic. One of the caregivers said, "if you care for somebody, you automatically get close to that person, and the relationship improves."

Stigma and avoidance mechanism of all sorts were associated with psychiatric patients and was so common and echoed in almost every FGD. One of the caregivers said, "The Patient is generally avoided and even scolded." (Mother of a young patient said, "The patients are looked upon as inferior and people treat them differently."

Another caregiver said, "esteem and social status of the family has been raised to ground, because people don't want to talk to us they avoid us."

One aged caregiver said, "Many people try to avoid mental patients and feel inferiority complex while talking to them."

The caregivers generally felt that the society does not sympathize and they lack in understanding of mental patients. They are often unappreciated, blamed and misunderstood by the general public and such attitude makes the situation more complicated as the backlash of patients anger is felt by the care givers.

Faith in god; A way of coping and riddance of dilemma

The sessions provided evidence of various ways of coping strategies as well as solution to dilemma sought by

the by the caregivers.

One of the caregiver's husband of a bipolar affective disorder patient, said, "I have become more compassionate and try more and more to learn about the disease and its management."

Husband of another patient revealed that when he comes across any patient like his wife, he tells the family members of the patient how to deal with the patient.

One of the caregivers said, "We are aware of the fact that this problem is long term and now part of our life."

Most of them reported that they felt the fear, concern, confusion, frustration, hope, caring, compassion, sympathy, love, sadness, grief, anger, resentment, and guilt at one point or another while caring the patients. They often spoke about each of these with both positive and negative emotions and also with great passion and intensity.

Brother of a patient suffering from bipolar affective disorder said, "I become so aggressive and think of either killing him or myself."

One caregiver said, "We have to fight with everybody and try to convince them that he is not doing it intentionally."

Wife of a bipolar affective disorder patient revealed that children were unable to concentrate on studies because of the problems the patient often created.

Non compliance with treatment was also a major concern. Because of the need for long duration of treatment, the patients many times out of frustration stopped treatment.

Sometimes, the caregivers also become careless. Emphasizing the need, one caregiver said, "Whenever, she stops treatment, she loses temper and does whatever she wants to do. But still I bear with it because I know it is not in her hands."

Husband of a schizophrenic wife revealed, "The patient loses temper, breaks things, shouts when her demands are not met. But the patient can be tackled by not arguing but by giving suggestions calmly."

Responses of caregivers show that they are hopeful of a good future. Father of a young schizophrenic said, "If good things change, so do the bad things, our bad time will also pass away." Mother of a young schizophrenic said, "If things are not good, tomorrow will be better."

Religion was often a source of support. Most of the caregivers believed in God and thought that He would help them out in this situation. One of the caregivers said, "I do weekly fast so that he (patient) gets well soon."

Another caregiver said, "I pray everyday and it helps me in difficult times."

Husband of a young patient said, "Best coping strategies are that there should be complete and timely treatment, and the rest depends on God."

Most of the caregivers interviewed spoke about the financial strains associated with caring for the relative with a mental illness. For example, the wife of a patient with bipolar disorder stated, "I can't control how he spends his money. All I can do is to make as much as I can."

One aged caregiver said,

“It takes time to treat this problem. People who do not have good source of income face financial problem.”

The wife of a patient, who was the only earning member of the family, said, “She feels financial problem, if he is not earning regularly or in less amount.”

A caregiver expressed that the caregiver has to curtail necessities, luxuries, as expenses on medicines are increasing day by day.

The wife of a bipolar patient said with heavy heart, “Once he ran away with all the jewelry, after that financial position got worse.”

Father of a young divorced schizophrenic patient said, “All responsibilities have to be met by me. No body is helping me financially, so tension increases.”

When asked whether the illness of the patient affect the health and day-to-day activities of caregiver, majority of them replied in positive. One caregiver said, “more or less life of every family member gets affected.” The wife of a young schizophrenic patient said, “When we are anxious we are not able to do the work. Only half of the work gets completed.”

A businessman husband of a schizophrenic patient revealed, “It affects my work efficiency, also sleeps to a great extent.” An old caregiver said angrily, “this disease should not happen even to an enemy.”

The health and daily routine were severely affected when the symptoms are on its peak. One caregiver revealed,

“The time is the hardest and affect the daily routine of the family members for at least three months.” A caregiver said, “ It affect the health to a large extent and sometimes I suspect whether I will also become a patient.”

Another caregiver said, “All of us (family members) have developed one or other physical problems”. In spite of various strife and torture of various kinds care givers did not give up hope in patients and their likelihood to be normal one day. They reposed faith in both treatment and doctors besides, god the almighty. It was evident through FGD that care givers were perseverant and resolute to get their patient cured.

Care giving an art or emotional bondage,

Another concern, which came up during discussion was, who will take care of the patient in caregiver’s absence and who will take the responsibility of dispensing medicines to the patient. All caregivers were concerned and equivocally said that there has to be someone at home in their absence. With improvement in the condition of the patient a sense of sincerity towards intake of medicine was evident. The prime cause of such commitment was a fear of relapse, if, medicine is not adhered with they may face the music once again.

One of the caregivers said, “If he has to go for some important work, he is always worrying about the patient, and remains tense for long.”

An aged caregiver with tears in his eyes said, “I take care of him all the time, but after me who? Now the situation is changing drastically. I am not able to do the work because of age.”

Mother of a schizophrenic said, “We have to leave one person at home for him, when we are away, we all keep on worrying, about him for the whole day.”

Wife of a schizophrenic said, “He is unable to do anything of his own. Everything has to be told clearly to him, and therefore one person is always engaged in his care only.”

During FGD it was discussed that whether fatigue or frustration while dealing with their patient over a long period of time ever led to an idea of abandoning him or her, Most of the caregivers emphatically said, “NO”.

Brother of a patient suffering from bipolar disorder said, “No, because we are the same blood. We have blood relation.

Father of a bipolar disorder patient said, “The time when the illness/disease is on its peak, we do think to leave him for good. But after sometime we think, he is not doing it intentionally.”

Similarly, brother of a patient said, “Sometimes we feel that we should leave him on his own. But this is because of frustration only.”

One old lady who is providing care to her son said, “Why God has given us this punishment.” The issue was raised during FGD as whether, the disease is the result of the bad deeds in past, there were varied opinions. Caregivers from low socio-economic status and having low education thought that it is because of either their bad deeds or the deeds of the patient in the past.

But those who were educated did not think so. Father of a patient said, “We have to think on this line, Yes, it is the result of our bad deeds of the past.”

Another caregiver who was a school teacher, said, “I think this is a disease and can happen to anybody.” One caregiver said, “No, I don’t believe in the past, I believe in the present. It is a disease and we have to treat it.”

Another caregiver said, “I don’t know about God but I believe in the present.”

It was clear from the FGDs that patients were having no affinity for gender of the care giver, for them who ever sympathized were close enough to be relied and confide upon.

Empathy of caregivers for the patient was quite clear in the FGDs. Brothers, fathers, mothers and spouses were candid enough to admit that the fatigue and frustration of care giving was paramount in their life but it was their duty to take care of these people. Many patients improved and they were taking medicine of their own and the care givers were delighted and said that their perseverance and empathy only made the patient apparently normal. Though, care givers were facing humiliation in one or the other platform (even the close ones sometimes did not spare them) but were not deterred and remained steadfast in duty.

### Intervention Sessions:

It was important to involve the patients actively along with their care givers to get a comprehensive picture of the improvement of the status of patient and well being of care givers. Intervention was done for the same group of care givers and their patients who were part of the FGD. No ethical norms were violated before, during and after intervention (the institutional ethical committee clearance was obtained before initiation of the study).

Informative chart were made in vernacular Hindi (lingua franca of the care giver and patients was used) were prepared about schizophrenia and bipolar affective disorder. The materials used were standardized one. The details included the clinical symptoms and treatment, problems faced by caregivers, guidelines to caregivers in day to day management of the patients. The patients as well as caregivers were given a brief presentation

including prevalence, clinical presentation, misconceptions and available treatments of severe psychiatric illness including schizophrenia. Role of family members in care of psychiatric patients, common problems faced by the family members in day to day care of their patients were also discussed.

Educational sessions were conducted during the same period when FGDs were conducted. A total of 22 educational sessions were organized. The sessions were made interactive so that caregivers could put questions about the problems. 8-12 patients were called for every educational sessions. Each session was attended by 4-5 patients and 6-8 caregivers. Sessions have been organized at a frequency of twice a month. The participants were encouraged to clarify their queries. They were also asked to give their feedback about the usefulness of the sessions. The research team also tried to give solutions to the vexing issues which were agitated during the FGD. In general, the sessions were taken well by the participants, the patients. In the later sessions, the patients and caregivers were also given copies of some educational material.

The sessions were carried out in the morning hours, so that the visiting caregiver who would be able to attend the outpatient service on the visit (the patient may or may not be accompanying) and also take the prescribed medications from the dispensary. The time was often overlapping with the outpatient hours, where the assessments for the study were also being carried out. Therefore, all the patients and caregivers could not be covered up in the educational (intervention) sessions.

The team was simultaneously monitoring the type and level of improvement in care giving and coping strategy of the care givers during intervention sessions in the later period. Monitoring was done by enquiring about the way the care givers been interacting with their patients after attending the session (whether they expressed the same problem for coping or no such repetition). It was encouraging to see the grimace free faces of care givers.

## Discussion and Conclusion

The study helped assess the burden and coping strategies used by caregivers of patients with schizophrenia and bipolar affective disorder (BPAD) in a prospective design. While carrying out the study different psycho social issues came up regarding care giving and strategies to cope up with the burden of care giving. It was felt appropriate to discuss the finer qualitative nuances involved in routine interaction of caregiver with the patient. These details were essential to know more about the disease and its progression and people's perception (both the family members, relatives and neighbours) of the individual and their sickness. Education session and its impact on the enhancement of care givers knowledge in presence of the patient and the team of researcher was incremental to the body of knowledge regarding coping with the ailment and strategies adopted by the care givers.

It was quite clear that the care givers were acting as 'therapy management group' (TMG), in the given circumstance. Therapy management group (the set of individuals who take charge of therapy management with or on behalf of the sufferer) was active in the present situation and keen interest and involvement of the group could help improve the over all situation in steady pace. ( Janzen 1978).

It is a group of relatives, friends, acquaintances, and neighbour, formed around the sick. It is a quasi-group, because it starts dissolving when the sick person is on the road to recovery. Although, the size of the group is directly proportional to the social status of the sick. It was evident that patient of relatively better socio economic footing were well cared for. Though, in the Indian situation such affection causes difficulties to deliver goods in the institutional setting (as they tend to create lot of noise and confusion) to the patients at times. However, its core members are mainly from the family and the extended kin group of the sick. As in other illnesses, in mental illness also, the TMG principally comprises the family members, who take all decisions regarding the treatment and rehabilitation of the mental patient. Apart from the family, there are no institutions of the traditional type concerned with the care decisions for people with mental illness.

In natural course in India support to mental health cases are very much in asking. Thousands of mentally sick persons, some of them afflicted quite seriously, who are neither on medication nor are institutionalized, lead the life of a destitute. Discarded by their families and uncared-for by any voluntary agency, their existence is woefully dehumanized. Secondly, joint families are capable of providing human as well as material resources for the care of mentally ill, but as these families are gradually breaking down into nuclear households, it becomes an onerous duty for the already extremely preoccupied and busy family members to look after persons with mental illness. In these families, having a mentally sick person at home would mean that at least one of them will have to resign from his job or extremely limit his preoccupations to extend constant care to the sick. We have observed that parents can still provide – or are able to provide – all possible help to their mentally ill children. To a large extent this principle holds true for the interdependency of spouses on one another during crisis (i.e. negotiating with mental illness). FGDs have brought out that both the parents and spouses are in spite of all odds remained committed to their onus of care giving.

The situation is dismal with respect to the issue of community supports. Rather than giving help, they have an ambivalent attitude towards persons with mental illness. It was often thrown open in the FGD that the neighbour or even the relatives looks down upon the patient and the care givers. Even the courtesy call or meeting in social gathering in the presence of such care givers were not a welcome proposition.

The families suffer silently – in the absence of community support structures, they are the sole institutions that care for the mentally ill, and, at the same time, suffer from the social stigma that is tied to it. David Karp in his “Mental Illness, Care giving, and Emotion Management” has explained in great detail about care giving and emotion management in mental illness.

Based on 50 odd in-depth interviews, his paper considered how caregivers to a spouse, parent, child, or sibling suffering from depression, manic-depression, or schizophrenia manage their emotions over time. By considering the turning points in the joint career of caregivers and ill family members, analysis moves beyond studies that link emotions to particular incidences, momentary encounters, or discreet events. Four interpretive junctures in the caregiver-patient relationship are identified. Before diagnosis, respondents experience emotional anomie. Diagnosis provides a medical frame that provokes feelings of hope, compassion, and sympathy. In the present situation the intervention sessions raised hope and confidence of the care givers, as their patients were not only diagnosed but also supported through different sessions.

Realization that mental illness may be a permanent condition ushers in the more negative emotions of anger and resentment. Caregivers’ eventual recognition that they cannot control their family member’s illness allows them to decrease involvement without guilt. Decreased involvement and no guilt feeling of the care giver was not allowed to creep in by constant boosters of different types (mainly moral) by the research team. Karp's thesis is that the moral boundaries of care giving necessarily shift as the mental illness emerges over time, and that it is imperative to balance the needs of the mentally ill person with the needs of those who provide care and support. Karp reminds readers of the 4 C's: (1) I did not cause it, (2) I cannot cure it, (3) I cannot control it, (4) all I can do is cope with it. The FGDs were replete with such coping strategy and as a result the intervention running over twenty sessions and adherence to the suggestions by the care givers yielded positive result. And even those who were not so optimistic about the whole process were seen to be changing in their thought process.

It was clear from the study that the diseases of severe chronicity i.e BAD and Schizophrenia can be well handled by the family or the near and dear ones contrary to health facility based care. Regular and systematic interventions for the care givers under such situation to handle the burden of coping strategies need to evolved in consultation with experts (both clinicians and social workers and allied scientists)and administered



there off. The caregivers health status and moral are required to be kept in good state so that the patents are taken care off appropriately.

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