International Journal of Psychosocial Rehabilitation

ISSN 1475-7192

(Proudly Serving our Web Based, International Readers Since 1996)

Volume 16

July 2011 - June 2012

A WEB BASED PEER REVIEWED PUBLICATION FOR MENTAL HEALTH 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.

WWW. PSYCHOSOCIAL. COM

IJPR Volume 16, Number 1

Feature Articles Page

Journal Information

This peer reviewed Journal was created in 1996 by practitioners, mental health program managers and mental health consumers to provide international practitioners, scholars and consumers with a forum to publish and discuss their work in program development, evaluation research, policy innovations, and therapeutic practices that have been successful in their particular region and cultures. IJPR is not associated with any university or governmental institution, nor is it part of any 'old boy' or other professional network. It was created to provide information to an international readership about issues related to psychosocial rehabilitation and associated topics.

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.

We invite comment from all readers on any and all subjects published in this journal, including the journal format itself. Feel free to comment on the Bulletin Board as well.

Publishing Information

The International Journal of Psychosocial Rehabilitation is published byADG, S..A .(ADG) ADG is a private non-profit, limited corporation in Honduras and operating in a limited capacity in the United Kingdom. All information in IJPR is provided for personal use. Reproduction for publication or other use is strictly prohibited. Written permission must be obtained ADG, S.A., to reprint any information contained within the Journal, either in part or its entirety . Such permission may be requested in writing at the address listed below:

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

Feature Articles

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 1
July 2011– June 2012

Motivational Interviewing and Assertive Community Treatment: A Case for Training ACT Teams

Trevor J. Manthey, LMSW

Office of Mental Health Research and Training
University of Kansas School of Social Welfare
1545 Lilac Lane, Lawrence, KS 66044-3184

Shannon Blajeski, MSW

Maria Monroe-DeVita, Ph.D.

Washington Institute for Mental Health Research and Training
University of Washington Department of Psychiatry and Behavioral Sciences
2815 Eastlake Avenue East, Suite 200, Seattle, WA 98102

Citation:
Manthey TJ, Blajeski S & Monroe-DeVita M. (2012). Motivational Interviewing and Assertive Community Treatment: A Case for Training ACT Teams. ***International Journal of Psychosocial Rehabilitation. Vol 16(1) 5-16***

All Correspondence can be sent to Trevor J. Manthey at trevormanthey@gmail.com

Abstract

Motivational Interviewing (MI) is an evidence-based clinical intervention that has shown positive outcomes for individuals with co-occurring serious mental illness and substance use disorders. Many of these individuals are similar to those served by Assertive Community Treatment (ACT) teams, highlighting that MI is an important intervention and a beneficial modality to be used within ACT teams. This article examines areas of treatment (assertive engagement, Integrated Dual Disorder Treatment and person-centered planning) which both utilize MI techniques and are considered an integral part of ACT services. These three areas of treatment are also assessed within the Tool for Measurement of Assertive Community Treatment (TMACT), an instrument used to assess fidelity to the ACT model. Lessons learned from the implementation, training and fidelity measurement of ACT teams in Washington State and recommendations for future MI implementation within ACT teams are described.

Keywords: Assertive Community Treatment, Motivational Interviewing, assertive engagement, person centered planning, Integrated Dual Disorder Treatment.

Introduction

Assertive Community Treatment (ACT) is a transdisciplinary team approach to providing treatment and rehabilitation to adults with severe and persistent mental illness, major functional impairments, and continuous high service needs within their community. It is the most widely studied evidence-based practice for this population and has consistently shown positive outcomes in the areas of decreased psychiatric hospitalization, improved housing stability, retention in treatment, and consumer and family satisfaction with services (Bond, Drake, Mueser, & Latimer, 2001).

Areas of service provision that are not always fully implemented by ACT teams include assertive engagement, Integrated Dual Disorder Treatment (IDDT) and person-centered planning. Based on IDDT research (Drake, Mueser, Burnette, & McHugo, 2004) and promising work in these areas with similar populations (e.g., Adams & Grieder, 2005; Tondora, Pocklington, Gorges, Osher, & Davidson, 2005) these three specific service areas are hypothesized to have additional positive outcomes within ACT, thereby improving the quality of ACT treatment and rehabilitation. The authors have utilized the Tool for Measurement of Assertive Community Treatment (TMACT), an instrument used to assess fidelity to the ACT model (Monroe-DeVita, Teague, & Moser, in press) in the implementation and ongoing training and technical assistance to ACT teams in Washington State. In addition to measuring other core elements of ACT, the TMACT encourages the acquisition and application of Motivational Interviewing (MI) skills, particularly in the areas of assertive engagement, IDDT, and person-centered planning. This article reviews the evidence base for utilization of MI within ACT teams across these three treatment areas and makes recommendations for ongoing training in MI within ACT.

The Evidence Base for MI in ACT

Motivational Interviewing, listed on the National Registry of Evidence-based Programs and Practices as an EBP (2009), has been included in over 200 published outcome studies (Wagner & Conners, 2010). In addition, many separate meta-analyses have reported an overall significant effect (Hettema, Steele, & Miller, 2005; Rubak, Sandboek, Lauritzen, & Christensen, 2005; Burke, Arkowitz, and Menchola, 2003; Lundahl, Tollefson, Gambles, Brownell & Burke, 2010). Based on these findings it has been suggested that MI outperforms traditional interventions in the treatment of a variety of behavior change issues. These behavior change issues are similar if not identical to those addressed by areas of ACT teams' service provision and include treatment of dual disorders (Martino, Carroll, Kostas, Perkins, & Rounsaville, 2002), mental health (Arkowitz, Westra, Miller, & Rollnick, 2007), physical health (Rollnick, Miller, & Butler, 2008), medication adherence (McCracken & Corrigan, 2008), prevention programming (Bennett, Stoops, Call, & Flett, 2007), homelessness (Fisk, Sells, & Rowe, 2007), HIV risk reduction (Koblin, Chesney, Coates, et al., 2004), probation (Harper & Hardy, 2002) criminal justice (McMurran, 2009), supported employment (Larson, 2008), and vocational rehabilitation (Lloyd, 2008; Manthey, 2009).

Findings further support using MI to decrease substance use with individuals who experience co-occurring schizophrenia or schizoaffective disorders and most substance abuse disorders (e.g. Barrowclough, Haddock, Tarrier, Lewis et al., 2001; Bellack & DiClemente, 1999; Graeber, Moyers, Griffith, Guajardo, & Tonnigan, 2003; Ziedonis & Trudeau, 1997; Martino et al., 2002; Handmaker, Packard, & Conforti, 2002, Steinberg, Ziedonis, Krejci, & Brandon, 2004; Carey, Purnine, Maisto, & Carey, 2001). Motivational Interviewing has also been found to help individuals with a psychiatric disability transition from inpatient to outpatient settings (Swanson, Pantalon, & Cohen, 1999), and to improve attendance and involvement in dual diagnosis treatment (Martino, Carroll, O'Malley, & Rounsaville, 2000). In addition, most consumers with a psychiatric disability who receive MI respond positively regarding its value and helpfulness (e.g. Franklin, Murphy, Cameron, Ramirez, et al., 1999).

A meta-analysis conducted by Hettema (2005) found that the effects of MI appear to persist or increase over time when added to an active treatment. This was termed the additive effect. The additive effect appeared to have more potency and effectiveness over time than either MI or the active treatment when delivered alone. This finding lends further credibility to the idea that adding MI to ACT teams (an active treatment model) could increase the effectiveness of ACT team intervention.

ACT Treatment Areas Utilizing MI

Kortrijk, Mulder, Roosenschoon, and Wiersma (2009) recommend utilizing MI for addressing problems of motivation for individuals within ACT. The following section expands on this recommendation by outlining three distinct areas of ACT treatment outlined within the TMACT where MI is recommended as a beneficial modality: assertive engagement, Integrated Dual Disorder Treatment, and person-centered planning.

Assertive Engagement

Individuals with a dual diagnosis (severe mental illness and co-occurring substance use disorders) often lack motivation to manage psychiatric symptoms and pursue employment or other functional goals (Drake, Essock, Shaner, Carey, Minkoff, et al., 2001). Therefore, ACT teams sometimes need to do some additional work to engage consumers to be an active participant in services. Further, to meet fidelity to the ACT model, teams are required to utilize assertive engagement techniques for the purpose of retaining consumers, engaging them in treatment and fostering therapeutic relationships (Monroe-DeVita, Teague, & Moser, in press). According to the TMACT fidelity protocol, the team should use an array of techniques including (a) collaborative, motivational interventions to engage consumers and build intrinsic motivation for receiving services from the team (b) when necessary, therapeutic limit-setting interventions to create extrinsic motivation for receiving services deemed necessary to prevent harm to the consumer or to others (when therapeutic limit-setting interventions are used, there is a focus on instilling autonomy as quickly as possible) and (c) thoughtful processes for measuring effectiveness of engagement techniques and adjusting them appropriately.

Helping individuals tap into intrinsic motivation can create long-term behavior change, while using external or compliance-based motivation often creates only short-term behavior change (Miller & Rollnick, 2002). Unfortunately, sometimes practitioners on ACT teams may sacrifice long term behavior change for short term compliance. Therefore, it is important for ACT teams to utilize MI to gain understanding of individuals' goals, wishes and values in order to facilitate engagement; rather than immediately jumping to therapeutic-limit setting techniques (such as outpatient involuntary commitment, payeeship, etc). Using MI allows the practitioner to both directly involve the individual in their treatment and retain them in the program.

Integrated Dual Disorder Treatment

Approximately 50 % of individuals with a psychiatric disability are affected by substance use disorders (Essock, Mueser, Drake, Covell, McHugo, et al., 2006). Further, Morrissey, Meyer, & Cuddeback (2007) found no significant reduction in substance abuse or jail days for individuals with co-occurring disorders when using the ACT model as a sole intervention. Implementing Integrated Dual Disorder Treatment (IDDT) within the structure of ACT teams has been necessary to meet the needs of individuals who experience co-occurring substance use disorders and severe mental illness.

The IDDT model (Mueser, Noordsy, Drake & Fox, 2003) suggests that consumers with co-occurring disorders be treated from a stage-wise treatment approach integrating the Transtheoretical stages-of-change model (Prochaska & Diclemente, 1992) with stages of treatment (see Table 1 for a description of how consumers in different stages can receive different treatment approaches). Specifically, the IDDT model proposes that consumers who are assessed to be in early stages of treatment, based on their early stages of change, be engaged utilizing MI to help them resolve their ambivalence and discover their own motivations for decreasing and/or abstaining from substances. This differs from a traditional chemical dependency treatment approach in that confrontation is not used when an individual is perceived as resistant.

Table 1
Examples of Stage-Wise Substance Abuse Treatment Interventions*

Early Stages of Change Readiness		Later Stages of Change Readiness	
Pre-Contemplation	Contemplation and Preparation	Action	Maintenance
The consumer does not recognize that s/he has a problem with substance use or has no interest in modifying use at	The consumer recognizes that substance use is causing some problems and is considering a change. In the contemplation stage, the consumer is more aware about the pros & cons, but ambivalent about change; whereas in the preparation stage, the consumer is	The consumer is committed to reducing or discontinuing substance use. Focus of treatment is helping her/him make change & sustain it:	The consumer has abstained from substance use for at least 6 months. Focus of treatment is maintaining abstinence: • develop a relapse

this time. Focus of treatment is outreach, assessment, and building a working alliance. Services are provided regardless of ongoing use.	planning for change. Focus of treatment is education about substances, mental illness, and their interactions, and identifying pros & cons of use. Motivational interviewing techniques are essential: • express empathy • offer reflective listening • assist with goal-setting • develop discrepancy between goals and substance use • conduct decision balance (pros & cons) • roll with resistance to change • emphasize personal choice	• cognitive-behavioral therapy • managing social environments • identifying & managing triggers and cravings • relaxation/coping skills • money management to avoid using • problem solving to reduce stress	• prevention plan • help consumer attend • self-help groups • help build and maintain social supports for sobriety • maintain awareness of vulnerability to relapse • help expand recovery to other areas of life (parent group, vocational supports)

*Adapted from the TMACT Protocol (Monroe-DeVita, Teague, & Moser, in press)

Given that research on consumer populations with co-occurring schizophrenia and substance use disorders cite that low motivation is often an explanation for poor outcomes in treatment (Drake et al., 2001) and that ACT teams are developing capacity to provide IDDT, it is beneficial that ACT clinicians become skilled in MI techniques.

Person-Centered Planning

In addition to utilizing motivational interventions to engage consumers in their treatment, it is necessary that ACT teams have a person-centered perspective (e.g., able to see a participant as a person with normative needs and desires, rather than a 'mentally ill person.'). Outcomes associated with a shift from traditional mental health treatment planning to person-centered planning include improved access to treatment, better retention in treatment and improved personal outcomes that are important to the client (Adams & Grieder, 2005). Motivational interviewing has been suggested as a means to help individuals with a psychiatric disability explore and develop individualized goals and attempt to achieve them (Corrigan, McCracken, & Holmes, 2001).

Inherent to the MI skill set is attending to an individual's goals and values. The MI practitioner attempts to evoke from within the individual how they envision themselves reaching their goals and determining how their current behavior fits or conflicts with what has been identified (Miller & Rollnick, 2002). Therefore, the process of training an ACT team in MI may assist clinicians in becoming more person-centered or more recovery-oriented in their framework. In this way, MI can add to or enhance a team's recovery orientation and their person-centered planning ability, helping them to better engage consumers in the treatment and rehabilitation process.

Measuring Fidelity for Performance Improvement

To assess program fidelity is to evaluate the extent to which a program adheres to the intended implementation model. Fidelity measures may assess program elements such as the population to be served, staffing and staff roles, and specific program processes and interventions. This is important because high fidelity is tied to better outcomes across many evidence-based practices, including ACT (McHugo et al., 1999; Becker et al., 2001).

The Tool for Measurement of Assertive Community Treatment (TMACT) (Monroe-DeVita, Teague, & Moser, in press) is an enhanced version of the original ACT fidelity scale, the Dartmouth Assertive Community Treatment Scale (DACTS) (Teague, Bond, Drake, 1998). The TMACT contains 47 items, grouped into six subscales, including: (1)

Operations & Structure, (2) Core Team, (3) Specialist Team, (4) Core Practices, (5) Evidence-Based Practices, and (6) Person-Centered Planning and Practices. It was designed, in part, to capture not only the structural components of an ACT team, but how core services such as assertive engagement, IDDT and/or person-centered planning are carried out by a team.

The organization of the TMACT and the DACTS is very similar; each item is rated on a five-point behaviorally-anchored scale, ranging from one (not implemented) to five (fully implemented) and ratings are based on the current structure and activities of the team (i.e., not future plans). Among the many changes from the DACTS, the TMACT expands the DACTS fidelity measurement by rating ACT teams' use of other evidenced-based clinical modalities including MI and IDDT. To date, the TMACT has been adopted and piloted in five states as well as in Japan and Norway, and is being used by several teams in other states. A recent study using the TMACT to evaluate ten Washington State ACT teams found that teams scored significantly lower on the TMACT than on the DACTS at baseline, six, and 12 months, while also demonstrating greater improvement over time in comparison, suggesting that the TMACT is a more sensitive measure of ACT (Monroe-DeVita, Teague, & Moser, in press). Teams also consistently scored lower in the areas of specialist roles, integration of other EBPs, and person-centered practices--areas not assessed by the DACTS--suggesting the need for ACT teams to better implement specialist roles and apply specific strategies to improve clinical, functional, and recovery outcomes.

In 2007, 10 ACT teams were concurrently implemented in Washington State (Bjorklund, Monroe-DeVita, Reed, Toulon, & Morse, 2009). All 10 teams received a TMACT fidelity review at six month intervals for a total of four reviews per team over a two-year period. Thereafter, TMACT fidelity reviews continued on a yearly basis.

At start-up, all 10 newly-implemented ACT teams were provided a one-day ACT overview followed by a variety of core skills trainings including an MI training meant as an exposure to basic skills. In fall 2008 and spring 2009, a Motivational Interviewing Network of Trainers (MINT) trainer also skilled in the TMACT fidelity scale provided two MI training sessions scheduled one month apart on-site to each of the 10 teams. The month lag time in between the MI training was purposefully scheduled in order to allow trainees the opportunity to practice their MI skills. The practitioners were then able to report to the trainers where they felt they needed added skill development and support. The follow-up training and consultations were then focused on these individualized areas.

A summary of TMACT items assessing for the use of MI and a Stage-wise Treatment approach is noted in Table 2. Performance improvement is one of the primary foci of a fidelity scale. The TMACT showed sensitivity to the needs of teams when their scores dropped on the items illustrated in Table 2. The need for continued MI training and consultation was noted and generally TMACT fidelity review feedback sessions often included recommendations for continued MI training.

Table 2

TMACT Fidelity Scale Items Assessing either Motivational Interviewing or Stage-Wise Treatment

Assertive Engagement (Core Practices) (CP2)	**Integrated Dual Disorder Treatment** (Evidenced-Based Practices) (EP7)	**Person-Centered Planning** (Person-Centered Practices) (PP2)
Team uses an array of techniques to engage consumers, including (1) collaborative, motivational interventions to engage consumers and build intrinsic motivation for receiving services from team and where necessary, (2) therapeutic limit-setting interventions to	Program uses a stage-wise treatment model that is non-confrontational and the FULL TEAM (1) considers interactions between mental illness and substance abuse; (2) follows cognitive-behavioral principles; (3) does not have absolute expectations of abstinence and supports harm reduction; (4) understands and applies stages of change	The team conducts person-centered planning: (1) development of formative treatment plan ideas based on discussion with the consumer; (2) conducting regularly scheduled treatment planning meetings; (3) attendance by key staff, the consumer, and anyone else she/he prefers (e.g.

create extrinsic motivation for receiving services deemed necessary to prevent harm to consumer or others. (3) the team has a thoughtful process for identifying the need for assertive engagement, measuring the effectiveness of these techniques, and modifying approach where necessary.	readiness in treatment; and (5) is skilled in motivational interviewing.	family), (4) meeting driven by the consumer’s goals and preferences; and (5) provision of coaching and support to promote self-direction and leadership within the meeting, as needed.
	The substance abuse specialist provides integrated dual disorder treatment to PACT consumers who have a substance use problem. Core services include: (1) systematic and integrated screening and assessment; interventions tailored to those in (2) early stages of change readiness (e.g., outreach, motivational interviewing) and (3) later stages of change readiness (e.g., CBT, relapse-prevention).	
	Full Responsibility for Dual Disorders Treatment: These include services provided by the substance abuse specialist as well as other team members well-versed in integrated, stage-wise treatment for co-occurring disorders. Core services include: (1) systematic and integrated screening and assessment and interventions tailored to those in (2) early stages of change readiness (e.g., outreach, motivational interviewing) and (3) later stages of change readiness (e.g., CBT, relapse-prevention).	
	Substance Abuse Specialist on Team: The team has at least 1.0 FTE staff member designated as a substance abuse specialist. Preferably this specialist has training or experience in integrated dual disorder treatment.	

*Adapted from TMACT fidelity instrument (Monroe-DeVita, Teague, & Moser, in press)

Training Motivational Interviewing

Performance improvement on ACT teams cannot be obtained without adequate training and some agencies have not fully appreciated the intricacy involved in learning MI (Cahill, 2008). Many agencies have begun training practitioners in MI through one day single shot workshops, the results of which have been mixed (Baer, Rosengren, Dunn, Wells, Ogle, & Hartzler, 2004). In addition, some agencies have tried to have their staff build MI skills through self directed learning, which is ineffective (Miller, Yahne, Moyers, Martinez, & Purritano, 2004). Recent training research has shown evidence that the typical one or two day workshop may not be the best way to learn MI (Miller & Mount, 2001; Walters, Matson, Baer, & Ziedonis, 2005), and that MI skills are not retained without added supervision (Heaven, Clegg, & Maguire, 2006). A more effective form of learning MI after initial training has been shown to be continued supervision in the form of feedback and coaching (Bennett, Moore, Vaughan, Rouse, et al., 2007; Miller et al., 2004). One of the benefits of using the TMACT fidelity scale is that it assesses for indicators to determine when continued supervision and coaching in MI is needed.

In the spirit of helping to facilitate effective trainings for performance improvement, suggestions are provided based on concerns verbalized during the training of MI in Washington State. These suggestions are depicted in Table 3. Some of the concerns described were originally detailed in a newsletter for an organization of motivational interviewing trainers in the context of vocational rehabilitation (Manthey, 2009) and are repeated here with some adaptations and additions for the ACT context.

Table 3

Suggestions for responding to selected concerns expressed by individuals learning MI.

Concern:	**Potential Response:**
"What if they're symptomatic?" It can sometimes be difficult to use MI with individuals with a psychiatric disorder who are experiencing symptoms.	· Emphasize that one can still function within the spirit of MI even if circumstances don't always permit using MI in its pure intervention form. · Emphasize that there are adaptations of MI made specifically for individuals with psychiatric disabilities. (See the following for further information on this topic, Carey, Leontieva, Dimmock, Maisto, & Batki, 2007; Corrigan, McCracken, & Holmes, 2001; Martino, Carroll, Kostas, Perkins, & Rounsaville, 2002; and, Rusch & Corrigan, 2002).
"Not all of us are therapists!" Not all ACT team practitioners are mental health clinicians (e.g. nurses, housing specialists, supported employment specialists, peer counselors etc) and for some there may be a desire to avoid interactions that could be construed as therapy.	· Emphasize that MI is a way of being with people. · Emphasize that MI has helped people make diverse behavior changes in a wide variety of settings, not just therapy. · Spend more time helping people grasp the spirit of MI.
"What if they don't change?" If an individual decides not to change or fails at their attempt to change than the practitioner may feel as if they have failed or done a poor job.	· Emphasize that within MI choosing not to change is a legitimate option (even though the likelihood that someone will change is increased). · Discuss the importance of not getting attached to an individual outcome. It is more helpful to improve/develop one's own skill set than to try to control the result for each participant.
"I already do this stuff." Some trainees report that they already posses the skills described in the MI training.	· Try to avoid confronting these statements, rather utilize analogies or conduct activities which develop discrepancy between what participants state they do and what they are

Concern:	Potential Response:
	actually doing.
"I need lots more practice." Some ACT team practitioners report a lack of confidence in their ability to do MI, even if they understand MI concepts.	· Adding monthly feedback and supervision portions to the training workshop series increases confidence and skill development (See Heaven et al., 2006; Miller & Mount, 2001; Miller et al., 2006).
"If they would just listen." Assuming the expert role is a common issue faced by practitioners when learning MI. Once in this role practitioners will offer unsolicited solutions or advice about how to fix an individual's problems.	· There are several behaviors that can help with this issue discussed by Rollnick et al. (2008): Avoid arguing for change when the service user is not ready, do not assume practitioners have to offer all the solutions for change, do not assume the consumer ought to change, wants to change or that recovery is the prime motivator for them to change. · Emphasize that giving information to consumers can be beneficial and can occur in MI consistent ways: such as asking permission before giving advice and providing a menu of opjtions (See Miller & Rollnick, 2002).
"There isn't enough time!" Some ACT teams consistently function in a state of crisis. Meaning the team is reactive, moving from crisis to crisis without believing they are able to slow down and conduct proactive or preventative interventions. When this occurs teams often spend a lot of time trying to push people into behavior changes rather than drawing out behavior change from within the person.	· Discuss avoiding the premature focus trap (See Miller & Rollnick, 2002). · Emphasize that MI has been used successfully in very brief settings such as healthcare and therefore can be a very short intervention if needed.

Recommendations

Although further research needs to be conducted to more fully assess the effectiveness and implementation of MI within an ACT model; this article clearly lays out the treatment areas where MI skills are necessary to meet fidelity to the ACT model. Utilization of fidelity scales are meant to be a continual process and not a one-time assessment. Therefore, utilizing the TMACT fidelity scale not only allows assessment of a team's adherence to the ACT model but also can provide information such as whether to implement further technical assistance in other evidence-based practices. Based on the information described here, recommendations for future implementation of MI into ACT teams include utilization of the TMACT fidelity protocol because of its ability to track the use of MI. It is also recommended that future efforts to implement MI within ACT teams include additional follow along supports such as supervision and coaching. This would provide practitioners continued support in implementing the practice as well as increasing their confidence and skills. Supervision and coaching would also allow for consultation with team leaders and staff around using MI to build relationships with difficult-to-engage participants. Most importantly, implementing MI provides practitioners on ACT teams with practical skills that increase their ability to engage consumers into services, provide Integrated Dual Disorder Treatment, conduct person-centered planning, and generally increase consumer motivation for behavior change and recovery.

References:

Adams, N & Grieder, D. (2005). Treatment planning for person-centered care: the road to mental health and addiction recovery. Burlington, MA: Elsevier Press.

Arkowitz H., Westra HA, Miller WR, Rollnick S (2007). Motivational interviewing in the treatment of psychological problems. Guilford Press. New York

Baer, J., Rosengren, D., Dunn, C., Wells, E., Ogle, R., Hartlzler, B. (2004). An evaluation of workshop training in motivational interviewing for addiction and mental health clinicians. Drug and Alcohol Dependence 73, 99–106

Barrowclough, C., Haddock, G., Tarrier, N., Lewis, S. W., Moring, J., O'Brien, R., et al.(2001). Randomized controlled trial of motivational interviewing, cognitive behavior therapy, and family intervention for patients with comorbid schizophrenia and substance abuse disorders. *AmericanJournal of Psychiatry,* 158, 1706-1713.

Bellack, A. S., & DiClemente, C. C. (1999). Treating substance abuse among patients with schizophrenia. *Psychiatric Services,* 50, 75-80.

Bennett, G., Moore, J., Vaughan, T., Rouse, L., Gibbins, J., Thomas, P., James, K.,Gower, P. (2007) Strengthening Motivational Interviewing skills following initial training: A randomised trial of workplace-based reflective practice Addictive Behaviors 32, 2963–2975

Bennett, L.W., Stoops, Call, C., & Flett, H. (2007). Program completion and re-arrest in a batterer intervention system. *Research on Social Work Practice, 17*(1), 42-54.

Bond, G. R., Drake, R. E., Mueser, K. T., & Latimer, E. (2001). Assertive community treatment for people with severe mental illness: Critical ingredients and impact on patients.Disease Management & Health Outcomes, 9, 141-159.

Bjorklund, R. W., Monroe-DeVita, M. M., Reed, D., Toulon, A., Morse, G. (2009). Washington state's initiative to disseminate and implement high-fidelity ACT teams. *Psychiatric Services,* 60(1), 24-28.

Burke, B.L., Arkowitz, H., & Menchola, M. (2003). The efficacy of motivational interviewing: A meta-analysis of controlled clinical trials. *Journal of Consulting and Clinical Psychology, 71*(5), 843-861.

Cahill, M.A., VanBenschoten, S.W., Walters, S.T. (2008). Motivational Interviewing training in criminal justice: Development of a model plan. *Federal Probation*, 72(2), 61-66.

Carey, K. B., Leontieva, L., Dimmock, J., Maisto, S. A., & Batki, S. L. (2007). Adapting motivational interventions for comorbid schizophrenia and alcohol use disorders. *Clinical Psychology: Science and Practice*, 14, 39-57.

Carey, K. B., Purnine, D. M., Maisto, S. A., & Carey, M. P. (2001). Enhancing readiness- to-change substance abuse in persons with schizophrenia. *Behavior Modification,* 25, 331-384.

Corrigan, P. W., McCracken, S. G., & Holmes, E. P. (2001). Motivational interviews as goal assessment for persons with psychiatric disability. *Community Mental Health Journal*, 37(2), 113-122.

Drake, R.E., Essock, S.M., Shaner, A., Carey, K.B., Minkoff, K., Kola, L., Lynde, D.,Osher, F.C., Clark, R.E., & Rickards, L. (2001) Implementing dual diagnosis services for clients with severe mental illness. *Psychiatric Services*. 52:469-476.

Drake, R., Mueser, K., Burnette, M., & McHugo, G. (2004). A review of treatments for people with severe mental illness and co-occurring substance use disorders. Psychiatric Rehabilitation Journal, 27(4), 360-374.

Essock, S.M., Mueser, K.T., Drake, R.E., Covell, N.H., McHugo, G.J., Frisman, L.K.,Kontos, N.J., Jackson, C.J., Townsend, F. & Swain, K. (2006) Comparison of ACT and standard case management for delivering integrated treatment for co-occurring disorders. *Psychiatric Services*. 57. 185-196.

Fisk, D., Sells, D., & Rowe, M. (2007). Sober housing and motivational interviewing: The treatment access project. *The Journal of Primary Prevention.* 28, 281-293.

Franklin, C. L., Murphy, R. T., Cameron, R. P., Ramirez, G., Sharp. L. D., & Drescher,K. D. (1999, November). *Percieved helpfulness of a group targeting motivation to change PTSD symptoms.* Poster presented at the annual meeting of the International Society for Traumatic Stress Studies, Miami, FL.

Graeber, D. A., Moyers, T.B., Griffith, G., Guajardo, E., & Tonigan, S. (2003). Addiction services: A pilot study comparing motivational interviewing and an educational intervention in patients with schizophrenia and alcohol use disorders. *Community Mental Health Journal,* 39, 189-202.

Handmaker, N., Packard, M., & Conforti, K. (2002). Motivational interviewing in thetreatment of dual disorders. In W. R. Miller & S. Rollnick, *Motivational interviewing: Preparing people for change (2nd ed.). New York: Guilford Press.*

Harper, R. and Hardy, S. (2002) ‘An Evaluation of Motivational Interviewing as a Method of Intervention with Clients in a Probation Setting’, *British Journal of Social Work* 30(3): 393–400.

Heaven, C., Clegg, J., & Maguire, P. (2006). Transfer of communication skills from workshop to workplace: The impact of clinical supervision. Patient Education and Counseling, 60, 313–325.

Hettema, J., Steele, J., & Miller, W. R. (2005). Motivational Interviewing. Annual Review of Clinical Psychology, 1, 91-111.

Koblin, B., Chesney, M., Coates, T. and EXPLORE Study Team (2004) ‘Effects of a Behavioural Intervention to Reduce Acquisition or HIV Infection among Men who have Sex with Men: The EXPLORE Randomised Controlled Study’, *Lancet* 364(9428): 41–50.

Kortrijk, H. E., Mulder, C. L., Roosenschoon, B. J., & Wiersma, D. (2009). Treatment Outcome of Patients Receiving Assertive Community Treatment. *Community Mental Health Journal*, DOI 10.1007/s10597-009-9257-9

Larson, J. (2008). User-friendly motivational interviewing and evidence-based supported employment tools for practitioners. *Journal of Rehabilitation.* 74, 18-30.

Lloyd, C., Tse, S., Waghorn, G., Hennessy, N., (2008). Motivational Interviewing in Vocational Rehabilitation for People Living with Mental Ill Health. International Journal of Therapy and Rehabilitation. 15(12), 572-578.

Lundahl, B. W., Tollefson, D., Gambles, C., Brownell, C., & Burke, B. (2010). Meta-analysis of Motivational interviewing: Twenty Five years of research. *Research on Social Work Practice*, 20(2), 137-160.

Manthey, T. (2009). Training motivational interviewing in a vocational rehabilitation context. *MINT Bulletin*, 15(1) 9-13.

Martino, S., Carroll, K. M., O’Malley, S. S., & Rounsaville, B. (2000). Motivational interviewing with psychiatrically ill substance abusing patients. *American Journal on Addictions,* 9, 199-213.

Martino, S., Carroll, K., Kostas, D., Perkins, J.,& Rounsaville, B. (2002). Dual diagnosis motivational interviewing: A modification of motivational interviewing for substance-abusing patients with psychiatric disorders. *Journal of Substance Abuse Treatment,* 23, 297-308.

McCracken, S. G., & Corrigan, P. W. (2008). Motivational Interviewing for Medication Adherence in Individuals with Schizophrenia. In H. Arkowitz, H. A. Westra, W. R. Miller, & S. Rollnick, *Motivational Interviewing in the Treatment of Psychological Problems. New York: Guilford Press.*

McMurran, M. (2009). Motivational interviewing with offenders: A systematic review.*Legal and Criminological Psychology*, 14, 83-100.

Miller, W. R., & Mount, K. A. (2001). A small study of training in motivational interviewing: Does one workshop change clinician and client behavior? Behavioural and Cognitive Psychotherapy, 29, 457-471.

Miller, W. R., & Moyers, T. B. (2006). Eight stages in learning motivational interviewing. Journal of Teaching in the Addictions, 5, 3-17.
Miller, W. R., & Rollnick, S. (2002). Motivational interviewing: Preparing people for change (2nd ed.). New York: Guilford Press.

Miller, W. R., Yahne, C. E., Moyers, T. B., Martinez, J., & Pirritano, M. (2004). A randomized trial of methods to help clinicians learn motivational interviewing. Journal of Consulting and Clinical Psychology, 72, 1050-1062.

Monroe-DeVita, M., Teague, G. B., & Moser, L. L. (in press). The TMACT: A new tool for measuring fidelity to assertive community treatment. *Journal of the American Psychiatric Nurses Association.*

Morrissey, J., Meyer, P., & Cuddeback, G. (2007) Extending assertive communitytreatment to criminal justice settings: origins, current evidence, and future directions. *Community Mental Health Journal*. 23:527-544. October 2007.

Mueser, K. T., Noordsy, D. L., Drake, R. E. & Fox, L. (2003). Integrated Treatment forDual Disorders: A Guide to Effective Practice. New York, NY: Guilford Press.

National Registry of Evidence based and Promising Practices. (2009). MotivationalInterviewing. Substance Abuse and Mental Health Services Administration. http://www.nrepp.samhsa.gov/listofprograms.asp?textsearch=Motivational+Interviewing&ShowHide=1&Sort=1. Accessed January 11, 2009.

Prochaska, J.O., DiClemente, C.C., & Norcross, J.C. (1992). In search of how people change: Applications to addictive behaviors. American Psychologist, 47, 1102-1114.

Rollnick, S., Miller, W. & Butler, C. (2008). Motivational Interviewing In Health Care: Helping patients change behavior. The Guilford Press. New York, New York.

Rubak, S., Sandboek, A., Lauritzen, T., & Christensen, B. (2005). Motivational interviewing: A systematic review and meta-analysis. British Journal of General Practice, 55(513), 305-312.

Rusch, N. & Corrigan, P. W. (2002). Motivational interviewing to improve insight and treatment adherence in schizophrenia. *Psychiatric Rehabilitation Journal,* 26(1), 23-32.

Steinberg, M. L., Ziedonis, D. M., Krejci, J. A., & Brandon, T. H. (2004). Motivational interviewing with personalized feedback: A brief intervention for motivating smokers with schizophrenia to seek treatment for tobacco dependence. *Journal of Consulting and Clinical Psychology,* 72, 723-728.

Swanson, A. J., Pantalon, M. V., & Cohen, K. R. (1999). Motivational interviewing and treatment adherence among psychiatrically and dually diagnosed patients. *Journal of Nervous and Mental Disease,* 187, 630-635.

Teague, G., Bond, G., Drake, R. (1998). Program fidelity in assertive community treatment: development and use of a measure. American Orthopsychiatric Association, Inc. 68(2), 216-232.
Tondora, J., Pocklington, S., Gorges, A., Osher, D., & Davidson, L. (2005).

Implementation of person-centered care and planning: From policy to practice to evaluation. Retrieved November 2, 2009, from The Center on Mental Health Services Research and Policy (MHSRP) at the University of Illinois at Chicago. Website: http://www.psych.uic.edu/uicnrtc/cmhs/pfcppapers.htm

Wagner C, Conners W, (2010). Motivational interviewing: Motivational interviewing bibliography 1983-2007. Mid-Atlantic Addiction Technology Transfer Center. http://motivationalinterview.org/library/biblio.html (accessed 11 April 2010).

Walters, S. T., Matson, S. A., Baer, J. S., & Ziedonis, D. M. (2005). Effectiveness of workshop training for psychosocial addiction treatments: A systematic review. Journal of Substance Abuse Treatment, 29(4), 283-293.

Ziedonis, D. M., & Trudeau, K. (1997). Motivation to quit using substances among individuals with schizophrenia: Implications for motivation-based treatment model. *Schizophrenia Bulletin,* 23, 229-338.

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 1
July 2011– June 2012

The Psychosocial Rehabilitation Needs Of Residents Of A Half –Way House For Mental Health Care Users In Durban, South Africa

Barbara Simpson, PhD

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

Thamary Zambuko,
B.Social Science (Social Work)
Masters Student
School of Social Work and Community Development
University of KwaZulu- Natal
Durban ,South Africa

Citation:
Simpson B. & Sambuko T. (2012). The Psychosocial Rehabilitation Needs Of Residents Of A Half -Way House For Mental Health Care Users In Durban, South Africa. ***International Journal of Psychosocial Rehabilitation. Vol 16(1) 17-26***

Correspondence to: Dr B Simpson : Simpson@ukzn.ac.za

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

Abstract

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

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

Introduction

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

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

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

Psychosocial Rehabilitation: A Brief Literature Review

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

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

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

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

The Research Study

Problem statement and aim of the study

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

Theoretical framework

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

Data collection and analysis

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

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

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

Ethical Issues

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

Discussion of Results

Skills for daily living

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

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

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

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

Management of illness and symptom control

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

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

Social support systems

Families

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

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

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

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

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

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

Friends

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

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

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

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

Housing aspects

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

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

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

Vocational aspects

Residents had a wide range of previous work experience. This included civil engineering technician, army officer lieutenant, computer technician, baker, assistant nurse, till operator, salesman, artist, architect, marketing manager, business person, recruiting agent and commodities trading planner. Their illnesses had impacted negatively on their ability to work and very few of the residents of Grace Home were employed at the time of the research. Most of the residents indicated however that they would like to be employed.

Six residents from Grace House work as car guards. They have received training and are registered. One resident has progressed to head car guard and was proud to report that he now gets paid leave. "Now I can live normal life, he commented." Another resident was proud of her efforts to improve herself. She did a computer course and applied for a supported employment job as an office administrator and now earns about R3000.00 per month.

For many of the residents, being ill had interrupted their education and training and they did not know how to proceed. Fees were identified as barriers to accessing further education and training. Typical comments were: "I passed matric and I have started Information and Technology, I am very good with computers. I dropped because I got sick. But I don't know how to get a scholarship" and "The problems I have are not knowing where to go in order to continue with adult school and also where to get financial help. I will be very glad to go back to school because I was very clever."

Not only was the need for vocational training identified, but life skills for coping in the work environment were lacking. Some were concerned about their monthly clinic appointments and how they would explain the need to take time off if they had permanent jobs. One resident said that although he wants to work, he would have a problem waking up for work everyday. Working with other people and having to concentrate would be difficult for some. They were also particularly worried about how they would cope with stress. Typical comments were: "It will be difficult for me to cope with meeting deadlines, pressure, and working quickly. I need to do things in my own time."

and "I can only cope with a minimum amount of stress".

Discussion and Recommendations

A number of themes, all of which have implications for psychosocial rehabilitation, emerged from this study. The first concerns the importance of individualized treatment which is central to the notion of psychosocial rehabilitation. A basic principle of pyschosocial rehabilitation is that rehabilitation needs must be determined in the context of the individual (Mowbray, Nicholson and & Bellamy, 2003) and that individual treatment plans should specifically be tailored to meet the needs of the MHCU as a unique person (Bachrach, 2000). The research findings indicate clearly that residents did not have individual treatment plans and that there was no long- term planning in respect of the residents. Treatment plans should be based on a comprehensive assessment of the MHCUs strengths, challenges and most importantly, their vision of how they want their future to be.

Drawing up individual treatment plans together with the resident, would serve several purposes. Goal setting, according to Egan (2002:250) helps "clients to focus their attention and action …. (and) helps to mobilize their energy and effort". An individual treatment plan would provide hope and motivation for the individual to move forward. It would also be useful from an organizational point of view and could assist the management of Grace Home in terms of planning future admissions and discharges. Some residents may not be able to live independently and will need on-going support and supervision. Management would need to decide whether Grace Home offers permanent supported accommodation for these individuals or whether transfer to other facilities might be a better option. In view of the fact that just over a quarter of the residents are over 50, planning for their care as older persons in the not too distant future seems to be a priority. Other residents might be able to live, with support, either independently or with their families but unless specific long- term plans are made nothing is likely to happen.

The second theme to emerge was the need for skills training in a number of areas. For many MHCUs, being exposed to institutionalized and custodial care for many years, has resulted in lowered self-esteem, an inability to socialize and interact, lack of motivation, skills, knowledge and resources to function in the community (Ekdawi, 1994). Chan, Lui, Wan & Yau (2002) suggest that skills training and social adjustment to independent living should be the main service objectives of half-way houses. Skills training has been subjected to much research and the available evidence indicates that systematic skills building through curriculum based psycho-educational and cognitive-behavioural interventions has a wide range of outcomes including symptom reduction, community adjustment, relapse prevention, and medication compliance (Barton, 1999).

The following skills training programmes would be useful at the Grace Home:
Skills for daily living: In terms of basic personal self care skills, most residents of Grace Home were coping well. However, it was clear that they have little opportunity to practice skills necessary for home maintenance. Nutrition, menu planning and meal preparation, for example, are not part of the every day experience of residents of Grace Home and more opportunities to be involved in these should be introduced to enable residents to prepare for more independent living.

Stress management: Many of the residents talked about their fear of not coping with stress of being with other people and of being in the workplace. Learning techniques for preventing and coping with stress would be helpful.

Confidence building and assertiveness: In many ways, the residents of Grace Home were fearful. They expressed fear of applying for employment because that will mean having to tell people about their illness, fear of making friends outside Grace Home because of the stigma associated with mental illness, and fear of being burden to others. Developing greater confidence and learning how to approach others in social situations would be important perquisites for more independent living.

Management of illness and symptom control: Understanding one's illness and learning to manage it is an important aspect of psychosocial rehabilitation and the residents of Grace Home would benefit from being encouraged to take more responsibility for their own well being. Educational programmes regarding the nature of psychiatric conditions and the advances in medication are recommended.

Skills training programmes, on their own, however, have not been shown to produce significant employment outcomes (Barton, 1999) and the need for vocational rehabilitation as part of a comprehensive psychosocial rehabilitation programme was evident in this study. International research evidence indicates that vocational rehabilitation enhances non- vocational outcomes such as functional status and activities of daily living (Chan, Lui, Wan and Yau, et al, 2002). Most of the residents expressed the desire to find meaningful employment but only a handful had been able to do so. Given the wide of range of skills and previous experience of many of the residents it would seem that a vocational rehabilitation programme would be essential.

A number of studies have now demonstrated that supported employment is an effective rehabilitation approach (Burns, Catty & Becker, et al, 2007; Bond, et al, 2008). Meaningful employment leads to improved social integration, normalized peer relationships and a source of identity (Warner, 2009). Successful supported employment programmes have demonstrated a commitment to a competitive employment goal (not a workshop placement), rapid job search and placement and jobs selected on the basis on individual preference, together with follow -up support. (Morris & Llyod, 2004). Unfortunately, supported employment programmes in South Africa are underdeveloped and in the area in which Grace Home is situated there are no such programmes. Given the lack of resources at Grace Home, a vocational rehabilitation programme at this time would not seem to be feasible. However, it is an area that deserves further attention and a creative option might involve sharing such a programme with other organizations.

The final major theme to emerge was the lack of social support and in particular, the fractured family relationships that existed for many of the residents. Social support is essential and it has been found that there is a significant association between good social support and perceived quality of life (Sharir, et al, 2009). The reasons for lack of social support especially from families were varied but some residents were clearly hurt by their childhood experiences and by what they perceived to be on-going unfair treatment by their families. Individual counseling would help residents to come to terms with the hurt and to move forward but counseling for families also seems indicated. Even if they are unable to offer the resident a home, education about the needs of their family members and the advances made in the management of mental illness might be helpful in beginning the process of restoring relationships. Healing some of the hurt caused by the behaviour of the resident when ill may also help to improve the quality of life of all concerned.

While the results of this study cannot be generalized to the broader population, they are of interest to social workers and health care professionals in the field of mental health and psychosocial rehabilitation. In comparison to many other facilities for people with mental health problems, especially in township and rural areas, Grace Home is fairly well resourced. In addition, a growing body of South African research indicates that many people who have been discharged from hospital to family care receive almost no services and that the burden on families is excessive (Kritzinger & Magaqa, 2000; Lazarus, 2005; van Rensburg, 2005; Reddhi, 2008). If the residents of Grace Home continue to experience so many challenges in respect of pyschosocial rehabilitation, one can only imagine the scale of problems that still need to be addressed. Social workers have an important role to play in identifying needs and designing programmes to address these at individual, family, group and community levels. In addition, if social workers are to be true to their commitment to social justice, they need to be far more vocal in respect of policy development and advocacy for better services for MHCUs.

Conclusions

Services to people with mental health problems in general, and psychosocial rehabilitation programmes in particular are underdeveloped in South Africa. This article has identified the need for a psychosocial rehabilitation programme at a particular residential facility for people with mental health problems. Programmes which encourage independent living and increase social skills to cope with the challenges of interacting with people in daily life seem to be most needed and would not require extensive resources to implement. More difficult to implement, but equally important for the long term well being of MHCUs would be vocational and supported housing programmes that would require far more resources.

References:

Babbie, E. & Mouton, J. (2001). The practice of social research. Cape Town: Oxford University Press.

Bachrach, L.L. (2000). Psychosocial rehabilitation and psychiatric in the treatment of schizopherenia: what are the boundaries? Acta Psychiatrica Scandinavica, 102(407),6-11.

Barton, R. (1999). Psychosocial rehabilitation services in community support systems: A review of outcomes and policy recommendations. Psychiatric Services, 50(4),525-534.

Bond, G.R., Drake, R.E. & Becker, D.R. (2008). An update on randomized controlled trials of evidence-based supported employment. Psychiatric Rehabilitation Journal, 31(4), 280-90.

Burns, T., Catty, J., Becker, T., Drake, R.E., Fioritti, A., Knapp, M., Lauber, C., Rössler, W., Tomov, T., Van Busschbach, J., White, S. & Wiersma, D. (2007). The effectiveness of supported employment for people with severe mental illness: a randomised controlled trial. Lancet, 29;370(9593), 1146-52.

Chan, C.C., Lui, W.W.S., Wan, D.L.Y. & Yau, S.S.W. (2002). Evaluating service recipient outcomes in psychiatric residential services in Hong Kong. Research on Social Work Practice, 12(4), 570-581.

Cook, J.A., Pickett, S.A., Razzano, L, et al: (1996). Rehabilitation services for person with schizophrenia. Psychiatric Annals, 26, 97-104.

Cnaan, R., Blankertz, L., Messinger, W. & Gardner, J.R. (1988). Psychosocial rehabilitation: Towards a definition. Psychosocial Rehabilitation Journal, 11(4), 61-77.

Department of Health. (1997a). National health policy guidelines for improved mental health in South Africa. Pretoria: Department of Health.

Department of Health. (1997b). White Paper for the transformation of the health system in South Africa. Pretoria: Government Gazette.

Ekdawi, M.Y. (1994). Psychiatric Rehabilitation: A Practical Guide. London: Chapman and Hall.

Egan, G. (2002). The skilled helper. A problem-management and opportunity- development approach to helping. (7th ed) Pacific Grove, CA: Brooks/Cole.

Jack, G. & Jack, D. (2000). Ecological social work: The application of a systems model of development in context. In: Stepney, P. & Ford, D (Eds.). Social work models, methods and theories. Lyme Regis: Russell Publishing House.

Kritzinger, A. & Magaqa, V. (2000). De-institutionalising the mentally ill in rural areas:A case study of the official care giver. Social Work/Maatskaplike Werk, 36(3), 296-309.

Lazarus, R. (2005). Managing de-institutionalization in a context of change: The case of Gauteng, South Africa, South African Psychiatry, 8(2), 65-69.

Littrell, K.H. & Littrell, S.H. (1998). Issues of re-integration and rehabilitation in schizophrenia. Psychiatric Annals, 28(7), 371-377.

Lund, C., Kleintjies, S., Campbell-Hall, V., Mjadu, S., Petersen, I., Bhana, A., Kakuma, R., Mlanjeni, B., Bird, P., Drwe, N., Faydi, E., Funk, M., Green, A., Omar, M. and Flisher, A.J. (2008). Mental policy development and implementation in South

Africa: a situation analysis. Phase 1 country report. Available: www.psychiatry.uct.ac.za/mhapp Accessed 1 September 2009.

Mowbray, C.T., Nicholson, J. & Bellamy, C.D. (2003). Psychosocial rehabilitation service needs of women. Psychiatric Rehabilitation Journal, 27(2), 104-113.

Morris, P. & Llyod, C. (2004). Vocational rehabilitation in psychiatry: a re-evaluation. Australian and New Zealand Journal of Psychiatry, 38(7), 490-494.

Republic of South Africa. (2002). MENTAL HEALTH CARE ACT, No 17 of 2002. Pretoria: Government Gazette.

Reddhi, A. (2008). Experiences of adult mental health care service users and their families. Unpublished Masters Dissertation. University of KwaZulu- Natal, Durban.

Sharir, D., Tanasescu, M., Turbow, D. & Maman, Y. (2007). Social support and quality of life among psychiatric patients in residential homes. International Journal of Psychiatric Rehabilitation, 11(1), 85-96.

Umansky, R., Telias, D., Tzidon, E., & Kotler, M. (1999). A school for mental health inpatient preparation for reinsertion in the community. International Journal of Psychosocial Rehabilitation, 4, 65-72.

Sheth, H.C. (2005). Common problems in psychosocial rehabilitation. International Journal of Psychosocial Rehabilitation, 10(1), 53.60.

Thomas, E.J. & Rothman, J. (1994). An integrative perspective on intervention research. In: Rothman, J. & Thomas, E.J. (Eds.). Intervention research. Design and development for human service. New York: The Haworth Press.

Van Rensburg, B.J. (2005) Community placement and re-integration of service users from long-term mental health care facilities. South African Psychiatry, 8(3), 100-103.

Warner, R. (2009). Recovery from schizophrenia and the recovery model. Current Opinion in Psychiatry, 22, 374-380.

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 1
July 2011– June 2012

A First-Person Exploration of the Experience of Academic Reintegration after First Episode Psychosis

Hiba Zafran, B.Sc. (O.T.), MSc.
Faculty Lecturer and PhD Candidate
School of Physical and Occupational Therapy
McGill University
McGill University Health Centre.

Beverlea Tallant, PhD., O.T. (C)
Retired Professor
Occupational Therapy program
School of Physical and Occupational Therapy
McGill University.
Email: beverlea.tallant@mcgill.ca

Isabelle Gelinas, B.Sc. (O.T.), Ph.D.
Researcher
Center for Interdisciplinary Research in Rehabilitation
Greater Montreal, Canada
Associate Professor
School of Physical and Occupational Therapy
McGill University
Email: isabelle.gelinas@mcgill.ca

Citation:
Zafran H, Tallant B, & Gelinas I (2012). A First-Person Exploration of the Experienceof Academic Reintegration after First Episode Psychosis. ***International Journal of Psychosocial Rehabilitation. Vol 16(1) 27-43***

Corresponding Mailing Address:
Allan Memorial Institute
1025 Ave des Pins West
Occupational Therapy Department, P2.168
Montreal, Quebec H3A 1A1 Canada
Telephone: 514.934.1934 ext. 34168
Email: hiba.zafran@mcgill.ca

Abstract

Many young people referred to occupational therapy desire to return to school and their student role after a first episode of psychosis. However, factors that mediate the process and experience of academic reintegration of young adults after a psychotic episode are unknown. This qualitative pilot study explored the phenomenon of returning to post-secondary school from the first-person perspective of five young adults in Montreal, Canada. They were interviewed individually to elicit narratives of their return to school experiences. A phenomenological lens was used in the qualitative analyses. Obstacles to returning to school included side effects of medications, cognitive difficulties, self-stigma and the fear of failure. Facilitators included desire, psychoeducation, social support, daily activities and occupational therapy interventions. Meaning-making for these five persons revolved around the overarching themes of ‘readiness’, ‘hope’ and ‘maturity’ in the process of developing selfhood after experiencing psychosis. These themes emerged as integral to understanding the successful experience of academic reintegration for the five participants, and in informing rehabilitation services.

Declaration of Interest: None
Key words: First episode psychosis, post-secondary school, qualitative research, readiness, occupational therapy

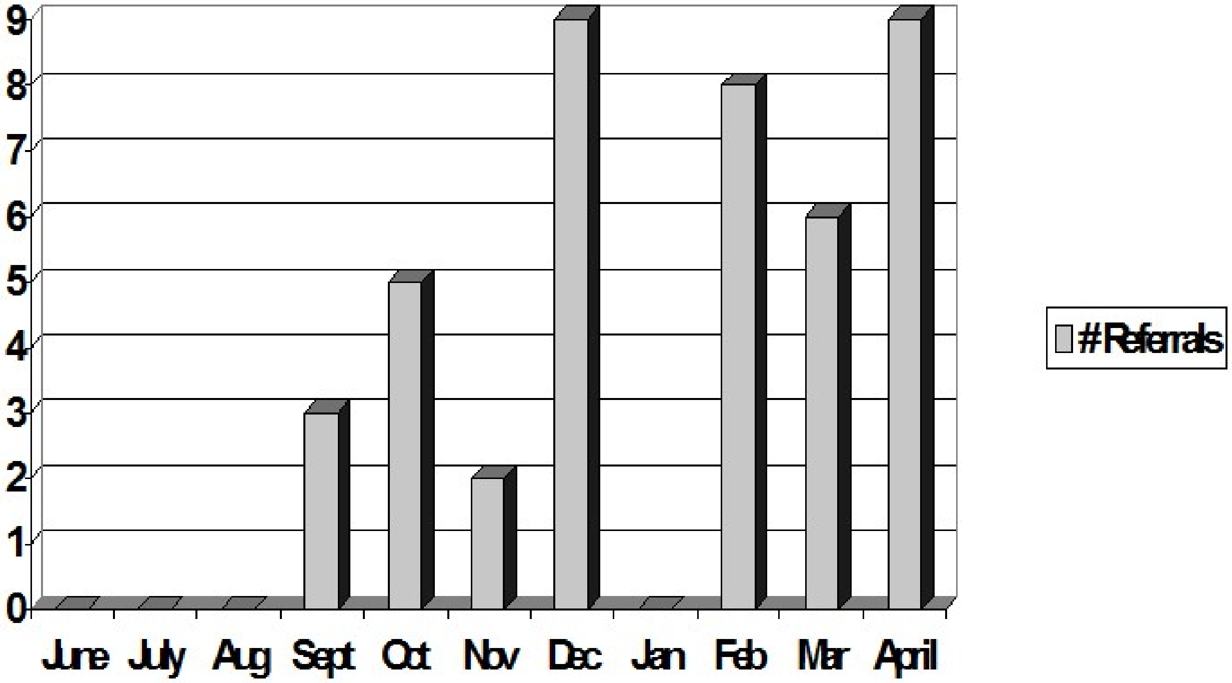
Introduction

The mission of early psychosis intervention is to prevent or attenuate the devastating effects of psychotic-spectrum disorders in youth. This is known as ‘secondary prevention’ whereby medical and psychosocial sequelae of psychotic illnesses, such as unemployment and loss of social networks, are targeted and minimized to improve recovery and long-term outcomes (Jackson & Birchwood, 1996; McGorry, 1992). In 2005, the International Early Psychosis Association (IEPA) and World Health Organization (W.H.O) issued a consensus statement promoting recovery as part of comprehensive early psychosis programs. The defined outcome is “2 years after diagnosis, 90% of affected individuals have employment/education rates similar to their age-/gender matched peers” (Bertolote & McGorry, 2005, p.s116).

Developmental models of the emergence of a first episode of psychosis (FEP) describe a prodromal period where deterioration in functioning can be seen from adolescence into young adulthood (Maier, Cornblatt, & Merikangas, 2003). This necessarily impacts on a person’s primary student role. Investigations conducted in the United States found that early-onset psychiatric disorders were responsible for 3.5 million persons not completing high school and a further 4.3 million who were unable to complete college (Kessler, Foster, Saunders & Stang, 1995). When it is noted in the research, educational status is more precarious than employment after a FEP (CMHA, 2004). In a 7.5 year follow-up of 341 persons receiving early intervention, 43% were found to be employed while only 8% were studying (Harris, Waghorn, Harrigan, Henry, Jackson, Schwartz et al, 2008). It may be that “functional changes [are] more problematic in school than work” (Woodside, Krupa & Pockock, 2007, p.129).

As an occupational therapist working on an early psychosis intervention team, I (researcher and first author) documented the needs of the young adults experiencing a FEP with whom I worked between June 2005 and April 2006. Forty two people aged 17-30 were referred to occupational therapy, of which 74% stated either returning to, or maintenance at, college or university as their goal. The temporal pattern of referral mirrored the stress of school registration, midterms and finals.

Figure 1 Pattern of occupational therapy referrals, 2005-2006 (N=42)



Narratives of desires and attempts to return to school after mental illness onset are available in the literature (Shephard, 1993; Padron, 2006). Successful outcomes and satisfaction with Supported Education Programs (SEP) by persons with a severe and persistent mental illness are also well-documented (Collins, Bybee & Mowbray, 1998; Cooper, 1993; Unger 1993). However, there is little published, from an academic rehabilitation perspective, for a heterogeneous early psychosis population treated within an early intervention model. Young adults treated for a FEP have diagnoses and ages which overlap with, but are not representative of, the SEP population (Neria, Bromet, Sievers, Lavelle & Fochtmann, 2002). Further, the research on SEP's in the United States may not translate directly to the population of concern in Canada because the academic, clinical and governmental structures are not the same.

In Montreal, early psychosis academic rehabilitation efforts, for those aged 18 and over, with the goal of post-secondary schooling are rooted in clinical experience and judgement. This includes case-by-case networking with schools and Offices of Students with Disabilities' (OSD), which provide the partial equivalent of on-site SEP services. A pre-study survey with the OSD's of three of the predominant Anglophone post-secondary schools in Montreal revealed that students with a psychiatric disability are their largest growing population. From the OSD staff's viewpoint, the obstacles are: (1) not enough students with mental illness accessing their services because of stigma (2) some OSD staff feeling that they did not have the training to provide useful support (3) poor accessibility to clinicians when needed and (4) lack of governmental funding for students diagnosed with mental illness.

If a person-centered approach to empower an individual is to be applied in the rehabilitation intervention (Corring & Cook, 1999), it is important to understand the experience of returning to school for this population from their perspective, prior to designing interventions. The purpose of this qualitative pilot study, using an interview-based design, was to phenomenologically explore the experience of young adults returning to school following a FEP diagnosis in the previous five years. This is especially relevant considering that mental health is subjectively experienced and often self-defined (Rebeiro & Cook, 1999).

Methods

Participants

After obtaining ethical approval from the McGill University Health Centre (MUHC), typical case purposive sampling identified five post-secondary students followed as outpatients by an early intervention team. All five were medically stable, able to give informed consent, and engaged with their primary therapist. They had also participated in developmentally appropriate occupational therapy, psychiatric and/or day program activities.

Data collection

A semi-structured interview was developed for this study based on the literature review and the phenomena in question. It was screened with a 25 year old woman who had experienced a psychotic depression three years prior and was currently completing a graduate degree. Subsequently, no further changes were made to the semi-structured interview questions. The one-on-one audio-taped interviews were conducted by the first author, ranged between 1-2 hours and took place between November 2005 and February 2006 at McGill University's School of Physical and Occupational Therapy. Participants were asked each of the primary questions, which were exploratory and open-ended (see Table 1). In-depth discussion was guided by the participant's answers. I (first author) kept a post-interview journal of thoughts, feelings and impressions to promote the maintenance of a critical reflexive stance.

Table 1: Primary questions for the semi-structured interview

How did the beginning of your illness affect your schooling?
Why did you decide to return to school?
What were your expectations? Your fears?
What helped you get back into school?
What made it difficult?
Can you think of anything now that may have been useful then?

Data Analysis

The audio-taped data were transcribed verbatim, and were analyzed using both categorization and contiguous methods subsequent to immersion in the data (Maxwell & Miller, 2002). Each participant's narrative was chronologically reconstructed to understand experiences from a temporal point of view. This was complemented by triangulation with information from the medical chart. Original interview narratives were then examined for themes pertaining to the research inquiry, and these were coded into meaningful themes. Data analysis was also triangulated by conducting a structural analysis of the narratives (Labov, 1982); which meant that following data immersion, transcripts were annotated for patterns of pauses, voice inflections, increased or decreased verbosity and emotional cues for both myself as interviewer and the interviewee. Each transcript was then analysed structurally, that is, an intersubjective interpretation of patterns of emotionality, pauses and the kinds of prompts used by the researcher. Notes were kept in the margins of the transcripts as well as organized by seemingly more dominant insights. Themes and processes were then compared across the five interviews. Individual stories were returned to in an iterative process of analysis to verify and clarify the emergent themes, and their relation to each other, as well as the iterative use of available literature and theory. Each participant received a written summary of the research results in person, and had the opportunity to give feedback with regards to the authenticity of the themes prior to completing the data analysis.

Although a phenomenological theoretical lens was maintained throughout the interpretive understanding of the meaning-making process of participants, theoretical triangulation occurred due to my clinical bias towards developmental and psychiatric rehabilitation frameworks. This was addressed through on-going reflective discussions with academic supervisors, maintaining an audit trail of the creation of themes, and post-interview memos. The ensuing thematic categories underwent independent review by the second and third authors.

Criteria for scientific rigor were attained through the triangulation of data analysis. As well, data re-coding was undertaken by peers and feedback from participants with ensuing revisions, to ensure the trustworthiness of the final interpretations. Transferability and theoretical saturation were not achieved in this study given the small sample size taken from an inherently variable population. It is noted that these preliminary results only pertain to the described population in terms of age range, experience and community status. Quotes from the participants in the study are reported in italicized font for readers to be able to compare the relevance of the results to their own clinical and personal experiences.

Results

The five participants were 20-25 years old, and included one female. All were diagnosed in the previous five years or less. They were dependent upon their families for their living and financial situation. With the exception of Bill, all the participants continued to experience residual symptomatology in varying intensities and forms.

Table 2: Description of the participants (pseudonyms assigned, N=5)

	Alex	***Bill***	***Cory***	***Debbie***	***Evan***
Age	21	22	25	23	20
Gender	♂	♂	♂	♀	♂
Origin	USA	USA	Canada	Caribbean	Canada
Age @ onset	17	19	22	20	17
Duration Untreated Psychosis (months)	12	18	10	0.5	4
Current diagnosis	Schizophrenia	Schizophrenia	Psychosis not otherwise specified	Adjustment disorder	Psychotic depression
History of drug use	ü		ü		ü
Time away from school (months)	None	5	24	7	12
Duration of return to school (months)	Stopped 2 months ago	24	10	7	2
Education level	College Y2	University UIII	College Completed	University UII	College Y1
Program	Business	Engineering	Social science	Art history	Pure science
Status	Part Time	Full Time	Part Time	Part Time	Part Time
Employment history	ü		ü		ü
Current employment			Part Time	Part Time	

They had been enrolled in full time course loads prior to the illness onset, with some holding part-time jobs and/or living independently at the time. All began to withdraw socially either due to the onset of paranoid symptoms or increased study efforts to overcome emergent cognitive difficulties. Alex, Cory and Evan attempted to cope by self-medicating with illicit drugs, “it’s kinda self-help”. Drugs were also used in terms of building an alternative peer network that was not based on academic performance. Alex said “there were some kids and they were good but some were kind of older and they smoked marijuana, so [I spent time with them]…”

All reported non-specific cognitive and affective signs prior to their decompensation such as insomnia and increased fears, anxieties or worries. Most had difficulty concentrating or remembering material that had been studied due to racing thoughts or paranoid anxiety. Debbie and Evan reported increased sadness and anger with suicidal ideation. None attempted suicide during this period.

All of the participants managed to stay in school while symptomatic and untreated for periods ranging between 3 months (Evan) to over a year. “No one knew I was unwell, only I knew…but I didn’t think it was a…I, I didn’t think it was like an episode, I considered it as something normal”; “I don’t think anyone knew anything was wrong. Even with all the anxiety and thoughts racing I’m pretty good at keeping a calm face, so…” Evan was the only one to have been approached by school staff regarding his well-being. The others were not identified by their schools, in spite of failing grades or aggressive paranoid behaviour. All participants were ultimately brought to the attention of the health care system by family or church members.

At the time of the interview, four were still actively engaged in post-secondary schooling, while Alex had chosen to quit his education goals two months prior to his interview. All five participants were dependent on their families for their living and financial situations. Debbie lived alone but was financed by her father. All five used public transport, with commuting times varying between 20-60 minutes to travel to school, although Cory had just bought a car, which he said cut down significantly on his commuting time. All were engaged in community-based leisure, social or spiritual activities beyond studying, with the four who were in school having developed significant social networks within school, both formally (organized student clubs) and informally. All five participants were comfortable with me as interviewer due to previous interactions in the clinical context. This allowed for greater depth of exploration.

Impact on the Self

The objective of this study was to use a phenomenological approach to understand the school experience of these five persons over time. Therefore, it is important to initially examine how this was narrated by the participants.

All the participants had a difficult time finding the right words to describe their experience. This was understood in terms of cognitive impairments, verbosity and the use of self-depreciative humour as a defensive or coping strategy. Questions pertaining to long term memory elicited either long pauses or repetitive answers that did not add further to the narrative. With the exception of Cory, who is the eldest in the sample and the only one who was completely symptom-free during the research period, participants had difficulty reflecting on and abstracting about their illness and its impact on their schooling in any specific manner. This difficulty in conceptualization and verbalization seemed to be related to cognitive deficits such as long term memory, abstraction and self-evaluation. It also appeared related to each participant’s self-concept and their continued difficulty in expressing the existence of an illness out loud. Examples of these moments during the interviews follow, with underlined words indicating tonal emphasis:
“[5 second pause] I can’t really say what the illness part was, I don’t really know that much about it [10 second pause] but I think it was a little bit of both, the illness, and school…yeah” (Alex, slowed speech)

“I think the hardest thing I feel is, ummm, when you get a low grade, it’s based on your…it’s based on my capability…well like ‘coz of my illness…that’s what makes it for me hard…to accept…because I work so hard, and I try to do the best that I can, and I guess, it’s not really about working hard, it’s about quality?”(Cory, unsure of his answer)

The structural analyses of non-& paraverbal communication significantly highlighted a central meaning-making process of the participants as being in an on-going continued search of who they were, are and can be. This was evidenced by the need to articulate the illness experience to a familiar health care professional who was not there to intervene but rather to listen. Humour in particular was seen at these times when the participants either failed to find words, or used colloquial terms such as “crazy”, “breakdown” and “insane”, punctuated by “I don’t know” and rueful chuckles; when relating important events or obstacles. Laughs were interspersed in the sections of the interviews where participants described their decompensation and hospitalization in detail, and when there was the realization that their delusions were not real. Each participant spontaneously elaborated on their acute psychotic episode, even though this was not directly questioned or explored in the interview.

“well, one of the paranoid delusions I had was I was afraid, which is very common, that somebody was going to hurt me, somebody was out there to hurt me, and after reading that that’s one of the most common delusions I was like ‘ok, that’s cool’ {Laugh}” (Cory)

The search for self-definition was inseparable from the process of adaptation to the many phases of the returning to school experience. This process of adaptation was not described as seamless or linear. The adaptation to self-as-unwell seemed to be temporally spread across the following transitional experiences of self-development and meaning-making:

(1) Recovery in the post-acute phase: Taking the time to understand what had happened, what it meant and to begin to integrate this into the self-concept. Alex never took the time to do so and after several repeated failures at school and three relapses, he changed his long term occupational goals.

"Well, I kinda felt like I was not able to do it, like I didn't have I guess first of all I wasn't able to go through with school after what happened, I don't know, I don't know, ... I kinda felt like...I kinda felt like I couldn't do it" (Bill, in a quizzical, lowered tone of voice).

"It's just like at the beginning, my family thought I was strange... {Laugh} the first few weeks there, they seemed scared of me, it was funny. Well, it wasn't funny but anyways, it was weird" (Evan)

(2) Current difficulties at school: Self-depreciative humour was also used when discussing their difficulties. All participants had expressed the expectation that both activities and hence their self, would eventually return to 'normal'. When faced with continued obstacles such as medication side effects, cognitive difficulties or residual symptoms, participants had to continue to negotiate or integrate the notion of 'self as unwell'. In addition, this seemed to be linked to their acceptance of lowered standards of academic or social performance in relation to the self-evaluation of capacity when confronted with ongoing impairments.

"Even now, at times like I stare at people and my friends make fun of me, that's funny {Laugh}, because I really stare at people a lot ... I don't know, maybe it's part of the illness" (Evan)

"Do you feel that you are getting the results you want at school for the effort that you put in?"
"No! {Laugh}" (Debbie)

"...it's a very big thing, is to keep in touch with reality, for sure.
Yes
{Laughter}" (Cory)

The centrality of the negative impact of the psychotic experience on the sense of self continued to significantly impact these five young adults in a difficult to verbalize dialectic between self-as-ill and self-as-student. What they were able to directly verbalize was also related to self-transformation; however, the meta-level themes emerging from the iterative coding of statements were more positive. They revolved around describing the ability to develop and sustain remission, recovery and a positive sense of self in the face of challenges.

The following analysis of the content of the participants' stories is illustrative of the experience of Returning to school, and Staying in school, as these were reflected on and narrated as separate processes by each participant (themes presented in bold type).

Returning to School

Returning to school after a first episode of psychosis includes negotiation of the school and medical system to obtain all the necessary paperwork to explain absences, behaviours and course failures, as well as choosing and registering for courses. It also includes the first month of starting classes. This was especially so, as with the exception of Debbie, the participants all had at least one attempt to return to school that failed during the first month of classes.
Readiness was a term spontaneously used by all the participants to describe their successes and failures in returning to school, and is conceptualized here as the over-arching process in recovery to be able to return to school. Readiness

was distinguished by the participants from the desire to return to school in that there was a sense of actually believing in their ability to try and succeed. Bill says: "It took me maybe… a whole year to recover completely"; and Evan shrugged: "I guess first of all I wasn't ready to go through with school after what had happened". Even though narratives were highly individualized, there were commonalities in the process of fostering or hindering readiness.

The main challenges to readiness and returning to school were two-fold. Side effects of medications were unanimously the first on the list. "Sometimes the medication would be, I would be too drowsy…and they would have to decrease it…I would always feel tired" (Alex). Waking up early in the morning for classes as well as maintaining focus during a class was found to be difficult in the first few weeks of school. This simply compounded the fear of failure: "it was like 'oh shit', I don't wanna get 30%'s again" (Evan). The four men described initial failed attempts to return to school due to an over investment in studying. "Instead of like studying normally, I was studying all the time" (Bill). A devastating parallel emotion noted in the chart reviews is the effect of shame at having failed the school experience during the prodromal phase. This was clearly articulated by Bill, stating that he "felt like I had disappointed my friends", and the "fear that someone might find out that … I was ill, I thought they would react". Evan chose a different community college when returning to school to avoid those who had observed his decompensation.

In spite of profound fears, and the practical issue of medications, all five participants kept trying to return to school even after initial failures for four of them. The desire to return to school was symbolic of normalcy, and included the developmentally appropriate milestone of re-establishing peer networks, "it was the desire to like rekindling those friendships" (Bill). The desire to be productive was articulated in terms of education as a necessary asset for future employment and identity goals "I wanted to be an Engineer; I wanted to have a future" (Bill).

Family, friends and community fostered belief in personal capacity. Positive familial expectations were primary "my mom, my mom always told me 'go back to school, go back to school'" (Alex), while others relied more heavily on their church communities, "God. That's first. He gives me the confidence…to do it" (Debbie). Family support provided a safe environment where the pragmatics of home management were taken care of; "they'd just kinda like be more sensitive, like my needs and stuff because I'd been sick and just being there for me more" (Cory). For the participants who were able to maintain their friendships during their illness process, these friends significantly encouraged them, saying things such as: "you're smart, you can do it, you know, just take it one day at a time" (Evan). Having a social support network facilitated the engagement in daily activities. Communities and friends helped to provide increased opportunities to be more active in preparation for returning to school through leisure activities and sports, "we saw each other often so instead of being alone all the time and doing nothing" (Evan).

In addition to personal and social resources, the services provided by the early intervention team were described by all the participants as helpful. Specifically, learning about psychosis helped with adherence to medication which all admitted was necessary in spite of side effects. Understanding the illness also helped with the reconstruction of meaning. "All the doctors say something different, like it was an adolescent crisis and stuff, but I just think 'Woah shit! What is this crap?' It's like, maybe it's like I fell insane […] you hunt a little bit everywhere [for the answers]." (Evan). Knowing more about mental illness within a stress-vulnerability model helped normalize the situation, as Debbie states "[the psychologist] said often that she knew lots of people […who…] had a hard time". Having a concrete reason for the unexplained difficulties provided relief in some instances: "I think if I knew I had this before, I would have dealt with it much better I think" (Debbie).

Other rehabilitation-oriented interventions were described as being helpful (day hospital, occupational therapy, psychiatric follow up). Cory explained that "Doing [day hospital] from 9 to 4, 9 to 2 everyday, it was really nice… helped me get back into the swing of things". The clinical support mentioned had commonalities with the aforementioned themes. They provided structured engagement with activities, peer support, and the opportunity to understand and work through what had happened. It was necessary for the five participants to have therapeutic support, beyond psychoeducation, to be able to reconstruct a meaningful narrative. Bill was grateful for"[relationship with a resident] was helpful getting over the fact that for like two years I believed that I was [telepathic] but it was not real".

Debbie "just started talking to people aaaand…I felt better"…"having a place where you can tell people what's going on…just telling them, …the one thing you should never do is isolate yourself". Having someone bear witness to their experience seemed crucial in the healing process, as all five had participated in various group therapies. The social support received from peers helped with the normalization of the psychotic experience, as "listening to other people's stories is really awesome to help you out" (Cory).

Beyond all of these, the passage of time was important for all of them. Bill explains: "after the time off, I kinda felt like I was ready, that I could do it […] it was really the time off, like I had time to realize, I had time to like get back into the mind set I needed to be in". This time was necessary to work through feelings of shock, sadness and trauma occasioned by the psychosis and hospitalization. Evan reveals that "at the beginning I felt so lazy, like I absolutely didn't want to do anything […] I don't know, it was like I was so empty". Debbie, Alex and Evan were officially diagnosed with depressive traits and along with Bill, were taking anti-depressants or mood stabilizers. Time helped to move past this sadness and towards hope, self-confidence and readiness to return to school.

Overall, in spite of initial failed attempts when not sufficiently ready, and the continued presence of symptoms, returning to school was achieved by these five young adults within two years of their first psychotic experience. Returning to school successfully was described as hinging upon the process of 'feeling ready' on the ongoing continuum described in the structural analyses, of a shifting sense of selfhood.

Staying in School

Staying in school in an enduring, productive academic role was experienced as more complicated than returning to school. All five participants were surprised to discover that after the initial rush of starting classes had waned, the need to continue to engage in, and manage academic life did not happen easily.

The most common obstacle was cognitive difficulties, most frequently described as difficulty "concentrating". For some it was related to fatigue and mental endurance secondary to the sedating side effects of the medications, "I would be too drowsy […] it was just hard, just focusing". Sedation was also a hindrance to effective time management and general efficacy, "not being able to go to school on time, even if it was 11, my classes started, I was just tired". A second source of cognitive difficulties was residual symptoms such as depressive features or anxiety states, "I had to walk into a class of 30-40 students, sit down, stay focused, make sure my thoughts don't run". For Alex and Evan the cognitive challenges pre-dated the psychotic episode, "I always had a hard time learning" (Alex).

Social anxiety linked to self-stigma was something poignantly described by every interviewee. In Evan's words, he" was a full reject". Social anxiety was expressed in relation to a fear of criticism or denigration. "Only my parents know about it […] no one at school knows about it, none of my friends know about it so…[…] it would be kinda embarrassing because it's kinda like a stigma to be…the way people think of people with mental illness is that…it's not exactly a positive thing." Included in this self-stigma was the negative body image linked to weight gain, a medication side effect. While the general social anxiety of returning to school faded within the first few weeks through "practice" (Cory), the insidious effect of self-stigma was still evident, as described in the structural analyses.

Experiences and meaning which countered the fear of failure and self-stigma were significantly present. All the participants expressed their enjoyment and satisfaction in developing mastery in achieving a personal goal, and this continued to fuel their efforts and hopes even when facing obstacles. "School is like a long term thing, it's a personal thing, it's not something you do because you have to or because somebody wants you to do it. It's something that you do, that you take your time to do, and it just makes you feel better as a person, it just educate yourself and bring yourself to a higher level, you know? That's what keeps me going, you know?" (Cory).

Integrating socially at school helped normalize the difficulties they were experiencing. "When I hear the kids- students- talking about 'well, I think I got a D or C' I was like 'I'm not alone!'" (Debbie). It also provided opportunities for dating “because you’re always meeting new people” (Cory). The three who were in school for over six months participated in school based clubs which they said brought “balance” into their lives.

Balancing and maintaining a healthy lifestyle was also described as imperative. Adhering to medications was mentioned by all as crucial, as well as consciously taking time off, “taking a day to myself, you know. I just stay home, watch TV, sleep for like 14 hours and just turn off my phone” (Cory). Time off was also part of the every day schedule, “you can just rest for 15 minutes, you refresh yourself again” (Debbie). Abstaining from drugs and alcohol was acknowledged as necessary and was facilitated by having developed alternate social networks at school.

The four participants, who successfully maintained their academic role, described coping strategies to compensate or remediate the obstacles presented by cognitive deficits and social anxiety. These varied between behavioral strategies such as a part-time course load, or avoiding early morning classes, and the more complex issues of organization and time management skills. “Because what happens is that when you arrive at school…you hurry and you hurry and then you have an exam after so it’s really like managing your time” (Evan). Maintaining a mindful approach and as Debbie said, “just focusing on the present” was found to be helpful.

Participants had to find ways of addressing their cognitive deficits, stating “I just can’t stay focused sometimes but I learnt to pick out the key points” (Bill). Debbie sought help from the OSD services to “help me write a schedule […] helps with when I write papers, I go to her, and she checks to see, like, the organizing, the pieces, the introduction, everything, make sure it’s OK”.

Bill and Cory found an occupational therapy group on cognitive skills useful to increase their awareness of attention difficulties and problem-solving methods. Although only Debbie used school-based services, the chart reviews revealed that all five had received individual and group interventions in occupational therapy. This included psychoeducation centered on understanding their illness from a functional perspective, problem-solving study skills and habits based on their individual impairments and strengths, and contextualized illness management strategies.

The on-going challenge associated with learning how to manage vulnerabilities and academic performance was strongly linked to the maintenance of hope. “I don’t know…the future…it leaves…I have lots of hope now”(Bill). The further along in the successful maintenance of the academic role, the more important hope became. Participants realized that the process may never become easier and the level of effort and compensation required would be high. “It’s just the fact, like, that I just want to be normal” (Evan).

After successful completion of a program in spite of illness, at transitional moments between college and university (Cory) or undergraduate and graduate degrees (Bill), doubts would re-emerge regarding personal capability to achieve new goals. Cory wanted a university degree but wondered: “maybe a trade school for landscaping that I might try, but I’m not sure yet, I’m still deciding”. Bill had a 2.75 GPA at the time of the interview, and said: “ I want to do a ummm Masters, but that would be about a 3.0 to get to a masters, so…”. Debbie’s concluding comments made it clear: “you feel that there’s still more to be done… keeping hope is the hardest thing sometimes”.

The most striking, over-arching theme which cuts through the thematic and structural analyses and across each participant’s experience is developmental. Maturity was described as necessary to maintain a healthy lifestyle and to accept and overcome illness-related difficulties. It linked to statements involving the importance of growing up, of becoming ready, of learning who they were, and of keeping hope. This included accepting a lowered standard of performance for overall grades, being enrolled part-time, managing the social repercussions of psychotogenic behaviours, and, for Alex, having to let go of an academic goal altogether, “I don’t think being in school is where I’m meant to be, is the way I look at it, just wasn’t meant to be” .

“I had absolutely no idea about what I wanted to do, now I know myself better and…I don’t know […] before, I don’t know, I was just, it’s as if I wasn’t, I wasn’t so serious. It’s like I f**ked around all the time and stuff. Now I’m more serious”(Evan). For these participants the consequences of not being self-responsible included psychosis and hospitalization. “Just ah, matured a lot, it’s just changed my life, you know. Different perspective of life” (Debbie).

For these participants, the mature acceptance of illness was intricately linked to identity development in the context of the onset of mental illness at a young age. It is a complex, transactional process in which each participant’s individual resilience seemed to be fostered by their social support, culture and clinical approaches. It is worth mentioning that all five found that their personal growth and maturity was significantly facilitated by their therapeutic psychoeducation experience in occupational therapy, within a treatment approach which focused on function, personal values and adaptation rather than symptoms. In addition, four of the five participants had attended occupational therapy groups whose focus was adaptation to illness using projective techniques. These groups were described as facilitating the process of developing readiness to return to school, self-acceptance, and the maintenance of hope, through peer support and self-exploration.

Discussion

Outcome research in early psychosis reveals that resuming a student role after a first episode of psychosis is not typical (Harris, et al, 2008). However, this exploratory study portrays that four out of five participants who had experienced a first episode of psychosis could and did reintegrate successfully into post-secondary school. In this sample, the variability in diagnoses, premorbid risk factors and drug use, cognitive complaints, duration of untreated psychosis and time to recovery, all fit within the population descriptions provided in the literature (McGorry, Yung & Phillips, 2003; Neria et al, 2002).

Returning to school involves recovery from the psychotic episode, and developing the readiness and desire to return to school and resume normalcy. Staying in school requires engagement in illness management skills, compensating for potential cognitive deficits, and continued support for a mature adaptation to illness. This study indicates that the central thread in designing rehabilitation services may be to understand the transactional effects between identity development, readiness, recovery and the dynamic adaptation to on-going challenges. The discussion will relate these concepts to the participants’ experiences, and link them to rehabilitation interventions.

The process of recovery is what leads to the development of self-confidence to invest the self’s energy in desired goals (Deegan, 1988; Anthony, 1994). What is notable in this study is the length of time needed for the participants to do this. A similar conclusion was reached in a study exploring barriers to employment in early psychosis (J.Bassett, C.Lloyd & H.Bassett, 2001). The narratives herein indicate that rehabilitation and reintegration may need to proceed slowly, allowing time for recovery and readiness to develop through individual and group interventions. For the participants in this study, services were offered beyond the two year lengths of stay characteristic of most early intervention programs (Harvey, Lepage & Malla, 2007).

All five began to experience functional difficulties in grades 11-13, in the transition from high school to post-secondary schooling. The recovery from a first experience of psychosis included understanding and reframing the difficult school experience as psychosis began to emerge. The structural analyses added a deeper layer of emotional meaning to the relationship between the fear of failure and readiness. It was notable how all of the participants spontaneously provided details of the process of their fragmentation, and attempted to justify or understand the reasons behind it. These portions of the narratives did not seem to be readily coherent, but rather were constructed during the session for a researcher who was also known to be a clinician. These narratives have been interpreted as an on-going need to create meaning out of an experience that continues to impact their sense of self (Tedeschi, 2005). In effect, there seems to be a dynamic need to re-negotiate the self-concept vis-à-vis the discrepancy between desires, expectations of remission, and actual performance. The interview session seemed to serve a partially therapeutic purpose as only two of the participants had ever disclosed their experience to anyone outside their immediate family or treating team.

With respect to understanding their psychotic episode, psychoeducation was useful in that the information shared about the illness went beyond facts. The participants were provided with a narrative space within the clinical services where these ‘facts’ could be incorporated into their self-concept (McGorry, 1995; Sumsion, 2005). This debriefing of the prepsychotic experience seemed to be important to minimize the shame and fear of failure when returning to school. Addressing secondary depression and anxiety in the post-acute phase was also part of this recovery (Gleeson, Larsen & McGorry, 2003). It seemed though, that this was not a one time, or phase-specific process, but rather a recurrent need to dialogue about, and integrate the illness experience as part of one's self. The provision of, and engagement in, therapeutic relationships in which these young adults could continually articulate and reconstruct what was happening to them was a significant component of the psychosocial rehabilitation services.

These comments are supported by the themes of self-stigma and maturity. Learning about psychosis is necessary to provide meaning to the experience and foster readiness; however, with time, accepting the label of mental illness and the lived experience of functional consequences led to self-stigma. Terms such as 'insane', 'crazy' and 'breakdown' all had deep ramifications on their sense of self. It is significant that four of the five participants had at least one failed attempt to return to school. This confrontation with longitudinal difficulties that are unanticipated or vary with time, demands an on-going adaptation to an illness identity by the young adult. Support in accepting different standards of performance, due to new cognitive or emotional stress thresholds, could be facilitated by the family network, peers or professional staff. This is especially important when looking at the academic rehabilitation process through a developmental framework. Adolescents and young adults develop significant peer social networks that foster their identity development and provide daily support in life (Harrop & Trower, 2003). Young persons who have experienced psychosis can, and do, develop these networks but are unlikely to disclose their diagnoses or difficulties to their friends due to the fear of stigma. The term 'psychosis' is a frightening word; one which is not easily shared. However, the need for these young adults to articulate and share with peers remains. This is where therapeutic efforts enabled success, as described in this study.

For these five participants, day programs were safe environments in which to fine tune medication levels and learn about psychosis, to access peer support and provide a daily structure to help re-habituate to an active lifestyle. The only participant who did not fail in their first attempt to return to school had attended a day program for 5 months prior to returning to school while the others had either attended day programs for shorter periods (ranging between 2 to 10 weeks) or a once a week, afternoon youth group for 6 months. To echo the conclusions of Lloyd, Bassett & Samra (2000), it is hoped that outcome-oriented research will emerge to support the efficacy of day programs in rehabilitation for persons diagnosed with a first episode of psychosis.

In terms of social support, Debbie was the only one who, although financially supported by her family, was living alone. The chart review validated her stated difficulties in organizing her time for school and also in preparing her meals. This also contributed to her fatigue and limited how much she could take on at school. Research supports the inclusion of family in the design of services as they provide a "comprehensive range of practical, emotional and financial support" to the young family member with psychosis (Sin, Moone & Wellman, 2005, p.589). Friends were also identified, by the participants, as fostering the process of readiness through emotional support and by providing normalized opportunities to engage in activities in a structured manner. In terms of social relationships, research with this population highlights the losses in social networks that occur. This can be compensated for in part by other young people who have also experienced psychosis (MacDonald, Sauer, Howie & Albiston, 2005). Again, this adds support for the therapeutic aspects of day programs or group interventions for this population.

The achievement of social integration within the school setting facilitated the return to school process for Bill, Cory, Debbie and Evan. Beyond the concrete stress management and leisure opportunities that this affords, developing competency in domains valued by self or society helps to maximize resilience in the face of increased pathological risk (Masten, Best & Garmezy, 1990). This competency helps balance out against injuries to the self-concept when not performing at desired academic standards.

Overall, the results of this study point towards some similar SEP needs in a population with early psychosis. These needs include psychoeducation and the development of illness management and study skills (Collins, et al, 1998). Although it was clear in the charts that all the participants were aware of their difficulties and had been informed of available school resources, only Debbie actually accessed the services offered by the OSD. She was able to identify and accept her need for help and accommodations. The others did not, either because they felt they didn’t need it or in part due to the fear of stigma. As previously stated, SEP’s in the United States focus on supporting persons with a diagnosis of schizophrenia towards adopting a more active, non-dependent role within normalized school environments. However, the central thread running through the resulting themes for persons with early psychosis is the opposite, that is, having to adapt to a self-concept which includes illness and new limitations.

Chart reviews of the four participants who did not use the OSD revealed prior experience in occupational therapy with interventions aimed at problem-solving study skills, lifestyle choices and contextualized illness management strategies. Examples included psychoeducation about the negative effects of drugs, designing a weekly schedule, choosing a course load and classes whose evaluation methods fit with the individual’s strengths, as well as cognitive strategies to minimize anxiety or compensate for new impairments. It seemed that these young persons were willing to receive support in these areas, but only when segregating their ‘normal’ school environments from their ‘medical’ support system. The perception may be that mental health professionals are already aware of what the person is going through, while school staff are not. This, for the participant, may be linked to the fear of stigma and, thus, their avoidance of disclosure within the school environment. This makes the provision of school-related support within the clinical milieu a useful approach. Examples of such support include groups to problem solve study strategies and habits, projective activities in occupational therapy to help with the articulation of difficult emotions (McGlashan, Wadeson, Carpenter, & Levy, 1977; Thompson & Blair, 1998), and vocational counselling at transitional moments to aid in goal setting and decision-making (Goulet, Rousseau, Fortier, & Mottard, 2008). Therapeutic counselling to facilitate the acceptability of linking to OSD’s could be a goal, in order to eventually normalize the environments in which young adults function after a first episode of psychosis.

Limitations of this pilot study include the small sample size, which did not allow for theoretical saturation. All five participants were well connected to their families and engaged in treatment, which makes it difficult to know from this pilot study which themes would remain salient in a more complex situation such as a young person with forensic issues, or no family support. As well, since the interview was a one-time event, there was less opportunity for the researcher to explore pertinent information about personal experience that may not have been as forthcoming during the first session. The recruitment difficulties were a significant limitation to the process of the study, resulting in a sampling bias whereby all the participants had received occupational therapy services. However, this seems to have been beneficial in terms of preliminary trust between the participants and the researcher as well as pointing towards pertinent rehabilitation approaches.

This study highlights areas for future research. In addition to research exploring academic reintegration with a larger sample to achieve theoretical saturation, two promising avenues for rehabilitation research include (1) exploring the development and practice of hope (e.g. Mattingly, 2010), with youth having experienced early psychosis and (2) promoting and evaluating the use of developmental theories in the design of rehabilitation services (e.g. Vogel-Scibilia, McNulty, Baxter, Miller, Dine & Frese III, 2009).

Conclusion

The process of identity development is useful in conceptualizing the experience of academic reintegration of young adults after a first episode of psychosis. The importance of ‘being ready and mature’ was clearly articulated when faced with on-going challenges and the discipline required in managing academic performance on a daily, long-term basis. Occupational therapy interventions to promote readiness, and to problem-solve on-going obstacles do exist, and include age-appropriate social integration as a goal. It may be necessary to engage these young persons in long term therapeutic relationships that vary between arm’s length monitoring to more frequent and tailored rehabilitation during critical transitional moments or at times of self-doubt. These therapeutic relationships can provide these clients with the opportunity to find strategies for success, to continually recreate the narrative of their lived experiences, and to maintain hope.

References:

Anthony, W.A. (1994). Characteristics of people with psychiatric disabilities that are predictive of entry into the rehabilitation process and successful employment. Psychosocial Rehabilitation Journal, 17, 91-110.

Bassett, J., Lloyd, C., & Bassett, H. (2001). Work issues for young people with psychosis: Barriers to employment. British Journal of Occupational Therapy, 64, 66-72.

Bertolote, J. & McGorry, P. (2005). Early intervention and recovery for young people with early psychosis: consensus statement. British Journal of Psychiatry, 48, s116-s119.

Canadian Mental Health Association. (2004). A Guide to College and University for Students with Psychiatric Disabilities. [pdf] http://www.cmha.ca/youreducation/

Collins, M.E., Bybee, D. & Mowbray, C.T. (1998). Effectiveness of supported education for individual with psychiatric disabilities: Results from an experimental study. Community Mental Health Journal, 34, 595-613.

Cooper, L. (1993). Serving adults with psychiatric disabilities on campus: A mobile support approach. Psychosocial Rehabilitation Journal, 17, 25-38.

Corring, D. & Cook, J. (1999). Client-centred care means that I am a valued human being. Canadian Journal of Occupational Therapy, 66, 71-82.

Deegan, P.E. (1988). Recovery: the lived experience of rehabilitation. Psychosocial Rehabilitation Journal, 11, 11-19.

Gleeson, J., Larsen, T.K., & McGorry, P. (2003). Psychological treatment in pre- and early psychosis. Journal of the American Academy of Psychoanalysis and Dynamic Psychiatry, 31, 229-245.

Goulet, C., Rousseau, J., Fortier, P., & Mottard, J-P. (2008). Factors influencing occupational competence in schizophrenia : Client and therapist perspectives. Occupational Therapy in Mental Health, 24, 5-30.

Harris, M.G., Waghorn, G., Harrigan, S., Henry, L.P., Jackson, H., Schwartz, O., Farrelly, S., Prosser, A. & McGOrry, P.D. (2008). Education and labour force activity: a 7.5 year follow-up of a first-episode cohort. Early Intervention in Psychiatry, 2, S1, A10. [Abstract]

Harrop, C. & Trower, P. (2003). Why Does Schizophrenia Develop in Late Adolescence? A Cognitive Developmental Approach to Psychosis. West Sussex, England: John Wiley & Sons, Ltd.

Harvey, P-O, Lepage, M. & Malla, A. (2007). Benefits of enriched intervention compared with standard care for patients with recent-onset psychosis: A metaanalytic approach. Canadian Journal of Psychiatry, 52, 464-472.

Jackson, C. & Birchwood, M. (1996). Early intervention in psychosis: Opportunities for secondary prevention. British Journal of Clinical Psychology, 35, 487-502.

Kessler, R.C., Foster, C.L., Saunders, W.B. & Stang, P.E. (1995). Social consequences of psychiatric disorders, I: Educational attainment. American Journal of Psychiatry, 152, 1026-1032.

Labov, W. (1982). Speech actions and reactions in personal narrative. In D. Tannen (Ed.), Analyzing discourse: Text and talk (pp. 219-247). Washington DC: Georgetown University Press.

Lloyd, C., Bassett, J., & Samra, P. (2000). Rehabilitation programmes for early psychosis. British Journal of Occupational

Therapy, 63, 76-82.

McGlashan, T.H., Wadeson, H.S., Carpenter, W.T., & Levy, S.T. (1977). Art and recovery style from psychosis. Journal of Nervous and Mental Disease, 164, 182-190.

MacDonald, E., Sauer, K., Howie, L., & Albiston, D. (2005). What happens to social relationships in early psychosis? A phenomenological study of young people's experiences. Journal of Mental Health, 14, 129-143.

Maier, W., Cornblatt, B. A., & Merikangas, K. R. (2003). Transition to schizophrenia and related disorders: Toward a taxonomy of risk. [Special Issue]. Schizophrenia Bulletin, 29, 693 – 701.

Masten, A.S., Best, K.M. & Garmezy, N. (1990). Resilience and development: Contributions from the study of children who overcome adversity. Development and Psychopathology, 2, 425-444.

Mattingly, C. (2010). The Paradox of Hope ~ Journeys Through A Clinical Borderland. Los Angeles, CA: University of California Press.

Maxwell, J. & Miller, B. (2002). Categorizing and connecting as components of data analysis. [Unpublished manuscript]. George Mason University, Fairfax, VA pp.14

McGorry, P.D. (1992). The concept of recovery and secondary prevention in psychotic disorders. Australian and New Zealand Journal of Psychiatry, 26, 3-17.

McGorry, P.D. (1995). Psychoeducation in first-episode psychosis: A therapeutic process. Psychiatry, 58, 313-328.

McGorry, P.D., Yung, A.R. and Phillips, L.J. (2003). The "Close-in" or ultra high-risk model: A safe and effective strategy for research and clinical intervention in prepsychotic mental disorder. Schizophrenia Bulletin, 29, 771 – 790.

Neria, Y., Bromet, E. J., Sievers, S., Lavelle, J., & Fochtmann, L. J. (2002). Trauma exposure and posttraumatic stress disorder in psychosis: Findings from a first-admission cohort. Journal of Consulting and Clinical Psychology, 70, 246-251.

Padron, J.M. (2006). Experience with post-secondary education for individuals with severe mental illness. Psychiatric Rehabilitation Journal, 30, 147-149.

Rebeiro, K.L. & Cook, J.V. (1999). Opportunity, not prescription: An exploratory study of the experience of occupational engagement. Canadian Journal of Occupational Therapy, 66, 176-187.

Shephard, L. (1993). School daze. Psychosocial Rehabilitation Journal, 17, 7-10.

Sin, J., Moone, N., & Wellman, N. (2005). Developing services for the carers of young adults with early-onset psychosis – listening to their experiences and needs. Journal of Psychiatric and Mental health Nursing, 12, 589-597.

Sumsion, T. (2005). Facilitating client-centred practice: Insights from clients. Canadian Journal of Occupational Therapy, 72, 13-20.

Tedeschi, R. (2005). Trauma and transformation, post-traumatic growth and facilitating post-traumatic growth. [Conference]. September 30th, 2005, Allan Memorial Institute, Montreal.

Thompson, M. & Blair, S.E.E. (1998). Creative arts in occupational therapy: Ancient history or contemporary practice? Occupational Therapy International, 5, 49-65.

Unger, K.V. (1993). Creating supported education programs utilizing existing community resources. Psychosocial Rehabilitation Journal, 17, 11-23.

Vogel-Scibilia, S.E., McNulty, K.C., Baxter, B., Miller, S., Dine, M., & Frese III, F.J. (2009). The recovery process utilizing Erikson's stages of human development. Community Mental Health Journal, 45, 405-414.

Woodside, H., Krupa, T. & Pocock, K. (2007). Early psychosis, activity performance and social participation: A conceptual model to guide rehabilitation and recovery. Psychiatric Rehabilitation Journal, 31, 125-130.

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 1
July 2011– June 2012

Study on the Perceived Exertion during a Graded Exercise Test in Patients with Depressive and Anxiety Disorders

J Knapen

D Vancampfort

J Raepsaet

M Probst

Faculty of Kinesiology and Rehabilitation Sciences
Katholieke Universiteit Leuven, Tervuursevest 101, 3001 Leuven, Belgium
University Psychiatric Centre K.U.Leuven, Campus Kortenberg, Leuvensesteenweg 517, 3070 Kortenberg, Belgium

Citation:
Knapen J, Vancampfort D, Prepsaet J, Probst M (2012). Study on the Perceived Exertion during a Graded Exercise Test in Patients with Depressive and Anxiety Disorders ***International Journal of Psychosocial Rehabilitation. Vol 16(1) 44-51***

Corresponding author:
Jan Knapen
University Psychiatric Centre K.U.Leuven, Campus Kortenberg
Leuvensesteenweg 517
3070 Kortenberg,
Belgium
Mail: jan.knapen@faber.kuleuven.be

Acknowledgements
The authors thank the patients who participated in the study and the physiotherapists for the evaluation of the physical fitness and the data collection. They have no conflicts of interest that are directly relevant to the content of this manuscript.

Abstract

Purpose: The aim of the present cross-sectional study was to explore which variables could explain the perceived exertion during a graded exercise test (GXT) in patients with depressive and anxiety disorders. **Method:** In three treatment units of a university psychiatric hospital in Belgium, 137 patients (49 males and 88 females) performed a submaximal GXT the first week of admission. The rate of perceived exertion (RPE) at 60% of the maximal heart rate reserve (MHRR) was measured by means of the Borg Category Ratio 10 Scale. Depression, anxiety, level of physical activity and perceived cardio-respiratory fitness were evaluated by means of questionnaires. The motivation towards exercise therapy was measured using a visual analogue scale. A linear multiple regression equation was used to ascertain the explaining variables for the perceived exertion. **Results:** The explaining variables for RPE at 60% of MHRR, in order of importance, were age, level of physical activity and state anxiety. **Conclusions:** Patients who are older, less active and/or patients with a high anxiety level perceive a high RPE during a GXT. These findings should be taken into account in the use of exercise tests and exercise prescriptions for depressed and anxious psychiatric patients.

Introduction

Physical (in)activity might be important for physical and mental health [1,2]. In general, patients suffering from depressive and anxiety disorders exhibit a more sedentary lifestyle and this results in a low level of fitness [3-7] and a poor physical health [8-10]. This is a first argument for the implementation of exercise therapy within comprehensive treatment programmes for these patients. Another argument is the therapeutic effect of regular exercise on severity of depression and anxiety [11-13]. Well-designed exercise therapy programmes for these patients require a measurement of their physical fitness and perceived exertion [5].

Direct measurement of maximal oxygen intake by way of a maximal exercise test is the most accurate indicator of cardio-respiratory fitness. Maximal tests, however, have the disadvantage of requiring the subject's optimal motivation to work to 'near exhaustion', and need the supervision of a physician and the use of expensive equipment [14]. In exercise therapy for psychiatric patients, however, submaximal measures are highly recommended because many patients have a poor physical health, low levels of fitness and physical self-confidence, few experiences with aerobic training, and less energy and motivation for heavy physical effort [4]. These clinical considerations usually lead to the application of submaximal exercise tests in exercise therapy programmes. Craft and Landers [15] concluded in a meta-analytic review of studies on the effects of exercise on clinical depression that submaximal measurements are common in psychiatric settings; 18 of 20 surveys used submaximal exercise tests.

A high level of perceived exertion during exercise is negatively associated with participation in physical activity [16]. When the effort perceived by an individual increases, so too does the chance of drop-out. For depressed and anxious patients who often exhibit a high level of fatigue and a low motivation towards physical exercise, the rate of perceived exertion (RPE) is an important parameter when designing an appropriate exercise programme [5]. Generalised fatigue and lack of energy are typical symptoms of the depressive syndrome [17]. Patients with anxiety disorders might fear that aerobic effort will provoke physiological reactions such as shortness of breath, tachycardia, dizziness or sweating, which they associate with symptoms of panic attacks [4,5]. The RPE is a valuable tool in teaching these patients to monitor exercise intensity by taking account of their own level of fatigue and pain, rate of breathing and muscular sensations.

Most commonly, the evaluation of degree of perceived exertion can be derived from the psychophysiological concept of Borg [16,18,19]. The Borg 15 Graded Category Scale and the Borg Category Ratio 10 Scale (Borg CR 10 scale) quantify the sensations that the subject experiences during physical effort. The Borg 15 Graded Category Scale has a score range from 6 to 20 (15 grades), and the Borg CR 10 scale from 0 to 10 (10 grades). Both scales show a linear relationship with heart rate during progressive incremental exercise ($r = 0.94$ and $r = 0.88$, respectively).

In a previous study [20], we investigated the likelihood of drop-out during a graded exercise test (GXT) in a group of depressed and anxious psychiatric inpatients (n=124). During the course of the study, 40.3% of the patients were unable to complete the incremental GXT to 80% of the maximal heart rate reserve (MHRR). The determining variables for drop-out, in order of importance, were: the severity of depression in interaction with gender, the motivation towards exercise therapy and the body mass index (BMI). Female patients suffering from high severity of depression, less motivated patients and those patients with a higher BMI all have a higher risk of dropping out during the GXT. In this study the RPE was not included as a potential explaining variable for the drop-out.

The purpose of the present study was to investigate which psychological and physical variables could explain the perceived exertion during a GXT in patients with depressive and anxiety disorders. To the best of our knowledge, this is the first study that investigates this topic in a sample of psychiatric patients.

Methods

Subjects

During the course of the research project, 142 patients suffering from depressive and/or anxiety disorders [17] were admitted into three treatment units in a university psychiatric hospital in Belgium. All patients were asked to take part in the study; only five individuals refused. The investigated group therefore consisted of 137 patients (49 males and 88 females). Exclusion criteria were psychosis, treatment with beta-blockers and somatic disorders that would rule out any form of submaximal exercise testing. Before performing the GXT, the subjects answered the questionnaires.

Cardio-respiratory fitness

Cardio-respiratory fitness was measured by means of a submaximal incremental Graded Exercise Test (GXT) on an electronically braked bicycle ergometer (Ergo 2000) according to the Franz test [5,21]. The protocol for this test is to increase the work load by 10 Watts every minute, starting with a work load that corresponds to the body weight. Since such a work load was not feasible for many of the patients, the first stage work load was reduced by 30 Watts for male subjects and 50 Watts for the females. At the end of each stage the heart rate was registered by means of a heart rate monitor. The subjects were advised to maintain a steady pace of 60 rotations per minute. The GXT was terminated when: (a) the participant showed certain symptoms making it necessary to stop the GXT (14), (b) the subject was no longer able to maintain the pace of 60 rotations per minute, and (c) the subject reached the predetermined end point heart rate: 80% of the estimated MHRR. Patients were requested to refrain from eating, drinking coffee or smoking during a two-hour period prior to the test. After the testing every participant performed a cooling down with the same intensity in the second stage. Previous research by Knapen et al. [5] showed that the Franz test has a good reliability in a sample group of psychiatric inpatients (r ranged from 0.74 to 0.90).

Perceived exertion

For the evaluation of perceived fatigue, the short Borg CR 10 Scale [19] was chosen for the reason that the longer Borg 15 Graded Category Scale requires a greater differentiation capacity. Considering that patients were not familiar with the evaluation of perceived exertion and that Franz's cycling test in most cases only lasts 10 minutes, the shorter test seemed more appropriate. Prior to the examination, the test leader gave clear information concerning the rating procedure and the range of the scale. At the end of each stage, patients indicated their perceived exertion. The Borg 60% at MHRR was the rate on the Borg CR 10 scale that was related to 60% of the MHRR.

Depression

The Beck Depression Inventory (BDI) was used to evaluate the severity of depression [22]. This is a 21-item self-reporting questionnaire consisting of symptoms and attitudes relating to depression. The range of possible total scores is 0-63; with higher scores indicating greater depression. The Dutch version of the BDI has been shown to be a valid and reliable measure of depression severity [22].

Anxiety

The State Anxiety Inventory (SAI) was used to assess state anxiety [23]. This self-rating scale consists of 20 items, with response scores on a scale from one to four. The range of possible total scores is 20-80; higher scores indicate higher levels of anxiety. The SAI represents one of the most reliable and valid instruments for assessing trait anxiety in psychiatric settings, and has been validated for use in Dutch by Hermans [23].

Level of physical activity

Habitual physical activity before admission was assessed using the Baecke questionnaire [24]. Philippaerts and Lefevre [25] showed the Baecke questionnaire to be a reliable and valid instrument in the assessment of regular physical activity in a Belgian sample group.

Perceived cardio-respiratory fitness

Perceived cardio-respiratory fitness was assessed using the sub-domain scale perception of sports competence and physical condition of the Dutch version of the Physical Self-Perception Profile [26,27]. This sub-domain scale consists of 12 items which measure perceptions of sport and athletic performances, level of stamina, capacity to learn sport skills and maintain physical fitness. Each item is scored on a scale from one to four, with higher scores indicating more positive self-perceptions. The range of possible total scores is 0-48. Van de Vliet et al. [27] demonstrated an adequate reliability and validity of the Dutch version of the PSPP in a sample group of Belgian psychiatric inpatients.

Motivation for participation in exercise therapy

Motivation was assessed by means of a visual analogue scale, ranging from zero (not at all motivated) to 10 (extremely motivated).

Anthropometric measures

For the calculation of the BMI, measurements of height and weight were assessed during the first week of admission. The BMI was calculated by dividing weight by the square of height.

Statistical Analysis

A linear multiple regression equation (backward elimination method) was used to ascertain the explaining variables of the RPE at 60% of MHRR [28]. The following variables were available for selection method: depression, state anxiety, level of physical activity, perceived cardio-respiratory fitness, motivation, BMI, age and gender. The statistical significance level was set at 0.05.

Ethical Committee

The study procedures were approved by the Ethical Committee of the Faculty of Medicine of the Catholic University of Leuven in accordance with the principles of the Declaration of Helsinki of 1975, and all participants gave their informed consent.

Results

Thirteen of 137 recruited patients were not used for the multiple regression equation because of missing values. The characteristics of the sample group are presented in table 1.

Table 1 Characteristics of the sample group

Variables	**Mean**	**± SD**
Age (years)	33.51	±10.62
Borg at 60% MHRR	4.95	± 2.16
Depression	25.37	± 10.29
State Anxiety	56.97	± 12.41
Level of Physical Activity	7.30	± 1.59
Perceived Cardio-respiratory Fitness	22.36	± 6.41
Motivation	6.28	± 2.47
BMI (kg/m²)	23.68	± 4.91

The higher the score, the higher the perceived exertion, severity of depression and anxiety, level of physical activity, perceived cardio-respiratory fitness and motivation

The regression equation revealed that age was the most important explaining variable for the scores on the Borg CR 10 scale at 60% of MHRR. The second most important explaining variable was the level of physical activity, and the third was found to be state anxiety. No additional variables met the 0.05 significance level for inclusion into the model. The analysis of variance of the final model is presented in table 2.

Table 2 Analysis of variance for age, level of physical activity and state anxiety

Table 2 Source	DF	Sum of Squares	Mean Square	F Value	Pr > F
Model	3	36.90379	12.30126	2.69	0.0495
Error	121	553.84421	4.57722		
Corrected Total	124	590.74800			

The parameter estimates and standard errors can be found in table 3

Table 3 Parameter estimate and standard error of age, level of physical activity and state anxiety

Variable	DF	Parameter Estimate	Standard Error	F Value	Pr> F
Intercept	1	4.55792	1.45719	9.78	0.0022
Age	1	0.00294	0.00154	3.63	0.0592
Level of P. Activity	1	- 0.20597	0.12124	2.89	0.0919
State Anxiety	1	0.01357	0.01536	0.78	0.3785

Discussion

The aim of the present study was to explore which variables could explain the degree of perceived exertion during a GXT at 60% of the estimated MHRR in a sample group of 137 depressed and anxious psychiatric inpatients. The investigated variables were age, gender, BMI, depression, state anxiety, level of physical activity, perceived cardio-respiratory fitness and motivation towards exercise therapy. The explaining variables, in order of importance, were age, level of physical activity and state anxiety.

Age was found to be the most important explaining variable for RPE at 60% of MHRR, reflecting Borg's finding that age is an important determinant of RPE response [16]. Similar results have been found by others. In a study of Allman & Rice [29] isometric task fatigue was evaluated considering different ages. During the intermittent contractions of the elbow flexors normalized to 60% of each subject's maximal voluntary contraction, perceived exertion was found to be significantly greater for the old men compared to the young men. In the investigation of Navalta et al. [30] significant differences were observed for age, where older subjects perceived walking down hill more effortful than younger subjects.

The level of physical activity was the second most important explaining variable. Less active patients perceived a higher level of RPE during the GXT than more active ones. Garcin et al. [31] found a similar difference in perceived exertion during exhausting runs among individuals with high and moderate fitness levels. Likewise, Travlos and Marisi [32] also concluded that relative submaximal workloads were perceived harder by untrained subjects in comparison with trained ones.

The third most important explaining variable was state anxiety. According to Morgan [18], anxious and depressive patients make less accurate interpretations regarding bodily sensations during physical activity than healthy controls. The depressed mood and anxiety causes certain physiological reactions such as perspiration, dyspnoea, tachycardia and the linked catastrophic cognitions that influence the perceptual process [5,33]. Morgan`s [18] research demonstrated a significantly positive correlation between perceived exertion and anxiety. These findings are in agreement with the present study.

It is conceivable to suppose that the results could be generalized to patients treated in other Belgium psychiatric hospitals. The following features of the study might guarantee a certain value of generalization: (a) an unselected sample group of 142 patients of both sexes was recruited in three treatment units of a large psychiatric hospital over a period of 16 months, (b) only five individuals refused to take part in the study, and (c) the complexity of psychiatric (co)morbidity of most patients seems to be representative of those of patients who are treated in other psychiatric hospitals.

Furthermore, in the present study no distinction was made between patients with depressive or anxiety disorders. The symptoms of depression and anxiety often overlap as most (90%) patients diagnosed with depression have comorbid symptoms of anxiety disorders. Similarly, it is common that patients diagnosed with an anxiety disorder get a diagnosis of depression [34].

The present study has some methodological limitations. A first limitation was that the maximal heart rate was not measured but estimated by means of the formula: 220 minus age [14]. The estimation of the maximal heart rate allows space for an estimation error although the measurement of the maximal heart rate is not easy for such populations. Secondly, the level of physical activity was recorded in a subjective manner by questioning the patient. The questionnaire technique was applied as it is the most commonly used physical activity assessment. It is a very cheap method and easily applicable in large samples. Other methods like accelerometers and heart rate monitoring are more accurate but on the other hand expensive and difficult in a sample of 137 subjects [35]. A third limitation was the use of a less specific measurement for the severity of anxiety. The SAI measures state anxiety in different situations, not exclusively in exercise conditions. The use of more specific instruments assessing fear to move, such as the Dutch version of the Tampa Scale for Kinesiphobia [36] or the Body Sensation Questionnaire [37], would be recommended for further research. A fourth limitation was that the physiological mechanisms (lactate accumulation, hyperventilation etc.) as well as the local muscular pain sensations that are responsible for the RPE during aerobic exercise were not examined [38]. Finally, further research will be needed to include other factors relating to the RPE. In particular, the influence of smoking and the adverse effects of psychotropic drugs, especially the cardiovascular adverse effects such as tachycardia, orthostatic hypotension and dizziness, should be taken into account [39].

From this study can be concluded that physiotherapists should take into account that older patients, less active patients and/or patients with a high anxiety level perceive a high exertion during aerobic exercise. The Borg CR10 Scale is a valuable tool, especially for these patients, to learn to monitor exercise tolerance. To avoid overload of these patients, the intensities from low to moderate corresponding to a value of 3-4 (moderate to somewhat strong) on the Borg CR 10 Scale should be prescribed.

References:

[1] World Health Organization. Global strategy on diet, physical activity and health. Geneva: World Health Organization; 2004.

[2] Pedersen B, Saltin B. Evidence for prescribing exercise as therapy in chronic disease. Scand J Med Sci Sports 2006;16:3-63.

[3] Martinsen E, Strand J, Paulsson G. Physical fitness level in patients with anxiety and depressive disorders. Int J Sport Med 1989;10:58-61.

[4] Meyer T, Broocks A. Therapeutic impact of exercise on psychiatric diseases. Guidelines for exercise testing and prescription. Sports Med 2000;30:269-79.

[5] Knapen J, Van de Vliet P, Van Coppenolle H, Peuskens J, Pieters G. Evaluation of cardio-respiratory fitness and perceived exertion for patients with depressive and anxiety disorders: A study on reliability. Disabil Rehabil 2003a;25:1312-5.

[6] Knapen J, Van de Vliet P, Van Coppenolle H, David A, Peuskens J, Knapen K, Pieters G. The effectiveness of two psychomotor therapy programmes on physical fitness and physical self-concept in nonpsychotic psychiatric patients: a randomized controlled trial. Clin Rehabil 2003b;17:637-47.

[7] Sørensen, M. Motivation for physical activity of psychiatric patients when physical activity was offered as part of treatment. Scand J Med Sci Sports 2006;16:391-8.

[8] Fenton W, Stover E. Mood disorders: cardiovascular and diabetes comorbidity. Curr Opin Psychiatry 2006;19:421-7.

[9] Kahl K, Greggersen W, Rudolf S, Stoeckelhuber BM, Bergmann-Koester CU, Dibbelt L, Schweiger U. Bone mineral density, bone turnover, and osteoprotegerin in depressed women with and without borderline personality disorder. Psychosom Med 2006;68:669-74.

[10] Whooley M. Depression and cardiovascular disease. Healing the broken-hearted. JAMA 2006;295:2874-81.

[11] Bartholomew J, Morrison D, Ciccolo J. Effects of acute exercise on mood and well-being in patients with major depressive disorder. Med Sci Sports Exerc 2005;37:2032-7.

[12] Dunn A, Trivedi M, Kampert J, Clark CG, Chambliss HO. Exercise treatment for depression: efficacy and dose response. Am J Prev Med 2005;28:1-8.

[13] Knapen J, Van de Vliet P, Van Coppenolle H, David A, Peuskens J, Pieters G, Knapen K. Comparision of changes in physical self-concept, global self-esteem, depression and anxiety following two different psychomotor therapy programs in non-psychotic psychiatric inpatients. Psychother Psychosom 2005;74:353-61.

[14] American College of Sports Medicine (US). ACSM's health/fitness facility standards and guidelines. 6th ed. Champaign, IL: Human Kinetics; 2006.

[15] Craft L, Landers D. The effect of exercise on clinical depression and depression resulting from mental illness: A meta-analysis. J Sport Exerc Psychol 1998;20:339-57.

[16] Borg G. External, physiological and psychological factors and perceived exertion. In: Borg G, editor. Borg's Perceived exertion and pain scales. Champaign, Il: Human Kinetics; 1998. p 68-74.

[17] American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 4th ed. Washington: American Psychiatric Association; 1994.

[18] Morgan W. Psychological components of effort sense. Med Sci Sports Exerc 1994;26: 1071-7.

[19] Borg E, Kaijser L. A comparison between three rating scales for perceived exertion and two different work tests. Scand J Med Sci Sports 2006;16:57-69.

[20] Knapen J, Van Gool M, Van de Vliet P, Van Coppenolle H, David A, Pieters G, Peuskens J, Knapen K. Likelihood of drop-

out during a graded exercise test in non-psychotic psychiatric patients. Int J Ther Rehabil 2003c;10:305-9.

[21] Franz I. Vergleichende Untersuchungen zur Messung der PWC 170 (Comparative investigations on the measurement of the PWC 170). In: Hansen G, Mellerowicz H, editors. Internationales Seminar für Ergometrie. Berlin: Institut für Leistungsmedizin; 1972. p 136-42.

[22] Bosscher R, Koning H, van Meurs R. Reliability and validity of the Beck Depression Inventory in a Dutch college population. Psychol Rep 1986;58:696-8.
[23] Hermans D. De 'Zelf-Beoordelings-Vragenlijst' (The state-trait anxiety inventory). Gedragstherapie 1994;27:145-8.

[24] Baecke J, Burema J, Frijters J. A short questionnaire for the measurement of habitual physical activity in epidemiological studies. Am J Clin Nutr 1982;36:936-41.
[25] Phillippaerts R, Lefevre J. Reliability and validity of three physical questionnaires in Flemish males. Am J Epidemiol 1998;147:982-90.

[26] Fox K. The physical self-perception profile manual. Dekalb, Il: Office for Health Promotion, Northern Illinois University; 1990.

[27] Van de Vliet P, Knapen J, Onghena P, Fox K, Van Coppenolle H, David A, Pieters G, Peuskens J. Assessment of physical self-perceptions in normal Flemish adults versus depressed psychiatric patients. Pers Individ Dif 2002;32:855-63.

[28] SAS Institute (US). SAS language and procedures: Usage 2, Version 6 (computer program). Cary, NC: SAS Institute; 1991.

[29] Allman B, Rice C. Perceived exertion is elevated in old age during isometric fatigue task. Eur J Appl Physiol 2003;89:191-7.

[30] Navalta J, Sedlock D, Park K. Physiological responses to downhill walking in older and younger individuals. Journal of exercise physiology online 2004;7(6):45-51.

[31] Garcin M, Mille-Hamard L, Billat V. Influence of aerobic fitness level on measured and estimated perceived exertion during exhausting runs. Int J Sports Med 2004;25:270-7.

[32] Travlos A, Marisi D. Perceived exertion during physical exercise among individuals high and low in fitness. Percept Mot Skills 1996;82:419-24.

[33] Broocks A, Meyer T, Bandelow B, George A, Bartmann U, Rüther E, Hillmer-Vogel U. Exercise avoidance and impaired endurance capacity in patients with panic disorders. Neuropsychobiology 1997;36:182-7.

[34] Kaplan H, Sadock B. Kaplan and Sadock's Synopsis of Psychiatry: Behavioral Sciences/Clinical Psychiatry. 9th ed. Philadelphia: Lippincott Williams & Wilkins; 2005.

[35] Vanhees L, Lefevre J, Philippaerts R, Martens M, Huygens W, Troosters T, Beunen G. How to assess physical activity? How to assess physical fitness? Eur J Cardiovasc Prev Rehabil 2005;12:102-14.

[36] Vlaeyen J, Kole-Snijders A, Boeren R, Van Eek H. Fear of movement/(re)injury in chronic low back pain and its relation to behavioural performance. Pain 1995;62:363-72.

[37] Bouman T. The body sensations questionnaire. Gedragstherapie 1998;31:165-8.

[38] Dishman R, Berthoud H, Booth F, Cotman CW, Edgerton VR, Fleshner MR, Gandevia SC, Gomez-Pinilla F, Greenwood BN, Hillman CH, Kramer AF, Levin BE, Moran TH, Russo-Neustadt AA, Salamone JD, Van Hoomissen JD, Wade CE, York DA, Zigmond MJ. Neurobiology of exercise. Scand J Med Sci Sports 2006;16:470-70.

[39] Martinsen E, Stanghelle J. Drug therapy and physical activity. In: Morgan W, editor. Physical activity and mental health. Washington: Taylor & Francis; 1997. p 81-90.

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 1
July 2011– June 2012

Programs That Support Employment for People With Severe Mental Illness: A Literature Review

Annette L. Becker MS, RN
Assistant Professor
Department of Nursing
Utica College
1600 Burrstone Road
Utica, NY 13502
abecker@utica.edu

Lisa L. Flack MS, RN
Assistant Professor
Department of Nursing
The Sage Colleges

Carole A. Wickham MS, RN, CNS-BC
Clinical Nurse Specialist
St. Peter's Hospital

Citation:
Becker AL, Flack LL, & Wickham CA(2012).Programs That Support Employment for People With Severe Mental Illness: A Literature Review ***International Journal of Psychosocial Rehabilitation. Vol 16(1) 52-58***

Abstract

Recovery is a complex process engaging the values of hope, empowerment and quality of life. Research from diverse fields has shown substantial evidence demonstrating the importance of meaningful employment in the recovery of individuals with severe mental illness (SMI). This paper will focus on the practice of supported employment by reviewing the literature and evaluating existing programs that support employment of people with severe mental illness. Over time, the Individual Placement and Support (IPS) model has emerged as the predominant program representing the supported employment principles and tested by IPS fidelity standards. The IPS model has consistently achieved better work outcomes than the traditional vocational rehabilitation models including the team approach (DPA) and transitional employment models. Gaps in the literature include attention to psychosocial/spiritual outcomes, quality of life outcomes and job satisfaction associated with supported employment. It is

recommended that future program development and evaluation address these outcomes to encourage all aspects of recovery.
Key Words: recovery, supported employment, serious mental illness

Introduction

Research from diverse fields has shown substantial evidence demonstrating the importance of meaningful employment for individuals with severe mental illness (SMI). Mental health experts view employment as important to the process of recovery in this population (Cook & Pickett, 1995; Crowther, Marshall, & Hurley, 2001; Mueser, Salyers, & Mueser, 2001). Recovery is a complex process engaging the values of hope, empowerment and quality of life. Successful recovery has associated outcomes of: (a) improved management and reduction of psychiatric symptoms, (b) decreased hospitalizations, (c) improvement in global functioning and (d) more meaningful participation in activities (Barbic, Krupa & Armstrong, 2009). Although many studies have shown those with SMI as able to successfully participate in the labor market, in the United States, it is estimated that 75-90% of people with psychiatric disabilities still remain outside the labor force (Mueser, Salyers & Mueser, 2001; Mueser, Clark, Haines, Drake, et al., 2004). Quality of life for this population is positively impacted by the improvement of psychosocial health and well-being thereby impacting the larger community by decreasing the financial burden on mental health systems and reducing poverty (Baron, 2000; Lucca, Henry, Banks, Simon, & Page, 2004). The public policy considerations related to this population are vast and need to include an understanding of how funding should include not only vocational but clinical services (Cook & O'Day, 2006).

Efforts to support and encourage recovery in this population have been as complex as the process itself and have included the evidence based practices of assertive community treatment, family psychoeducation, illness management and recovery, integrated dual disorders treatment, medication management and supported employment (Bond & Campbell, 2008). This paper will focus on the practice of supported employment by reviewing the literature and evaluating existing programs that support employment of people with severe mental illness. By definition, supported employment is a model designed to enable people with psychiatric disabilities to attain competitive employment (Drake & Bond, 2008; Mueser et al., 2004). Competitive employment for persons with SMI is an outcome of the programs that will be evaluated. Unlike volunteer opportunities or sheltered workshops, competitive employment refers to employment in integrated settings receiving at least minimum wage (Mueser et al., 2004; Bond, Drake & Becker, 2008; Schonebaum, Boyd & Dudek, 2006).

Programs to support employment in the SMI population have been developed, implemented and evaluated primarily in the field of vocational rehabilitation within the context of psychiatric rehabilitation. Although limitations to these programs exist, studies evaluating these programs continue to add to a body of knowledge affirming the benefits of supported employment as an evidence-based practice contributing to the recovery of people with SMI (Drake & Bond, 2008; Cook and O'Day, 2006).

Comparison of Existing Programs

Several models have been implemented over the past twenty years to support persons within the SMI population to achieve and maintain competitive employment. The supported employment programs that will be addressed in this paper are the application and implementation of varying Individual Placement and Support Models (IPS), compared with the traditional Team Model also referred to as the Diversified Placement Approach (DPA) and the Transitional Employment Model.

The Individual Placement and Support (IPS) model is the most recognized and supported employment program with the most compelling evidence (Bond & Campbell, 2008; Kulka and Bond, 2009; Lucca, et al., 2004; Mueser, Aalto, Becker, Ogden, et al.,2005). This model is not different from supported employment (SE), but rather is an intervention using the principles of SE. (Twamley, Veste & Lehman, 2003). The IPS model supports the client in securing and maintaining a job as long as the client and employer agree. There is an integration of mental health services with employment services and individual support is provided in an ongoing manner in the context of small case loads

(Lucca et al., 2004; Mueser et al., 2005). The studies reviewed were conducted to evaluate the effectiveness of the IPS model as it has been applied in different settings and in comparison to older non-IPS models.

Mueser et al. (2004) compared the effectiveness of an IPS model with the non-IPS transitional model in the Hartford Study. Unlike the IPS model, the Transitional Model secures a number of available jobs and offers them to clients for a limited period of time (6-9 months). A contract exists between the employer and the agency, rather than the client. A client assumes one of these positions for the appointed period of time and is able to move to other designated jobs thereafter. The transitional model has been implemented most exclusively within day treatment programs. The Hartford Study measured employment rates, days to the first job, annualized weeks worked and job tenure in the longest job held during a follow-up period of time. The Structured Clinical Interview for DSM-IV (SCID) and the Positive and Negative Syndrome Scale (PANSS) were used to determine diagnostic background information. Overall functioning was measured using the Global Assessment Scale (GAS) and social and leisure functioning was assessed with a Social-Leisure subscale from the Social Adjustment Scale Social network information was obtained using a Social Network Interview and the Quality of Life Interview assessed areas of general life, social, leisure and finance. Self-esteem was also assessed using the Rosenberg Self-Esteem Scale. In this study, clients in the IPS program had statistically modest improvements in both vocational and nonvocational outcomes than clients who were not in the IPS program.

Interestingly, two independent studies were published in 2006 comparing supportive employment (SE) programs in two different treatment models. Schonebaum, Boyd and Dudek (2006) and Macias, Rodican, Hargreaves, Jones, Barreira and Wang (2006) conducted studies comparing outcomes of SE programs in Clubhouse participants (an established psychosocial rehabilitation model) and Assertive Community Treatment (ACT) program participants. ACT is an evidence-based team treatment approach designed to provide comprehensive, community-based psychiatric treatment, rehabilitation, and support to persons with serious and persistent mental illness (Assertive Community Treatment Association, 2007). Schonebaum et al. (2006) conducted a five year longitudinal study while Macias et al. (2006) used a randomized controlled trial (RCT) to make the comparison of employment outcomes in Clubhouse and ACT participants who were participating in SE programs. In both studies, demographic and diagnostic baseline data was obtained and both studies utilized quantitative measures to determine effectiveness of the supported employment. These measures included job placement rates, weeks worked, total jobs worked, job duration, hours and wages. In addition, Schonebaum et al. (2006) enlisted independent interviewers to collect information on service satisfaction, symptoms, social networks, medication, job history and hospitalizations, while Macias et al. (2006) focused on performance benchmarks to address the need to standardize supported employment models. In the Schonebaum et al. (2006) study, outcomes demonstrated higher job placement rates in the ACT model participants than those in the Clubhouse model, but higher wages and longer employment duration were demonstrated for Clubhouse participants. Macias et al. (2006) concluded that both models integrated with supported employment programs can achieve employment outcomes comparable to the exemplary SE programs, but suggested that this might also be related to whether participants were assigned a preferred program and/or the amount of job search services received.

Services for Employment and Education (SEE) was developed as an IPS program and implemented in Massachusetts. While RCT's have assisted in establishing evidence-base IPS programs, this study set out to test whether the SEE would achieve comparable outcomes. Extensive data was collected from three locations in the state to determine employment outcomes and predictors of employment success (Lucca et al., 2004). Participants in this study were also recipients of Massachusetts Department of Mental Health case management services, which allowed for diagnostic information to be included in the baseline data and tracked along with level of functioning and work related information. To evaluate the effectiveness of the program, the IPS Fidelity scale was used. The IPS Fidelity Scale was developed in 1997 to evaluate the quality of IPS models (Bond, Becker, Drake, & Vogler (1997). This scale defines the key aspects of supported employment and has been described as a compass giving direction to obtaining good vocational outcomes (Bacon, Lockett & Rinaldi, 2008). In this study, the average score of 74 on the fidelity scale showed good implementation of the SEE ISP model. Although the study intended to correlate employment outcomes with the implementation of SEE, limited employment data pre-SEE was available to effectively compare outcomes post- implementation of the SEE program. However, correlations between individual experiences in SEE and employment outcomes indicate that participants who were more involved in the SEE program and given more employer accommodations tended to improve their job tenure (Lucca et al., 2004). These results continued to add to the body of knowledge that implementing an ISP program such as the SEE program improve vocational outcomes including job tenure.

A two-year longitudinal study (Kulka and Bond, 2009) compared the strength of the working alliance in a traditional model utilizing a team approach (DPA Diversified Placement approach) to an evidence-based supported model (IPS) utilizing individual caseloads. The working alliance is defined as "the trusting, collaborative relationship, in a counseling relationship has long been demonstrated as a key element in positive therapeutic outcome and more recently linked to important outcomes in psychiatric rehabilitation programs" (Kulka and Bond, 2009, p. 157). One of the major questions this study addressed was whether numerous players as in DPA approach dilute a bond between caseworker and client. Studies show that people with SMI take longer to develop relationships (up to 6 months) versus general population (2 weeks) (Kulka and Bond, 2009). Like the other studies evaluating IPS, demographic data, employment information and an assessment of psychiatric symptoms using the PANSS was obtained. The working alliance scale was developed for this study and has six measurement areas to assess the client's social network and relationship with vocational worker and was used to determine the impact of the working alliance as it influenced employment outcomes. Authors found that those studied who were more independent and stable had better job performance and less need for a relationship with vocational worker than those who have a less stable job history needed more of a relationship with the vocational worker. The relationship between participants in the ISP (individualized approach) had a stronger "working alliance" with their vocational workers than those in the DPA (team approach) (Kulka & Bond, 2009).

One of the major challenges of mental health organizations is the dissemination of complex innovative practices. While there has been substantial progress in evidenced-based practices of people with SMI, mental health experts believe the development of approaches for dissemination on a large-scale has lagged, creating a gap between research and practice. Implementation of programs like SE is needed in order to promote a recovery-oriented culture (Resnick & Rosenheck, 2007).

A descriptive SE study by Bond, McHugo, Becker, Rapp & Whitley (2008) examined the dissemination plan of nine new SE programs from three states and evaluated fidelity changes over two years: at baseline and every six months thereafter. Experienced expert trainers were utilized. The study utilized a mixed-methods research design. Mixed-method design is the blending of qualitative and quantitative data that has the potential to avoid the limitations of a single approach (Polit & Beck, 2004). Quantitative methods consisted of ongoing SE fidelity evaluation; qualitative techniques consisted of semi-structured interviews that were transcribed verbatim that were coded along twenty-six dimensions of implementation activity, and then examined to identify factors that could improve fidelity. The SE fidelity scale is the gold standard of fidelity assessment, extensively validated and used in all recent randomized controlled trials of SE. The 15 items are rated on a 5-point scale and organized into 3 subscales: staffing, organization, and services. The SE fidelity scale successfully differentiates between types of vocation programs with empirically validated cut-off scores (Bond, et al., 2001). Site-level fidelity outcomes were reported as follows: at baseline all sites rated in the low fidelity range; at six months high fidelity was attained in four of the eight sites, at 12 months in all sites, and six of the nine sites at 18 months. At a two-year follow-up, eight of the nine sites were operating at high fidelity (Bond, et al., 2008). Competitive job rates were not provided.

In 2004, Resnick and Rosenheck of the Veterans Health Administration initiated a national SE dissemination effort. It is the largest dissemination initiative of any psychosocial rehabilitation model of any single healthcare system to date in the United States. The goal of the program was to train employment specialists at the 21 mentor-trainer sites to both practice and teach with a "train the trainer" model. This study also utilized a mixed-methods research design, a similar dissemination plan, and utilized expert trainers. Due to limited resources, Resnick and Rosenheck (2007) developed and evaluated a mentor-trainer system at two intensity levels (basic and intense) over a three-year period. All 21 sites received the basic training, which consisted of an initial visit, follow-up site visits and fidelity visits every six months and thereafter, provision of manuals an other resources, data-based performance feedback, and access to national telephone conference calls. The intensive sites received more frequent individualized feedback. Fidelity scores were reported as a composite over time (baseline not completed): at six months – no fidelity, at 12 and 18 months, low fidelity, and at 24 months high fidelity). SE implementation was evident at mentor-trainer sites with 29% of veterans working at competitive jobs as a part of SE compared with 16% at the non-mentor training sites (Resnick & Rosenheck 2007) .

The goal of the Johnson & Johnson – Dartmouth Community Mental Health Program was to develop high fidelity SE programs over nine states. Unlike the other two studies, this study was a private- public- academic collaboration to disseminate SE. While the researchers employed a similar mixed-methods research design compared to the other two studies, this study in contrast occurred over four years, dedicating one year to building support and implementation and evaluation in years two to four. The competitive employment is reported as 50%. In addition, this study utilized a three-site pilot for one year and provided strategies for program sustainability (Becker, Lynde, & Swanson, 2008).

Key Themes

The studies reviewed in this paper generally agree that employment is an important factor contributing to recovery in the population of those who have severe mental illness. Supported employment described in the 1980's has been accepted by many as a preferred outcome of vocational services. Over time, the Individual Placement and Support (IPS) model has emerged as the predominant program representing the supported employment principles and tested by IPS fidelity standards. The IPS model has consistently achieved better work outcomes than the traditional vocational rehabilitation models including the team approach (DPA) and transitional employment models. When applied in various treatment settings, the IPS model has contributed to better work outcomes regardless of the treatment setting. Most of these studies were conducted by researchers within the vocational rehabilitation discipline, thus the consistent focus was on employment outcomes.

Critical Gaps

Although the research over the past 20 years on supported employment has provided a strong body of knowledge for the benefits of ISP programs for vocational outcomes, several critical gaps were identified as they relate to clinical outcomes of the consumer. The following outcomes were not fully addressed and studied in the programs reviewed and have an impact on the consumer with SMI in their recovery process: psychosocial/spiritual outcomes, quality of life outcomes and job satisfaction.

People with SMI have the same desires and aspirations as those in the general population to achieve personal goals and improved quality of life. Recovery not only includes positive job outcomes and tenure, but also a person's psychosocial and spiritual wellbeing. Recovery as defined by Deegan is "…the need to re-establish an new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration to live, work, and love in a community in which one makes a significant contribution." (Deegan, 1988, p.12) The reality for many suffering from a SMI is a lack of meaning in life and this has a tremendous impact on ability to obtain and maintain employment (Bond & Campbell, 2008). Historically, research in this area has neglected the role of spirituality in the recovery process, yet some studies suggest that in review of self-reports of spiritual wellness has been associated with improvement of symptoms and outcomes (Comptom & Furman, 2005).

Another critical gap that was identified in all but one study was related to the acknowledgement of the varying level of symptoms that often exist between participants in these programs and how this relates to the overall vocational outcomes. However, in Lucca's study where individual diagnostic and functioning levels were gathered, the study did not find a relationship to the employment outcome (Lucca et al., 2004).

Measuring the vocational workers perspective of SE would give the body of knowledge new information in regard to how relationships are formed and maintained with those with SMI (Kulka & Bond, 2009). As SE is a relationship oriented program, obtaining the perspective of the vocational worker could provide a more well-rounded approach to assisting those with SMI on their road to recovery and stabilization.

Further research to identify to factors that promote SE implementation would be important for future dissemination efforts.

The notion that recovery is multifaceted is one that needs to be further developed and studied in the future. The quality of life beyond work has been shown to impact vocational outcomes, yet has not in itself been included in many research studies of IPS/SE programs to this point. The quality of life/job satisfaction scales is a large part of the recovery picture and should be included in the program and researched to see the statistical impact it has or doesn't have on the recovery of a person with SMI. SE programs need to be developed holistically to ensure all aspects of recovery.

References:

American Psychological Association. (2010). Publication Manual of the American Psychological Association. Washington, DC: American Psychological Association.

Assertive Community Treatment Association (2007, March 21). ACT Model. Retrieved from http://www.actassociation.org/actModel/

Bacon, J., Lockett, H. & Rinaldi, M. (2008). What's in a name? The IPS approach to supported employment. A Life in the Day.12, 4, 9-13.

Barbic, S., Krupa, T. & Armstrong, I. (2009). A randomized controlled trial of the effectiveness of a modified recovery workbook program: Preliminary findings. Psychiatric Services, 60, 491-497.

Barron, R.C. (2000). Employment policy: Financial support versus economic independence. International Journal of Law and Psychiatry. 23, 375-391.

Becker, D.R., Lynde, D. & Swanson, S.J. (2008). Strategies for state-wide implementation of supported employment: The Johnson & Johnson-Dartmouth Community Mental Health Program. Psychiatric Rehabilitation Journal, 31, 296-299.

Bond, G.R., Becker, D.R., Drake, R.E., & Vogler, K.M. (1997) A fidelity scale for the Individual Placement and Support model of supported employment. Rehabilitation Counseling Bulletin, 40, 265-284.

Bond, G.R. & Campbell, K. (2008). Evidence-based practices for individuals with severe mental illness. Journal of Rehabilitation. 74 (2), 33-44.

Bond, G.R., Drake, R.E. & Becker, D.R. (2008). An update on randomized controlled trials of evidence-based supported employment. Psychiatric Rehabilitation Journal, 31, 280-290.

Bond, G.R., McHugo, G.J., Becker, D.R., Rapp, C.A., & Whitley, R. (2008). Fidelity of supported employment: Lessons learned from the National Evidence-Based Practice Project. Psychiatric Rehabilitation Journal, 31, 300-305.

Compton, M.T. & Furman, A.C. (2005). Inverse correlations between symptom, scores and spiritual well-being among African American patients with first-episode schizophrenia spectrum disorders. Journal of Nervous and Mental Disease. 193, 346-349.

Cook, J.A., Blyler, C.R., Leff, H.S., McFarlane, W.R., Goldberg, R.W., Gold, P.B., Mueser,

K.T., Shafer, M.S., Onken, S.J., Donegan, K., Carey, M.A., Kaufmann, C. & Razzano,

L.A. (2008). The Employment Demonstration Program: Major findings and policy implications. Psychiatric Rehabilitation Journal, 31, 291-295.

Cook, J.A. & O'Day, B. (2006). Policy brief: Supported employment- A best practice for people with psychiatric disabilities. Ithaca, NY: Cornell University Rehabilitation Research and Training Center on Employment Policy for Persons with Disabilities, retrieved 9/19/09 from http://digitalcommons.ilr.cornell.edu/edicollect/1230/.

Cook, J.A. & Pickett, S.A. (1995). Recent trends in vocational rehabilitation in people with psychiatric disability. American Rehabilitation, 20 (4); 2-12.

Crowther, R.E., Marshall, M. & Hurley, P. (2001). Helping people with severe mental illness obtain work: Systematic Review: British Medical Journal, 322, 204-208.

Deegan, P.E. (1988). Recovery: The lived experience of rehabilitation. Psychosocial Rehabilitation Journal. 11 (4), 12-19.

Drake, R.E.& Bond, G.R. (2008). The future of supported employment for people with severe mental illness. Psychiatric Rehabilitation Journal, 31, 367-376.

Kukla, M. & Bond, G.R. (2009). The working alliance and employment outcomes for people with severe mental illness enrolled in vocational programs. Rehabilitation Psychology, 54 (2), 157-163.

Lehman, A.F., Goldberg, R., Dixon, L.B., McNary, S., Postrado, L., Hackmann, A. et al. (2002). Improving employment outcomes for persons with severe mental illnesses. Archives of General Psychiatry. 59, 165-172.

Lucca, A.M., Henry, A.D., Banks, S., Simon, L. & Page, S. (2004). The evaluation of an individual placement and support model (IPS) program. Psychiatric Rehabilitation Journal, 27, 251-257.

Macias, C., Rodican, C.F., Hargreaves, W.A., Jones, D.R., Barreira, P.J. & Wang, Q. (2006). Supported employment outcomes of a randomized controlled trial of ACT and Clubhouse models. Psychiatric Services, 57, 1406-1415.

Mueser, K.T., Aalto, S., Becker, D.R., Ogden, J.S., Wolfe, R.S., Schiavo, D., Wallace, C.J. & Xie,H. (2005). The effectiveness of skills training for improving outcomes in supported employment. Psychiatric Services, 56, 1254-1260.

Mueser, K.T., Clark, R.E., Haines, M., Drake, R.E., McHugo, G.J., Bond, G.R., Essock, S.M.,

Becker, D.R., Wolfe, R. & Swain, K. (2004). The Hartford study of supported employment of persons with severe mental illness. Journal of Consulting and Clinical Psychology, 72, 479-490.

Mueser, K.T., Sayles, M.P. & Mueser, P.R. (2001). A prospective analysis of work in schizophrenia. Schizophrenia Bulletin. 27, 281-296.

Polit, D.F. & Beck, C. (2004). Nursing research: principles and methods. (7th ed.). Philadelphia: PA: Lippincott, Williams & Wilkins.

Resnick, S.G. & Rosenheck, R. (2007). Dissemination of supported employment in Department of Veterans Affairs. Journal of Rehabilitation Research & Development. 44, 867-878.

Schonebaum, A.D., Boyd, J.K., Dudek, K.J. (2006). A comparison of competitive employment outcomes for the Clubhouse and PACT models. Psychiatric Services, 57, 1416-1420.

Twamley, E.W., Jeste, D.V., & Lehman, A.F. (2003). Vocational rehabilitation is schizophrenia and other psychotic disorders: A literature review and meta-analysis of randomized controlled trials. The Journal of Nervous and Mental Disease. 191, 515-523.

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 1
July 2011– June 2012

Action Research on Impact of Emotional Resilience Curriculum on Children affected by communal violence in Gujarat

Dr. Dipti Sethi

Ms. Deepika Singh

Citation:
Sethi D & Singh D (2012). Action Research on Impact of Emotional Resilience Curriculum on Children affected by communal violence in Gujarat. ***International Journal of Psychosocial Rehabilitation. Vol 16(1) 59-85***

Keywords: Emotional resilience, Children, Communal Violence, Gujarat, India

Acknowledgement: The authors wish to thank all the children who took part in this study, the families of the children who shared their pain and trauma with us for the purpose of this study. We are thankful to Janvikas, Udaan and Samerth Trust for providing the space in their schools and centers and to all the teachers from Samerth Trust and Janvikas, Udaan who were wholeheartedly engaged in implementing the curriculum and sharing their observations with us.
Conflict of interest: none declared
Sources of Funding: NEG Fire, New Delhi, India

Introduction

Context

The country is facing violence in various forms such as communal violence, insurgency and terrorism. Families affected by violence usually struggle to secure shelter and food. Children are generally last in the list of priority of these families. Mostly the trauma remains unaddressed and is manifested in the behaviour of children.

Children living in families with crisis such as families where parents are going through divorce, where parents are unemployed, alcoholic or families that are displaced due to war, conflicts etc are exposed to risks. The children are exposed to risks through the day to day processes that happen in such families and also by the end result of such crisis. However different types of such crisis have shown different impact on children.

Maltreated children, who experienced some risk factors (e.g., single parenting, limited maternal education, or family unemployment), showed lower ego-resilience and intelligence than non maltreated children Furthermore, maltreated children are more likely than non maltreated children to demonstrate disruptive-aggressive, withdraw, and internalized behavior problems. Finally, ego-resiliency, and positive self-esteem were predictors of competent adaptation in the maltreated children. (Cicchetti et al., 1993)

Emmy Werner (1982), She was one of the early scientists to use the term resilience in the 1970s. She studied a cohort of children from Kauai, Hawaiia. Kauai was quite poor and many of the children in the study grew up with alcoholic or mentally ill parents. Many of the parents were also out of work. Werner noted that of the children who grew up in these very bad situations, two-thirds exhibited destructive behaviors in their later teen years, such as chronic unemployment, substance abuse, and out-of-wedlock births (in case of teenage girls). However one-third of these youngsters did not exhibit destructive behaviours. Werner called the latter group 'resilient'. Resilient children and their families had traits that made them different from non-resilient children and families.

The communal violence in Gujarat left over 2000 dead, more than 300 women were sexually brutalized in horrific ways and over 2 lacks people were internally displaced in Gujarat (95% were Muslims). Even after eight years of communal violence in Gujarat most of the families are living in ghettos in the relief colonies and camps. The children who witnessed the violence in Gujarat have grown to adolescents. The relief and rehabilitation colonies that were temporary arrangements for the families have become permanent place of residence. The survivors did not receive any Post Trauma Counselling except in one of the camps in Ahmedabad and through Voluntary organizations and NIMHANS.

Janvikas, Udaan and Samerth are working with families affected by communal violence in Gujarat in 2002. For relief and rehabilitation of the families, organization undertook various interventions. Both the organization’s have long-term interventions for rehabilitation of the community and specifically of the children. The organizations have been able to respond to certain needs at a very intuitive level but a planned work to help the children cope with the trauma was not undertaken.

NEG Fire and Corestone provided training on Emotional resilience to Janvikas, Udaan and Samerth in 2010. Janvikas, Udaan and Samerth decided to implement the Emotional Resilience Curriculum with selected children and there by take first steps to respond to the special needs of the children.

Concept: What is ‘emotional resilience’?

Emotional resilience is the ability to cope with stressful life experiences, disappointments, and challenges in an effective and meaningful way that helps to preserve self-esteem, build social aptitude, and prevent frustration, anger, and even depression. Emotional resilience learned early in life assists in recovering from misfortunes and disappointments, thus fostering emotional health.

Emotional resilience is the ability to bounce back from the effects of adverse situations.

It's also:

- § Being able to stop yourself from getting extremely angry, down or worried when something 'bad' happens
- § Being able to calm down, feel better, and bounce back when you get overly upset
- § Being able to control your behaviour when you are very upset.

COD, 1990: Resilience - **act of ‘springing back’**

Corstone: The ability to function competently, powerfully and peacefully under stress. Emotional resilience reinforces people’s confidence that they can help themselves and others. It enables individuals, families and communities to face challenges, develop and maintain a positive attitude, make healthful choices, and solve problems on every scale.

Ways of Building Emotional Resilience:

Dr. Emmy Werner: After following a large group of children from the embryonic stage to their mid-thirties, researchers in a project headed by Dr. Emmy Werner of the University of California at Davis revealed that more than a third of "at risk" kids acquired the self confidence to do well in school, in social life, and later in love and in work.

This success was in spite of such significant obstacles as prenatal problems, discordant home lives, poverty, and significant personal loss. Similar or even better odds emerged from other studies.

And so the resilience researchers began to ask why. For if they could determine the protective factors the successful kids shared, those could be imparted to many more at-risk children — maybe even *all* children, preventively. Careful observation led to a formula: Protective factors minus risk factors predict the likelihood of being a resilient child and adult.

Rutter 1985: identifies 3 fundamental components that determine resilience.

- A sense of self-esteem & self -confidence
- A belief in one's own self-efficacy & ability to deal with change and adaptation
- A repertoire of social problem-solving approaches

Close association between resilience and self-esteem, self-efficacy and social competence is noted by various authors (e.g. Daniel and Wassell, 2002)

Lown (2002) and others assert that low self-esteem seems to be 'rife' amongst those struggling at school.

Factors influencing/determining emotional resilience:

Literature refers to wide range of protective and risk factors inherent in resiliency, the researchers adapted the protective factors and resilient traits used by the developed by Norm Constantine and Bonnie Benard for the study "California Healthy Kids Survey Resilience Assessment Module", 2001.

Protective Factors

Family connection:

Loving and caring environment at home. Availability of adults to share problems, encouragement and appreciation from parents or other adults at home. Parents interest in child's engagement at school, with friends or community also serves as protective factor. Parents or other adult's faith in child that he/she is worthy and can do what he or she determines to do act as a protective factor for the child.

School Connection:

Expectation and support system available in school. Encouragement, motivation, faith in students, appreciation and space to share any problems with teachers or any other adult in school serves as protective factor.

Pro- Social Peer:

Children spend lot of time playing with friends. Children are influenced by peers and also learn from peers. Friends with pro social behaviour act as a protective factor.

Pro- Group Participation:

Child's participation in activities at home, school or community for some meaning full contribution creates sense of fulfilment, self efficacy and contributes towards self esteem.

Resilience Traits:

Empathy:

The ability to read others behavioural clues to understand their psychological and emotional states and thus build better relationships. Resilient people are able to read others non verbal cues to help build deeper relationships with others and tend to be more in tune with own emotional state.

General Self Efficacy:

The sense that we are effective in this world- the belief that we can solve problems and succeed. Resilient people believe in themselves and as a result, build others confidence in them placing them in line of more success and more opportunity.

Effective help seeking:

Knowledge about help providers and ability to seek help in times of crisis is also a resilience trait.

Self Awareness:

(Lewis and Brook Gunns 1979) Although this term has no standard definition it is referred to those processes that permit the recognition of one’s ability to act, to feel and to regard oneself as an entity different from others.

Goals and aspiration:

Goals and aspirations in life act a constant source of motivation in life to move forward.

Expressing Feelings and Conflict resolution

Emotions shape our interactions with others and affect our behaviours resulting from those interactions. In order to prevent conflict, or deal with conflict effectively when it arises, child should learn to understand his or her feelings, be able to identify them, and regulate them. It is important to teach children that there is a whole gamut of emotions that can be expressed in various ways. However, knowing how to express them in a meaningful way will help child in solving social conflicts and maintaining relationships. One way of promoting development of emotional competence is to help your child develop vocabulary that expresses feelings.

The purpose for developing emotional literacy is to help children to precisely identify and communicate their feelings. Children must know how they feel in order to be able to fulfil their emotional needs. The child must communicate their feelings in order to get the emotional support and understanding needed from others, as well as to show their emotional support and understanding to others.

The objectives of the present study were articulated as under:

- § To study the curriculum implementation process for its adequate contextualization.
- § To study the influence of emotional resilience curriculum on well being of children.
- § To study extent of integration of emotional resilience practices in daily lives of children.

Methods

Research Design:

The research problem/question

Looking at the prolonged neglect of mental health needs of the children impacted by communal violence Gujarat based NGO's like Janvikas,Udaan and Samerth decided to implement the Emotional Resilience Curriculum with selected children and there by take first steps to respond to the special needs of the children.

Research Questions:

- Do the curriculum activities facilitate children to develop a positive self image?
- Do the curriculum activities facilitate children to develop coping mechanisms to deal with conflicts in schools?
- Do the curriculum activities facilitate children to develop empathy?
- Do the curriculum activities facilitate children to recognize own strengths and put them to use in multiple ways.
- Do the curriculum activities facilitate children to recognize own feelings?

The research also closely studied the process of implementation, need based changes if any in the curriculum, challenges faced by teachers and the learning's while implementing the curriculum.

Sample size:

About 100 children were part of the research.

The **research design** was explorative. The researchers studied implementation of curriculum and learning's from the same. The impact of curriculum on emotional, psychological and social well being of children after the implementation of the curriculum was also studied. The researchers have made no claims or hypothesis about the same.

Details about the tools implemented for data collection:

At the on set of the study information was collected regarding each child's family background, family income, sibling information, time spent with family and friends and history with communal violence.

To study the implementation of curriculum:

§ Teacher's daily logbook**:** To study behavioral changes of children. To aid the process of gathering teacher's observation an appropriate checklist was developed. The daily logbook for teaches was introduced in the refreshers training for teachers. Teachers were trained to make classroom observations and documentation.

- Reflection meetings: To share the observations and further sharpen observation skills of facilitator's regular reflection meetings were conducted with teachers. To enhance facilitator's capacities for group facilitation, review the observations and analyse the log books weekly meetings were conducted with the teachers. The weekly meetings also aided the process of tracking the behavioural change amongst children and the changes required in facilitation process.

- Case studies: Selected pre and post case studies of children were done. Appropriate formats for case studies were developed in consultation with the teachers.

- Feedback from children: At the end of each session (weekly sessions) the children and teachers were administered a feedback form to gather quantitative feedback on the classroom process and content.

Tools adapted to study influence of curriculum on well being of children

The researchers developed formats with pictures and closed ended questions to elicit children's response to their current emotional status.

- **Understanding the Protective factors and resilient traits of children:**

The team adapted the tools on measuring protective and resilience traits of children developed by Norm Constantine and Bonnie Benard for the study "California Healthy Kids Survey Resilience Assessment Module", 2001.

- **Self esteem of children:**

The Rosenberg self-esteem developed by Morris Rosenberg was also adapted.

- **Understanding predominant feelings of children:**

Exercise provided by Core stone in the activity manual were adapted to understand predominant feelings of the children.

- **Mapping strengths of children:**

To map the awareness about the strengths of children, a small tool was developed. The children had to draw a picture of them and write five adjectives describing them in the blanks.

Tool to understand conflict resolution strategies:
Another tool enlisting various conflict resolution strategies was prepared to understand various strategies used by children to resolve day-to-day conflicts.

Scope of Study:

a) Conceptual scope:

The research closely studied the process of implementation of the curriculum and the impact of curriculum on emotional resilience of children. The research made use of baseline test to understand the emotional, psychological and social support status of children before the implementation of the curriculum and after the implementation of the curriculum.

The study taook an account of protective factors to understand social support available to children.

It also studied the impact of curriculum on resilient traits of children such as self-esteem, general self-efficacy, problem solving, conflict resolution, expression of feelings, self-awareness and effective help seeking.

Children were the main source of information for the assessment of protective factors and resilient traits, the researchers did not included community or teachers for this purpose.

The curriculum was implemented with the hundred children spread in two schools of Janvikas ,Udaan and two centres of Samerth. The same children were part of the research study.

Limitations:
The study was conducted after a substantial gap since the communal violence. The sites for the study of the impact of curriculum were schools and centres that run in the habitation where the internally displaced families have settled.

The study can be used for contextual purposes and not large-scale generalizations.

b) Operational Scope:

The researchers did not take into account the support and participation of children in community activities.

Variables:

The variable of the study were derived from the protective and resilient traits required for emotional resilience. The study took into consideration the following variables.

a) Caring relationships and high expectation in home

b) Meaning full participation in the home

c) Caring relationships and High expectations in the school

d) Meaningful Participation: In the school

e) Cooperation and communication/Self Efficacy

f) Empathy

g) Problem Solving

h) Self Awareness

i) Caring Relationships: Peers

j) High Expectations- Pro social peer

h) Self esteem

i) Conflict Resolution

J) Feelings

h) Strengths

Process of Data Collection:

a) Steps followed to collect Baseline data:

- Briefing the children about purpose of the survey
- Briefing the teachers about the tools and process of conducting the survey
- Giving instructions:
- One of the researchers gave instructions for the exercise followed by other teacher's explaining the questions to children in smaller groups.
- Checking completeness of response:

The researchers checked the response sheets submitted by the teachers. In case child missed out responding to the questions, the sheet was given back to respective child to fill up.

b) Case Studies: Teachers prepared six children's case studies. Teachers got feedback and inputs from the researchers to prepare the case studied.

c) Review meetings: Review meetings focused on

- Discussion about implementation of curriculum and class room observations. Preparation of case studies and
- Providing continuous feedback to teachers.

The major challenge was to bring together all the teachers to share the experiences.

d) Administering the end line test:

Teachers with the support of the coordinators of the respective organisations administered the end line test.

Content of the curriculum:

The Emotional Resilience Curriculum for children prepared by Corestone builds on the principles of positive psychology focusing on attitudinal healing, building positive self image. The research studies impact of the curriculum and implementation of curriculum.

The major outcomes of the programme include

- Decrease in levels of symptoms of stress and anxiety
- Decrease levels of conflict and /or disruptive actions
- Increase levels of optimism and self esteem
- Increase internal locus of control
- Increase sense of belonging and social connection

The initial curriculum is for three months with exercises and practices that can be conducted by a trained educator.

Table: Break-up of curriculum for initial 12 weeks.

Week No	Purpose of Activities
Week 1	o Orienting students to reasons for groups and basic themes
Week 2	o To create group guidelines and 'group agreements' for safety in group o Set the tone of the group o Confidentiality is necessary in groups to build trust among group members and to encourage self disclosure.
Week 3	o To identify student's 'strengths' and to increase self-esteem and self-awareness
Week 4	o Identify and acknowledge our individual strengths. o Increase self-esteem and self-awareness
Week 5	o Help students identify how others see them o To familiarise themselves with what their and other's strengths look like

Week 6	o One month evaluation of identifying group/individual progress
Week 7	o Identify our feelings
Week 8	o Identify how we hold our feelings in our body o Begin to learn how having physical others or physically soothing activities help us to feel better.
Week 9	o To learn ways to manage big feelings
Week 10	o To learn ways to manage nig/deep feelings
Week 11	o Identify good communication skills to foster friendships and resolve conflicts
Week 12	o Three month evaluation to identify group and individual progress.

Methodology for implementation of the curriculum:

The curriculum was implemented once a week by the teachers. Method of circles was used to encourage children to participate and engage in activities. Specific incidents where any student's feelings were hurt were taken up for discussion by the teachers.

Inputs provided to teachers for implementation of the curriculum:

1) Orientation workshop of teachers:

A three day orientation workshop was conducted with all the teachers and coordinators involved in implementation of the curriculum. The workshop was conducted by Dr. Dipti Sethi and Ms. Deepika Singh.

The Objectives of the workshop were:

1) To share findings of the base line tests with the teachers.
2) To re-orient teachers about the research design.
3) To sensitize and sharpen teachers comprehension abut concept of Emotional Resilience.
4) To equip the teachers with the know how of imparting the curriculum to children.

5) To enhance facilitation skills of the teachers.

6) To discuss and clarify the ‘observation tools and teachers log book’ so that teachers are enabled to apply them.

Outputs of the workshop:

- Framework on emotional resilience was developed
- Curriculum mapping was done
- Participants applied the concepts in practical life (Stories of application)
- Understanding and restructuring of tools for reflection and observations

Results

Major Findings at a glance:

The research studied the Protective and Resilient factors that contribute towards building emotional resilience for the study. The curriculum has contributed to all the major outcomes that the study sought to observe

Increase in level of optimism and self esteem:

Overall the self esteem of children has improved. The responses to the question regarding being satisfied with oneself indicate need for improvement. The responses to having positive attitude towards oneself and feeling worthy of one self have increased.

The responses towards feeling not good at all, feeling useless and feeling that one does not have much to be proud of have considerably decreased. Similar responses can be seen while children share about meaningful engagement in schools and family.

Increase sense of belonging and social connection/ Protective factors:

An aggregate positive move in following supportive factors is seen.

- Caring relationships and high expectation in home
- Meaning full participation in home
- Care relationships and high expectations in the school
- Meaningful participation in the schools

Similarly an overall positive change in the following resilience factors is seen.

- Cooperation communication and self efficacy
- Problem solving

- Self awareness

Decrease in levels of stress and anxiety: As considerably less number of children reported experiencing anger. Further higher percentages of children have reported experiencing feeling of pleasure and amusement. Overall maximum children reported experiencing love, pleasure and amusement.

Data of Positive outcomes at glance: Outcomes where the movement is equal or more than five percent indicating increase in resilience traits or strengthening social connection are considered as major positive outcomes.

Sr. No	***Resilience traits and social connection***	***Baseline (%)***	***End line (%)***
1	Meaning full participation in home § Help make decisions with family	80	**91**
2	Caring relationships high expectation in schools § Teacher or some other adult who always wants me to do my best	87	**95**
3	Meaningful participation in school § I do things in school that make a difference	72	**87**

4	Cooperation communication self efficacy			
	§ Can work with some one who has different opinion than mine	62	**94**	
	§ I stand up for myself without putting others down	61	**85**	
	§ I can do most of the things myself if I try	92	**99**	
5	Empathy			
	§ I try to understand what other people feel and think	91	**98**	
6	Problem Solving			
	§ When I need help I find some one to talk with	88	**98**	
	§ I know where to go for help with a problem	83	**95**	
	§ I try to work out my problems by taking about them	91	**97**	
7	Self Awareness			
	§ I understand my moods and feelings	95	**100**	
8	Self Esteem			
	§ Take positive attitude towards self	52	**59**	
	§ Can do most of the things as good as the others.	36	**53**	

	§ Feel that they do not have much to be proud of.	15	**8**
	§ Feel that I am a person of worth, at least equal of others.	52	**59**
	§ Feel useless as times.	16	**7**
9	**Feelings**		
	§ **Pleasure (Almost always)**	**46**	**53**
	§ **Amusement (Almost always)**	**10**	**20**
	§ **Anger**	**15**	**8**

Areas of improvement:

The responses to questions about conflict resolution were mixed. The percentage of children accepting others view point without much of dialogue has increased. Similarly percentages of children who make efforts for acceptance of own view point by others has increased considerably. At the same time percentage of children who bring in a third person to talk about the conflict with the other person has increased too. Further sharing about conflict with some third person to understand the reasons of conflict has increased considerably. The researchers concluded that through the regular practice of sharing own views in circle and expressing own feelings; the children are learning to assert. At the same time children are learning to listen to others and accept others view point through practice of listening. A movement in all the directions is seen as children are becoming aware of own feelings, others feelings and also learning to resolve conflicts.

High expectation and pro social peers is the only supportive factor where a gap is seen. The percentage of children experiencing fear has increased. The researchers of the opinion the external environment did not change considerably during the period of study to create such an impact. Hence the possible reason could be that children have got in touch with own feelings resulting into changes.

Data of areas of improvement: *Outcomes where the movement is equal or more than five percent indicating decrease in resilience traits or weakening of social connection are considered as areas of improvement.*

Sr. No	***Resilience traits and social connection***	***Baseline (%)***	***End line (%)***

1	Caring relationships peers		
	§ I have a friend about my own age who talks with me about my problems	95	**84**
2	High Expectations : Pro social peers		
	§ My friends get into lot of trouble	67	**76**
3	Conflict Resolution:		
	§ Accept the view point of other person with whom you have conflict without much of dialogue.	50	***61***
	§ Make efforts for acceptance of your view point by the other person with whom you have conflict.	54	**85**
4	**Self Esteem**		
	§ Satisfied with self	75	**62**
5	**Feelings**		
	§ **Fear**	**1**	**7**
	§ **Love**	**70**	**54**

Discussion

7. Analysis and Interpretation of data:

Table showing children's responses in PERCENTAGE

7.1) Caring relationships and high expectation in home:

No	***Questions***	***Yes*** *Base line*	***Yes*** *End line*	***No*** *Base line*	***No*** *End line*	***Total***
6	In my home, there is a parent or some other adult who is interested in my school work.	92	*97*	8	*3*	**100**
9	In my home, there is a parent or some other adult who talks with me about my problems.	87	*88*	13	*12*	**100**
11	In my home, there is a parent or some other adult who listens to me when I have something to say.	95	*99*	5	*1*	**100**

5	In my home, there is a parent or some other adult who expects to me to follow the rules.	90	*91*	10	*9*	**100**
7	In my home, there is a parent or some other adult who believes that I will be a success.	98	*95*	2	*5*	**100**
10	**In my home, there is a parent or some other adult who always wants me to do my best.**	**95**	***96***	**5**	*4*	**100**

97% of the children have a parent or some adult at home who listens to their problems, talk to them as compared to 95% children.

Similarly, 99% children shared that they have parent or some other adult who talk with them about their problems as compared to 95%.

91% children's parents expects them to follow rules, is interested in child' work at school and has high expectations from them in terms of their success and behavior as compared to 90%.

91% children shared that they have parents or some other adult who always wants them to do best as compared to 95% previously.

7.2: Meaning full participation in the home:

2	***Meaning full participation in the home***	***Yes Base line***	***Yes End line***	***No Base line***	***No End line***	***Total***
14	I do fun things or go fun places with my parents or other adults.	98	*99*	2	*1*	**100**
25	**I help make decisions with my family.**	**80**	***91***	**20**	***9***	**100**

99% of children reported of engaging in fun things or going to fun places with parents or other adults as compared to 98% children.

91% reported that they help to make family decisions as compared to 80%. This shows high rate of participation of children in home.

7.3: Caring relationships and High expectations in the school

Sr. No	**Question**	Yes Base Line	Yes End line	No Base line	No End line	**Total**

35	At my school, there is a teacher or some other adult who really cares about me.	98	*96*	2	*4*	**100**
37	At my school, there is a teacher or some other adult who notices when I' m not there.	99	*98*	1	*2*	**100**
40	At my school, there is a teacher or some other adult who tells me when I have something to say.	99	*98*	1	*2*	**100**
36	At my school, there is a teacher or some other adult who tells me when I do a good job.	98	*100*	2	*0*	**100**
39	At my school , there is a teacher or some other adult who always wants me to do my best	87	*95*	13	*5*	**100**
41	**At my school, there is an adult who believes that I will be a success.**	**97**	***98***	**3**	*2*	**100**

100% children have some teacher or adult in school who notices good work done by them, the response for same question was 98% during baseline study.

The percentage of children reporting that there is some teacher or adult that notices their presence and absence from school and is available to listen to them reduced from 99% to 98%. About 96% children reported that the teachers or some other adult in school care compared to 98% in baseline.

98% children as compared to 97% children shared that there is an adult or teacher who has faith that the children will be successes full. About 95% children reported that they have a teacher or some other adult at school who wants them to always do best as compared to 87% during baseline.

7.4: Meaningful Participation: In the school

Sr. No	***Questions***	*Yes Base line*	*Yes End line*	*No Base line*	*No End line*	*Total*
26	At my school, I help decide things like class activities or rules.	91	*93*	9	*7*	**100**
21	I do interesting activities at school.	94	*97*	6	*3*	**100**
28	**I do things at my school that make a difference.**	**72**	***87***	**28**	***13***	**100**

As compared 94% children in baseline test about 97% children shared that they are **engaged in doing interesting activities in school.**

As compared to 72 % children in baseline, 87% of the children shared that they do things at school that make a difference.

7.5: Cooperation and Communication/self efficacy:

5	***Questions***	***Yes Base line***	***Yes End line***	***No Base line***	***No End line***	***Total***
45	I can work with someone who has different opinions than mine.	62	*94*	38	*6*	**100**
47	I enjoy working together with other students my age.	99	*95*	1	5	**100**
48	I stand up for myself without putting others down.	61	*85*	39	*15*	**100**
43	I can work out my problems.	94	*93*	6	*7*	**100**
44	I can do most things if I try.	92	*99*	8	*1*	**100**
46	**There are many things that I do well.**	**98**	***98***	**2**	*2*	100

Sr. No	***Questions***	***Yes Base line***	***Yes End line***	***No Base Line***	***No End line***	***Total***
13	I feel bad when someone gets their feelings hurt.	94	*92*	6	*8*	**100**
15	I try to understand what other people go through.	92	*92*	8	*8*	**100**
49	**I try to understand what other people feel and think**	**91**	***98***	**2**	***9***	**100**

Almost all the children enjoy working together with children of their age. Significant improvement (from 62% to 94%) children shared that they can work with someone who has different opinion then theirs. Similarly a significantly high number of children (form 66 % to 85%) children shared that they can stand up for them selves without putting others down. 99% children shared that they can do most of things if they try as compared to 92% children during baseline test.

7.6: Empathy

About 98% of children they understand what other people feel and think compared to 91% children in the baseline test. The percentage of children who shared that they feel bad when some one gets their feeling hurt reduced from 94% to 92%. Similar percent of children (92%) shared that they understand what other people go through.

7.7: Problem Solving

Sr. No	*Questions*	*Yes Base line*	*Yes End line*	*No Base line*	*No End line*	*Total*
17	When I need help find someone to talk with.	88	*98*	12	*2*	**100**
18	I know where to go for help with a problem.	83	*95*	17	*5*	**100**
19	**I try to work out problems by talking about them.**	**91**	***97***	**9**	**3**	**100**

Many more children (98%) as compared to the baseline test (88 %) shared that they find some to talk with when they need help and they try to work out problems by talking about them.

Similarly about 95% of children shared that they know where to go for help with a problem whereas the result for baseline stood at 83%.

The percentage children trying to work out their problems by talking about them increased from 91% to 97%.

7.8: Self Awareness

Sr. No	*Questions*	*Yes Base line*	*Yes End line*	*No Base line*	*No End line*	*Total*
53	There is a purpose to my life.	98	*97*	2	*3*	**100**
54	I understand my moods and feelings.	95	*100*	5	*0*	**100**
55	**I understand why I do what I do.**	**99**	***99***	**1**	*1*	**100**

About 97% children as compared to 98% children during baseline test shared that they have a purpose in life. The percentage of children sharing that they understand their moods and feelings remained same i.e. 95%. Similarly 99% children shared that they understand why they do what the do in baseline and end line test.

7.9: Caring Relationships: Peers

Sr. No	*Questions*	*Yes Base line*	*Yes End line*	*No Base line*	*No End line*	*Total*

1	I have a friend about my own age who really cares about me.	98	*98*	2	*2*	**100**
2	I have a friend about my own age who talks with me about my problems.	94	*83*	6	*17*	**100**
4	**I have a friend about my own age who helps me when I' m having a hard time.**	**97**	***99***	**3**	***1***	**100**

Percentage of children sharing that they have friends of own age that cares about them remained the same i.e. 98%. Whereas 99% compared to 97% children shared that they have friend with whom they can share about their problems and who help them when they are having hard time. The number of children who shared that they have friend of own age that talks to them about their problem significantly reduced from 94% to 83%

7.10: High Expectations: Pro - social peers

Sr. No	*Question*	*Yes Base line*	*Yes End line*	*No Base line*	*No End line*	*Total*
20	My friends get into a lot of trouble.	67	*76*	23	*24*	**95**
22	My friends try to do what is right.	99	*97*	3	*3*	**95**
24	**My friends do well in school.**	**90**	***89***	**10**	***11***	**95**

From 67% the percentage of children sharing that their friends get into lot of trouble increased to 76%. The percentage of children who shared that their friends try to do what is right reduced from 99% to 97%. Compared to 90% in baseline test 89% children shared that their friends do well in school.

7.11: Self Esteem

Questions esteem Self	*Strongly agree*	*Agree to some extent*	*Do nor agree or disagree*	*Disagree to some extent*	*Strongly disagree*

	Base	End line	Base	End line	Base	End line	Base	End line	Base line	**End**

	line		line		line		line			**Line**
1. On the whole I am satisfied with myself.	75	62	12	22	8	8	0	5	5	**5**
2. At times I think that I am no good at all.	8	13	46	33	8	12	20	22	18	**21**
3. I feel that I have a number of good qualities.	68	64	22	12	3	15	4	8	3	**1**
4. I am able to do things as well as most other people.	36	53	18	25	12	8	29	7	5	**6**
5. I feel I do not have much to be proud of.	15	8	35	29	18	12	17	28	15	**22**
6. I certainly feel useless at times.	16	7	23	11	14	20	25	33	22	**29**
7. I feel that I am a person of worth, at least the equal of others	50	64	28	15	12	3	5	12	5	**6**
8. I wish I could have more respect for myself	63	53	20	23	6	9	6	7	5	**7**
9. All in all, I am inclined to feel that I am a failure	8	16	23	14	23	13	26	24	20	**34**
10. I take a positive attitude toward myself	**52**	**59**	**12**	**14**	**15**	**11**	**9**	**6**	**11**	**12**

The comparison between baseline and end line data reveals some negative changes:

§ Only 62% children shared that they are satisfied with themselves as compared to the 75%.

§ Only 64% children strongly agree that they have number of good qualities as compared to 68%. But while considering the cumulative result of strongly agreeing and agreeing to some extent the result actually turns out to be positive as the baseline result comes to 90% and end line turns out to be 76%.

§ Similarly considering the results of statement “At times I think I am not good at all” the percentage of children strongly agreeing increased from 8 to 13. But if cumulative result of those strongly agreeing and those agreeing to some extent is considered the percentage of children reduced from 54 percent to 46 percent.

The positive outcomes are:

§ 59% children shared that they have positive attitude towards themselves as compared to 52%

§ Percentage of children who felt that they can do most of the things as good as the others increased from 36 percent to 53 percent.

§ Only 46% (cumulative result of strongly agree and agree to some extent) children feel that they are not good at all compared to 54%.

§ The percentage of children who felt that they do not have much to be proud of reduced from 15 percent to 8 percent.

§ Percentage of children who strongly agreed to the statement "I feel that I am a person of worth, at least equal of others" increased from 52 percent to 59 percent.

§ Only 7% children that they feel useless as times as compared to 16%.

§ The percentage of children who strongly agreed to the statement "I wish I could have respect for my self" reduced from 63 to 53.

7. 12: Conflict Resolution

Sr. No	*Questions*	*Yes Base line*	*Yes End line*	*No Base line*	*No End line*	*Total*
1	Try to keep away from the conflict situation	85	*88*	15	*12*	**95**
2	Try to find out a mid way by having a dialogue with the other person/persons with whom you have conflict.	88	*86*	12	*14*	**95**
3	Accept the view point of other person with whom you have conflict without much of dialogue.	50	*61*	50	*39*	**95**
4	Make efforts for acceptance of your view point by the other person with whom you have conflict.	54	*85*	26	*15*	**95**
5	Bring in a third person to talk about the conflict with the person with whom you have conflict	31	*71*	69	*29*	**95**

6	**Share about the conflict with some third person and try to understand the reason for conflict.**	**68**	*78*	**32**	*22*	**95**

Comparison with baseline

About 88% of children try to keep away from conflict situation as compared 88%

About 86% of children shared that they try to find a mid way by having dialogue as compared to 88%.

61%% of children also accept the view point of other person with whom they have conflict as compared to 50%.

About 85% children make an effort for acceptance for his/her view point by other person as compared to 54%.

About 71% of the children bring in a third person to talk about the conflict with other person as compared to 31%.

About 78% children share about the conflict with some third person and try to understand the reason for conflict as compared to 68%.

7.13: Feelings:

Frequency	*Almost always*		*Often*		*A few times*		*Hardly*		*Not at all*	
Feelings	Base line	End line	Base line	End line	Base line	End line	Base line	End line	Base line	**End line**
Pleasure	46	53	19	22	29	22	4	3	2	**0**
Fear	1	7	18	19	38	28	31	26	5	**19**
Amusement	10	20	23	24	34	36	25	15	8	**5**
Love	70	54	13	6	9	18	5	17	3	**5**
Anger	**15**	**8**	**16**	**17**	**27**	**27**	**25**	**29**	**17**	**18**

The children were asked to mention how frequently they experienced the feelings of pleasure, fear, amusement, love and anger in the last week. The table clearly shows that maximum number of children experienced pleasure, amusement and love. The number of children experiencing fear continuous has increased. The number of children experiencing anger has decreased considerably.

About 75% of children experienced feeling of pleasure (cumulative response of almost always and often) as compared to 65%.

60% children experienced the feeling of love (cumulative response of almost always and often) as compared to 83% previously. About 55% of children experienced fear (cumulative response of hardly and sometimes) as compared to 69% previously. About 19% children shared that they did not experience fear at all as compared to the 5% during baseline study. Percentage of children who expressed feeling of being amused increased from about 33% during baseline to 44%.

8.14: Strengths

Sr. No	*Strength*	*Base line* *Number of responses*	*End line* *Number of responses*
1	Creativity (includes dance, music, drawing, putting henna)	38	**37**
2	Hard working	31	**70**
3	Fearless	0	**39**
4	Loving others	0	**32**
5	Kindness	25	**4**
6	**Ask for help**	**0**	**52**

Maximum number of children responded that they are hard working; the number of responses are more than double as compared to baseline test. Being fear less and loving others are new responses which did not at all appear during baseline. Kindness appeared as one of the strengths during baseline test but in end line very few responses were seen. 52 responses emerged for demanding help which was not seen during baseline test.

7. 15 Observations from Case Studies:

Six case studies were conducted during the implementation of the curriculum. The case studies were prepared by teachers with guidance of the researchers. Children whose families were displaced due to communal violence in Gujarat, who were directly victims of violence or witness of violence were studied. The children themselves do not remember anything about the violence but have memories based on what they heard from parents and others.

Changes in behaviour were seen in a child who is survivor of the mob attack and witness of violence and killing of his family members at a tender age of less then two years. Initially he faced difficulty in concentration during discussions started sharing his views with the group and by the 6th week he also initiated the discussion. The child use to call his second mother by her name but during the programme he stated calling her aunty.

Another chld whose family was displaced due to communal violence and was identified as a very quite child by the teacher was studied. The child had expressed that she dislikes noise very much. She revealed liking for peace and silence. Initially the child spoke at the end of the discussion by the fifth week she started taking initiative and also talking to other children of the group. By the end of the programme the child had made friends in the group with whom she sat regularly.

All the children studied showed the pattern of increased participation and sometimes initiating the discussion. All the children have largely expressed the feeling of being happy and satisfied at the end of the sessions. Some of the children even acknowledged that the programme has helped them to bring about certain changes in behaviour with friends and families.

Changes and impact as observed by the teachers while implementing the curriculum.

- Children who were tight lipped during regular school sessions were speaking during the emotional resilience session and also initiating discussion.
- Children looked forward to the session and informed the teachers if they could not participate.
- Children shared how they felt at the end of the session. Issues such as being hurt during the session due to other child's behaviour were discussed and sorted.
- Children were able to recognising feelings.
- Children were able to recognising where in body they experience the feelings.
- Children could act the strengths very beautifully and the other children were easily able to recognise them.
- Children were using the learning's to cope up with tension. They talk friend when they experience some kind of tension.
- After recognising the feelings and understanding where they are experienced in body, children themselves shared about how they deal with their feelings.
- Children interact more freely with teachers without any kind of fear. They even share domestic problems with the teachers.
- The teachers shared that children have understood strengths and feelings very well.

8) Suggestions for way forward:

Timeliness of study: The researchers recommend studying the impact of curriculum in context where the time incident of crisis is in recent past.

Conduct a longitudinal study: Conducting a longitudinal study would generate an overall picture about the impact of curriculum. It may also help to observe the impact of external environment on children coping after the crisis situation.

Capacities of teachers: Process sensitivity and need to work with own sensitivity is crucial for the teachers engaging on the curriculum.

The teachers should be inducted into the implementation only after undertaking a basic training on curriculum implementation.

Building a community of practitioners: Teachers can build a community of practitioners implementing the curriculum. The community can facilitate sharing of reflections and learning's of teachers while implementing the curriculum.

Contextualizing the curriculum: The curriculum should be contextualized, activities to externalise the hurt and trauma could be worked out. The community of practitioners can also initiate the process to contextualise the curriculum.

Review the curriculum: Teachers suggested that more activities to deal with strong feelings should be developed.

In India from crisis such as communal violence, children also face systemic discrimination such as gender discrimination, caste discrimination and religious discrimination. The curriculum should be reviewed reworked to make it more relevant to Indian context.

Conclusion

Data provides indication that the curriculum has improved the resilience traits of children. Besides this the curriculum has initiated process of dealing with bottled up feelings. Well being issues of children need to be addressed in a systematic way as an increase in number of children experiencing is seen.

Teacher's observation indicated that the method of sharing and discussing in circles seems to have done well. Teachers share that the silent kids opened up, participated and initiated discussions.

Sharing by children also indicated that children liked most of the activities of the curriculum except those that involved writing.

It can be concluded that the curriculum activities have impacted the well being of children positively. It can also be said that teachers and children have appreciated different aspects of the curriculum. The curriculum should be implemented further to help children deal with strong feelings experienced by them. Constant handholding and sensitivity towards process needs to be further developed in the teachers.

References

1. Norm Constantine and Bonnie Benad. (2001). California healthy kids survey resilience assessment module technical report

2. Kumar Ravi Priya, Psychological impact of trauma o post riot displaced children of Panchmahal, Gujarat: A preliminary report.

3. Poppy Nash and Jackie Lown, Evaluation of Emotional resilience materials for primary school children.

4. Core Stone, Emotional resilience curriculum

5. Article by Adele M. Brodkin, http://www2.scholastic.com/browse/article.jsp?id=11275

6. http://ezinearticles.com/?Emotional-Resilience-in-Children&id=3670269

7. Donald Meichenbaum. How educators can nurture resilience in high risk children and their families.

Appendix / Tables

5.2) Review meetings (please refer annexure 2 for process report of review meetings)

Sr. No	***Focus of the meetings***	***Discussion, Observation/ reflections shared by teachers***	***Suggestions by the researchers and outputs of the meetings***
1	Separate meeting with teachers of Janvikas, Udaan and Samerth Sharing of experiences of the first two weekly sessions Discussion about data keeping and case studies	Children had many questions such as, “Why this work is done only with us” “Why no one younger or elder to us is included” Teachers needed more time then expected to formulate the rules. Positive experiences of working in circle with children, all the children could see each other, listen to each other and speak. Children of Samerth centres shared that sitting in circle was a new experience and they have never done it in their schools. Children who did not speak initially spoke in smaller circle. Children encouraged each other to speak and share. Children engaged in the process intensely right from the beginning that most of the children Children themselves brought up issues like trust and faith while forming the rules for the programme. Children also expressed some kind of confusion about the programme but after the first session once they got a little familiar with the process they open up. Feedback at the end of the sessions; Mostly children said “I liked	The researchers suggested the teachers to discuss response such as “I liked it” with children by asking them “what did you like” The researchers suggested the teachers to ask the children about how they felt at the end of the session and help children themselves articulate it. The teachers were reminded about the exact format of data keeping. It was decided that within a couple of days the data sheets would be prepared. The researchers and teachers finalised children for case studies and disused how the case study could be done.

		it”. The researchers also discussed about children’s ability to share the feelings at the end of the session. The teachers shared that they have written about how they experience the children. The teachers had not prepared the sheets for classroom observation; the data was kept in a notebook.	
2	Equipping teachers to conduct case studies.	Discussion about the format of case study with the teacher. Support teacher in preparing the case study. Review the information and experience of the teachers while preparing case study	The researchers suggested collecting all the information and not leaving any gaps.
3	Discussion of mid term test Collectively analyse the mid term review outcomes	The researchers discussed the mid term review analyses plan with the teachers. The team sat together and analysed responses of few questions. Similarly the classroom observations were discussed and the researchers helped the teachers to find out patterns e.g. children who always initiate discussion, children who always speak at the end. The team also went through the main aspects of the curriculum that were already covered and the remaining ones.	The researchers helped the teachers to understand that the data is to be used by them to find out what aspect have to be focus and what kind of efforts need to be put with which child.
4	Synergizing learning’s	A very interesting discussion emerged when all the teachers started to speak about the responses from children. (Please see section on impact)	

End Note: The uprooted – Caught between Existence and Denial. A document on the State of the internally Displaced in Gujarat

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 1
July 2011– June 2012

The Nature of Informal Learning of Mental Health Caseworkers

Janice M. Iseminger, Ph.D.
Pathways Behavioral Healthcare, Inc.

Joe F. Donaldson, Ph.D.
Professor, Department of Educational Leadership and Policy Analysis
University of Missouri
202 Hill Hall
Columbia, MO 65211
donaldsonj@missouri.edu

Citation:
Iseminger JM & Donaldson JF (2012). The Nature of Informal Learning of Mental Health Caseworkers. ***International Journal of Psychosocial Rehabilitation. Vol 16(1) 86-94***

Abstract

Objective :This paper describes the informal learning activities in which mental health caseworkers in two mental health community agencies engaged to maintain their knowledge and skills. Such a focus is important given current emphases within the health professions on accountability, assessment of learning and competence, and reduction of risk to clients.
Methods :A qualitative research design was employed to identify and describe patterns of learning in which caseworkers in community mental health centers engage. We interviewed eleven caseworkers, eleven supervisors, and eleven peers from two mental health facilities located in two Midwestern states. Further, document analyses and observation were conducted to triangulate the data.
Results: Data analysis revealed three interrelated themes about caseworkers' informal learning. The first, engaging in authentic work activities, included the activities of learning-by-doing, learning through assessment, and learning through trial-and-error. The second, learning from mentors, included observing and imitating more experienced peers, and receiving and acting on feedback from others. The third theme, using physical and social resources and tools, included deliberate networking with others, discussing practice protocols and problematic situations, meeting in teams, and taking advantage of information found in various media, including the internet and articles.
Conclusions and Implications: Caseworkers learn primarily through the on-the-job experiences and practice embedded in their work contexts. Therefore, supervisors, management, and caseworkers must recognize the importance of informal learning and related activities that further caseworkers' professional development. More detailed analysis of the ways organizational processes influence informal learning and the development of caseworkers' professional competences is needed.
Key Words: Community Mental Health, Professional Development, Informal Learning, Case Management

Introduction

Mental health caseworkers must maintain their competence with up-to-date skills, knowledge, information, judgment, and performance in order to serve clients and team members effectively with appropriate clinical processes. A range of quality mental health services is needed which are individualized and responsive to client needs. Understanding the learning activities that influence the development of mental health professional competence is important in order to ensure accountability in the forms of risk minimization, the delivery of error-free quality services, and professional development.

Although professional practitioners learn through their participation in formal instructional programs sponsored by educational institutions, professional associations, and the employing agency, research (e.g., Anthony, 1992; Farkas & Anthony, 2001) has shown that much of professional learning that is highly valued by professionals occurs informally within the workplace. This informal learning is, however, an area that has received little treatment in the research literature (Eraut, 2002). Therefore, this study was designed to explore the informal learning activities of mental health caseworkers that increase the effectiveness of their professional practice.

Methodology

A qualitative research design was employed to identify and describe patterns of learning in which caseworkers in community mental health centers engage to develop and maintain professional competence. One central question guided the present study: According to the perspectives of the study participants, what different learning activities do caseworkers use in their professional development?

We obtained approval to conduct the study from the University of Missouri Institutional Review Board prior to collecting any data. We interviewed eleven caseworkers, eleven supervisors, and eleven peers. Caseworkers were employed in two mental health centers. The two community mental health facilities were located in a mid-western metropolitan city within the United States. Because the metropolitan area crossed state boundaries, each mental health center was located in a different state.

Seven caseworkers were female and four were male. All of the caseworkers had obtained bachelor's degrees in social science, sociology, rehabilitation psychology, psychology, clinical psychology, social work, and criminal justice. Four of the caseworkers had master's degrees, two in social work, one in telecommunications, and one in counseling psychology. Two caseworkers were working on their master's degrees, one in counseling and the other in psychology. Two caseworkers were planning to start working on their master's degree the following year; one in social work and the other in family and marriage counseling.

The caseworkers' experiences also differed in terms of years of practice within the field of mental health, ranging from seven to 17 years. Only one caseworker had been at the same facility where she had begun her career; the other ten caseworkers had worked at several facilities but had stayed with case management work in the different work settings.

We completed unstructured interviews over a period of two months. Interviews with supervisors and peers, as well as review of state policies and mental health center policies and procedures were also conducted to triangulate the data and their sources in order to address issues of trustworthiness and dependability (Silverman, 2001; Lincoln & Guba, 1985; Creswell, 1998).

We transcribed interviews verbatim and analyzed the data inductively (Strauss & Corbin, 1998). The first stage of data analysis consisted of reducing the data by assigning codes to small pieces of information until all transcribed data had been coded; this process led to identification of categories. In the second stage, we looked for relationships between the categories (Strauss & Corbin; Creswell, 1998). These relationships constituted themes concerning the learning activities that contributed to caseworkers' competence development. By using qualitative methods, we were able to explore the experiences of mental health caseworkers as they voiced how they remained current with professional knowledge, skills, and applications in their work.

Theoretical Frameworks

This study was informed by four theoretical frameworks:

1. Nowlen's (1988) Competence Models;
2. LaDuca's (1980) Situated Model of Competence;
3. Eraut's (1994;2004) conceptualization of the practitioner performance period; and
4. Theories of situated learning developed by Wenger, McDumott, and Snyder (2002), Brown and Duguid (2002), and Rogoff (1990).

Nowlen's Models

Nowlen's (1988) framework contains three models: Update, Competence, and Performance. The Update Model's focus is on updating knowledge of disciplinary-based theories and concepts specific to a practitioner's profession, and enhancing the relationship between knowledge, skills, and performance. This model draws attention to practitioners as consumers of knowledge that they use in practice settings.

The Competence Model (Nowlen, 1988) focuses on the effective, efficient, thorough, and appropriate use of professional skills and abilities to perform a professional role, as well as on maintenance of up-to-date knowledge about one's profession. Competence in this case includes generic skills that are valid across a range of jobs and professional practice, as well as competencies unique to a field of practice. Techniques involving task analyses are used to define competencies which are then stated in performance (behavioral) terms. These capabilities involve a "synthesis of behavior objects as well as some elements of covert behavior" (p. 32). Both the update and the competence models focus exclusively on the individual with little, if any, consideration of the social nature of practice and the mutually constitutive role that context plays in practice.

The Performance Model (Nowlen, 1988), in contrast, goes beyond the Update and Competence Models and views professional practice as a social activity occurring within particular practice environments. "Performance is a function of both individuals and ensembles. Even when viewed as an individual matter, performance is the result of interacting social and personal influences" (p. 86).

LaDuca's Situated Model

LaDuca's (1980) Situated Model of Competence shares many characteristics with Nowlen's performance model. The Situated Model focuses on the interactions of the client, the clinical problem, and the clinical setting. When a professional works with a client, the client's behaviors become part of the context; at any specific instance, the situation imposes requirements for performance, and one cannot judge professional competence without "situation reference for. . .described tasks" (LaDuca, p. 255). "[P]erformance is not simply equivalent to competence because an individual's competence does not reside solely in the ability to perform a task or activity, but in performing the task correctly and at the appropriate time" (LaDuca, Engle, & Risely, 1978, p. 151).

Eraut's Performance Period

Eraut (1994, 2004) viewed practice as operating within a performance period. "The analysis of a performance period is concerned with everything done by the performer during a specified period of time, particularly with such aspects as reading the situation, deciding what to do, changing one's plan, responding to unforeseen events, allocating time and managing the transitions to other periods" (Eraut, 1994, p. 150).

Time is an important element of a performance period (Eraut, 1994, 2004). When time and action coincide in the action-present, the professional acts in an instant/reflex, semi-explicit mode, reading the situation via pattern recognition, making decisions instantaneously, and using learned practice routines. When the length of time expands beyond the action-present, the practitioner acts in a rapid/intuitive mode. The professional reads a situation via rapid interpretation, and intuitively employs routine activities of which they are aware. When ample time is available to reflect back on a performance period, the practitioner employs a deliberative/analysis mode of thought. The professional reads a situation and makes decisions via discussions and analysis with others and acts on the basis of plans developed through deliberation.

Eraut (1994) uses the concepts of "hot" and "cold" action to describe the speed that the practice environment requires for the practitioner to act. The characterizations of professional action within different lengths of time coupled with the concepts of "hot" and "cold" action provide a framework for exploring the role that time plays in the informal learning of practitioners.

Situated Learning

Professionals interact with others in communities of practice (Wenger, McDumott, & Snyder, 2002; Brown & Duguid, 2002). Communities of practice are "…groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an on-going basis" (Wenger, et al., p. 4). Through mutual engagement, members "… think, invent, and find solutions together. . . .They share a basic body of knowledge that creates 'common ground,' allowing members to work together effectively" (Wenger et al., 2002, pp. 37-38), in order to solve problems. Brown and Duguid (2002) concluded that communities of practice develop and transfer the most accepted professional practices and skills because members learn from each other and from the more skilled professionals in the community.

New professionals learn through a process that Rogoff (1990) termed cognitive apprenticeship, or participation in an activity with the guidance of more skilled people. The apprentice observes a practitioner who is more knowledgeable and skilled. The apprentice also participates in the work, beginning at the periphery in terms of essential practices but still engaging in legitimate (genuinely associated) practices and ultimately moving to the core of practice, where the apprentice will achieve required levels of competence."Communication between social parties [within communities of practice] provides a medium for new members…to participate in more skilled problem solving with the guidance of partners. . . .It facilitates growing skills and participation in activities" (Rogoff, p. vii).

Findings

Data analysis revealed three interrelated themes about caseworkers' informal learning. The first theme, engaging in authentic work activities, included activities of learning-by-doing, assessing situations, and making mistakes. The second theme, learning from mentors, included activities of observing, imitating, and receiving and acting on feedback. The third theme, using physical and social resources and tools, included actively networking, dialoging, meeting with teams, and reading. Table 1 provides a list of themes and the individual learning activities that comprised them. Pseudonyms are used in illustrative quotations below to protect caseworkers' identities.

Table 1

Caseworker Learning Activities

Major Themes	Learning activities
Engaging in authentic work	Learning by doing
	Transacting with context
	Experimenting
	Assessing situations

	Making mistakes
Learning from mentors	Observing
	Imitating
	Receiving and acting on feedback
Using physical and social resources and tools	Networking
	Dialoguing
	Asking questions
	Meeting with teams
	Reading

Engaging in Authentic Work

Caseworkers learned from engaging in authentic work, by doing their jobs, transacting with context, experimenting with solutions to problems, assessing situations, and making mistakes.

Learning by doing. Caseworkers reported that their most valuable learning outcomes were achieved through engagement in job activities that occurred over a length of time and in actual practice settings. Jo remarked: ". . .learning kind of as you go, day to day, what's effective. . .experience is definitely the key." Francis thought that she gained knowledge about her job by doing it: "I—learned on the job…gaining knowledge through my job… knowledge through the clients that I've worked with." And Gale said that "I really think that the actual experience of doing it [casework] has taught me way more than anything the books could have ever taught me." Lennie added to this understanding the importance of working in the actual practice setting: "…but I think to do case management, it's really the [case work] activity—you have to be in the community day-to-day…that's the most important---engage in activity."

Transacting with context. A major part of learning on the job consists of the process of contextual transaction in which mutual influence is exerted by the context on the practitioner and the practitioner on context. In this case context is defined to include problematic situations, clients, and other caseworkers. Jo thought that getting together with co-workers and "learning from each other was very helpful." Francis described situational interactions as:

… a combination of different things: resources that you have out there for your own professional career. Information that you glean from your co-workers; what you learn from your co-workers. Hearing your doctor talk. Having a dialogue with your supervisor. Knowing your clients. You have to be able to take in the information.

Experimenting. By working in contexts that are uncertain and ambiguous, caseworkers learned by trying out different styles, techniques, and skills and seeing what did and did not work. Alexis stated, "I think that's something that I learned over time. . .a kind of trial and error type situation working with different types of clients." Jo thought of her learning occurring "…kind of through trial and error."

Assessing situations. Caseworkers experience new situations each day and learn by assessing their various situations, circumstances, and clients: “kind of do an assessment on how I’m going to do what I need to do. . .I just go out there and see what’s going on” as one caseworker defined this process. CJ reported that “probably one of the first things that I had to learn when I first got into this field is how to assess someone, to see what level of psychiatric crisis they were in and therefore be able to incorporate the right intervention for them. . . .It’s all about assessing their situations and assessing their level of need…”

Making mistakes. Caseworkers briefly discussed learning from their mistakes. They reported that if they did something wrong with assessment or treatment, they would commit that learning to memory and would use those memories as references if they encountered similar situations in the future. Ira admitted that along “with any job you start, you learn from your mistakes; and you really have to do that.” Dot noted, “I know we all make mistakes and I remember talking to co-workers…and realized that I had to get [things] down pat [correctly].”

Learning through Mentors.

Caseworkers observed and imitated co-workers who had expertise in particular situations or from co-workers who provided feedback about job performances.

Observing and imitating. Caseworkers discussed how, when they first started their jobs, they learned primarily through mentorship, role-modeling, and observations. When Ira began his job, his reliance on his co-workers “to initially help me was the key to really learning what I needed to learn.” Alexis reported that ‘They set me up with another caseworker and that caseworker would teach me what I needed to know.” Bo identified that the “ride a-longs” were important to her learning processes: “We would go with an experienced case manager to the clients on home visits. And tag along and learn about community resources. The actual experience is so beneficial.” Huie also reported, “But a lot of it was a growing situation, learning from peers in my field and from supervisors in my field.”

Receiving and acting on feedback. Caseworkers identified clients, co-workers, and supervisors as the principal people who provided them with feedback about their job performance. Gale described a feedback experience: “I just had an incident last week and there was another co-worker in the room and the client was getting really upset and I didn’t think I was doing my job.” And then her co-worker provided her constructive feedback about how she handled the situation. Gale also praised her supervisor for her feedback: “That’s one thing [with which]…I have been really blessed—her willingness to let me know that what I am doing well, and maybe this is what I can improve…”

Using Physical and Social Resources and Tools

Physical tools consisted of technology such as computers and cell phones and other non-human resources such as buildings and printed materials. Social tools consisted of co-workers, supervisors, agency staff personnel, subject matter experts, and community resource personnel. Caseworkers used these tools in several ways to learn.

Networking. Caseworkers actively networked when they exchanged and shared information with co-workers, when they connected with community agencies, and when they talked with community personnel about how to obtain services for clients. Contact would be made either by face-to-face encounters or through the telephone. As Ira explained, “I had very limited knowledge on that [topic] and I had a co-worker that had been doing the job for quite a few years and was connected with those folks in the community and he kind of guided me through. I met some key people in the community that basically you could go to.”

Dialoguing. Talking with others was a mechanism used by caseworkers to share ideas and information. If caseworkers did not know about a needed resource or information, they used their cell phones to call other caseworkers to obtain information. One caseworker would say to another caseworker, "hey, I have a question" and then discuss the situation with her colleague. Dialoguing and listening assisted caseworkers with understanding how to do their jobs and locate and find needed information and resources. Dot added: "And that's how I've learned—just through talking to other people, getting new techniques on how to handle certain situations, going to treatment team, overhearing my office mate while she's on the phone with somebody." Francis also stated that "it's just acquiring knowledge…day by day, paying attention in team meetings, listening to my co-workers talk, having conversations with them, talking with my supervisor."

Asking questions. Caseworkers said they also learned by asking questions. Bo asked questions of her co-workers, therefore using them "as a resource." Gale used her supervisor as a resource for asking questions and obtaining information: "I can ask her how…I do certain things or ask her for suggestions and then she's wonderful coming up with things." If caseworkers were out in the field, they asked questions of their colleagues and even of community resource personnel over their cell phones.

Meeting with teams. Caseworkers discussed how team meetings provided a setting where learning occurred as they discussed problematic situations and listened to ideas and opinions expressed by co-workers. Gale thought that meetings were important to her job: "We do have team meetings and during that time, we'll talk about problem solving." Jo saw the importance of using her team members as resources for learning: "We get together as a team and think or brainstorm to think of ideas to help with clients."

Reading. Caseworkers read reference materials, books, policy and procedure manuals, Internet web sites, email messages, articles, newspapers, community bulletins and resource guides. By reading, caseworkers again obtained information that was related to job performance. Bo discussed how she "looked to the DSM [Diagnostic and Statistics Manual-IV] and I go through it and I look in there to see what the criteria is [sic] for such and such a diagnosis." Another caseworker discussed how she would read "a good book on psychopharmacology and that's been very helpful because clients are always asking questions about their medications and side effects."

Discussion and Conclusions

The findings of this study were consistent with the literature on professional learning. Further, the findings were likewise consistent with the insights provided by the theoretical frameworks used to guide the study. The following paragraphs provide illustrations of these consistencies.

Caseworkers reported that they learned primarily through on-the-job experiences and situations embedded in their work. They did not perform alone or engage in solitary activities but instead participated in social interactional processes (Wertsch, Minick, & Arms, 2002) located within performance periods (Eraut, 1994). Therefore, they learned because they constructed their knowledge as they engaged in practice (Daley, 2002), being present within and actively involved in events and situations that took place within their working environments (Brown & Duguid, 2002; Nowlen, 1988; Rogoff, 1990).

The findings of this study are congruent with Nowlen's (1988) and LaDuca's (1980) focus on the central role that social context plays in professional learning. The findings of this study demonstrated that most of the caseworkers' learning resulted from social interactions with clients, colleagues, supervisors, and community members. Learning was also fostered and influenced by their working environments and the clinical situations and problems presented by those environments.

Caseworkers interacted with each other and used tools of practice within communities of practice (Wenger, McDumott, & Snyder, 2002; Brown & Duguid, 2002). Caseworkers learned from each other. They observed and discussed techniques and skills that worked in certain situations while more expert caseworkers role-modeled how to apply skills and techniques.

New caseworkers learned from more experienced caseworkers. They shadowed their more experienced co-workers by going with them into client's homes and observing the interactions and treatment interventions as their experienced colleagues modeled, explained, provided feedback, and reinforced what was going on in the situational interactions (Lave & Wenger, 2002).

Caseworkers worked in teams. As team members, they learned by building a shared knowledge base about practice and treatment protocols. Regular team meetings provided a networking context in which to network in order to exchange information and learn through such activities as asking questions and dialoguing about clients and work performance techniques.

Caseworkers consistently worked with novel and ambiguous situations and under conditions Eraut (1994) termed "hot action." Caseworkers learned to solve problems as they dealt with diverse client needs that had unknown solutions and made decisions rapidly and responded instantaneously to problematic situations (Eraut). By learning from experiences and situational contexts, caseworkers acquired the skills and techniques to perform their jobs effectively. As Eraut (1994) stated, the caseworkers developed expertise when they developed the ability to cope with difficult, ill-defined problems, demonstrated the ability to correctly read situations, and resolved client's problematic situations. Caseworkers continuously learned as the demands of the situations shifted and changed. Shared learning and knowledge creation, coupled with authentic work engagement, enabled caseworkers to develop skillful behaviors and deliberative processes.

Implications for Practice

In interviews, supervisors and management concentrated on the formal learning processes that are viewed by the mental health centers as important to caseworker learning. One implication for practice therefore is to begin the process of improving supervisors' and management's recognition of the importance of informal learning and related activities that help develop caseworkers' professional competence. In relation, another implication for practice is making sure that caseworkers' understand that most of their learning occurs because of these informal learning activities. As such, supervisors should help caseworkers use these learning activities to extract knowledge and further the development of their professional development.

Implications for Future Research

During the course of the literature review, we uncovered very few studies that specifically explored the informal learning activities of caseworkers. Thus, we conducted this study to contribute to a deeper understanding of the types of informal learning activities mental health caseworkers actually use in their professional development. We trust that we have made a contribution in this area. However, more must be done. A continuing need is for more detailed analysis of the ways organizational processes influence informal learning, the exact content of caseworker informal learning, and the relation between informal learning and the development of particular mental health caseworker competences.

References:

Anthony, W. A. (1992). Psychiatric rehabilitation: Key issues and future policy. Health Affairs, 11(3), 164-171.

Brown, J. S., & Duguid, P. (2002). The social life of information. Boston, MA: Harvard Business School Press.

Creswell, J. W. (1998). Qualitative inquiry and research design: Choosing among five traditions. Thousand Oaks, CA: Sage.

Daley, B. J. (2000). Learning in professional practice. New Directions in Adult and Continuing Education, 86, 33-42.

Eraut, M. (1994). Developing professional knowledge and competence. Washington, D. C: Falmer.

Eraut, M. (2004). Informal learning in the workplace. Studies of Continuing Education, 26(2), 247-273.

Farkas, M., & Anthony, W. A. (2001). Overview of psychiatric rehabilitation education: Concepts of training and skill development. Rehabilitation Education, 15(2), 119-132.

LaDuca, A. (1980). The structure of competence in health professionals. Evaluation and the Health Professional, 3(3), 253-288.

LaDuca, A., Engel, J. D., & Risley, M. E. (1978). Progress toward development of a general model for competence definition in health professions. Journal of Allied Health, 149-156.

Lave, J., & Wenger, E. (2002). Situated learning: Legitimate peripheral participation. Cambridge, MA: Cambridge University Press.

Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry. Newbury Park, CA: Sage. Nowlen, P. (1988). A new approach to continuing education and the professions. New York, NY: MacMillan.

Rogoff, B. (1990). Apprenticeship in thinking: Cognitive development in social context. New York, NY: Oxford University Press.

Silverman, D. (2001). Interpreting qualitative data: Methods for analysing talk, text, and interaction (2nd ed.). Thousand Oaks, CA: Sage.

Strauss. A., & Corbin, J. (1998). Basics of qualitative research: Techniques and procedures for developing grounded theory (2nd ed.). Thousand Oaks, CA: Sage.

Vygotsky, L. (1986). Thought and language. Cambridge, MA: MIT Press.

Wenger, E., McDumott, R., & Snyder, W. M. (2002). Cultivating communities of practice. Boston, MA: Harvard Business School Press.

Wertsch, J. W., Minick, N., & Arms, F. J. (2000). The creation of context in joint problem solving. In B. Rogoff, & J. Lave (Eds.), Everyday cognition: It’s development in social context (pp. 151-171). Bridgewater, NJ: Replica Books.

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 1
July 2011– June 2012

Understanding Psycho-Social Issues in Persons with Spinal Cord Injury and Impact of Remedial Measures

Roop Singh, M.D. a
Professor

Rajesh Kumar Rohilla, M.D. a
Associate Professor

Ramchander Siwach, M.D. a
Professor& Head

Satyavir Singh Dhankar, M.D. a
Resident

Kiranpreet Kaur, DA, DNB b
Assistant Professor

(a) Department of Orthopaedic Surgery, Paraplegia & Rehabilitation
and (b) Anesthesiology and Critical Care;
Pt. B.D. Sharma PGIMS, Rohtak-124001 (Haryana) INDIA

Citation:
Singh R, Rohilla RK, Siwach R, Dhankar SS, & Kaur K (2012). Understanding Psycho-Social Issues in Persons with Spinal Cord Injury and Impact of Remedial Measures ***International Journal of Psychosocial Rehabilitation. Vol. 16(1) 95-100***

Corresponding author:
Dr. Roop Singh
Professor
9-J/ 52, Medical Enclave
PGIMS, Rohtak-124001
Haryana, INDIA.
E-mail : drroopsingh@rediffmail.com

Abstract

Background: Spinal cord injury (SCI) is a devastating event that has not only physical but also social and psychological ramifications for the injured person. These can adversely affect the psycho-social life of SCI persons.
Purpose: The present study aimed (a) to assess psycho-social problems of patients with SCI and (b) to evaluate the impact remedial measures.
Method: Fifty persons with SCI were assessed for various psycho-social issues, remedial measures were taken to address them, and follow-up assessment was performed 6 months later to examine the impact of these over time.
Results: The affects of SCI on the areas like psychology, sexual functions, social adjustments, burden on family, partner relationships, and sleep disturbances are quiet evident. Various remedial measures taken to address these issues showed good results after six month follow-up.
Conclusions: Simple instructions and interventions are effective in decreasing psycho-social problems, and health professionals should use them in rehabilitation of persons with SCI.

Key words: Spinal cord injury; Psycho-social; Social adjustment; Autonomy; Mobility; Burden on family.

Introduction

Spinal cord injury (SCI) affects all aspects of a patient's life, including the physical, behavioral, psychological and social functioning (North, 1999). As life expectancy is steadily improving through modern spinal unit care, the increased survival in SCI patients is associated with secondary complications, which continue to pose management challenges (Devivo., et al, 1992; Kreuter., et al, 2005). These all, secondary disabilities are usually not fatal and they impair independent living and are costly to treat. With rehabilitation and good follow up life expectancy of SCI patients can approach to normal (Kreuter., et al, 2005).

Common neuropsychological deficits among SCI patients include poor attention span, limited initial learning ability, poor concentration ability, impaired memory function, and altered problem solving ability and these deficits may interfere with rehabilitation following SCI (Roth., et al, 1989). 20-25% patients experience an anxiety disorder and 30-40% develop a depressive disorder (Kennedy & Rogers, 2000). Post traumatic stress disorder (PTSD) is the development of characteristic symptoms following exposure to an extreme traumatic stressor. PTSD after SCI patients is observed in 10-40% patients (Kennedy & Duff, 2000). The person with SCI is at high risk for undergoing the "Four D Syndrome," i.e. dependency, depression, drug addiction and if married - divorce. Two more "Ds" - debilitation and demanding can also be added to this list (Gill, 1999). Spinal cord injury affects both genital and sexual functioning (Siosteen., et al, 1990). 42% of males with SCI are not satisfied with their sex lives (Phleps., et al, 1983). 34% SCI patients are not satisfied with partner relationships (Franceschini., et al, 2003). Spinal cord injured patients are reported to have sleep disturbances like restless sleep, difficulty in initiating and maintaining sleep, snoring, often awaking in the early hours of the morning (Bonekat., et al, 1990).

The present study aimed to assess these psycho-social problems of patients with SCI, taking remedial measures to minimize these problems, and to evaluate the impact of these measures. This study is a part of a larger ongoing study investigating epidemiology, treatment, rehabilitation, adjustment, psychosocial, quality of life, and community reintegration outcomes.

Material and methods:

Fifty patients (36 males and 14 females) of SCI more than 6 months duration with or without persisting deficit, who presented at our, tertiary level health care institute, were included in the present study. The patients with SCI of less than 6-month duration or having pre-morbid and/co-morbid conditions such as severe psychiatric illness and traumatic brain injury were excluded from study. The mean age of the patients was 37.7 (range, 18-73) years. Patients presented at a mean of 3.7 years (range: 6 months to 20 years; SD± 4.34) after injury. The patients were given detailed information about the purpose of study and written consent was obtained from all the participants. First of all the complete history of patients was recorded to rule out any traumatic brain injury or severe psychiatric illness, then the complete general physical examination and neurological examination was done. The grade of neurological deficit in

SCI was classified according to the ASIA Impairment scale (Maynard., et al, 1997). Neurological deficit as per ASIA Impairment Scale were as follows: A in 12; B in 8; C in 10; D in 14 and E in 6 patients. Patients were interviewed and examined for various psychosocial issues. Social adjustment was measured as good, average, and poor. Burden on the family was measured as severe, moderate, mild, and nil. Mobility was defined as bed-ridden, restricted mobility or fully mobile. Autonomy was measured as full autonomy, routine active, and nil autonomy. Relationship was defined either cordial or uncordial.

After assessment of the psychosocial problems, following remedial measures were taken to cure or minimize these problems:
Psycho-neurogenic problems: Psychologist's opinion was taken, counseling and medical treatment were given.

Sexual dysfunctions: partner counseling, privacy at night, proper positioning, emptying bladder prior to intercourse and medications in the form of sildenafil citrate (Viagra) were used in the affected patients.

Social adjustment: Regular psychologist's counseling, minimizing barriers hindering with mobility both at home and work place, and optimizing the home environment.

Burden on family: The patients were advised various means of self dependence, vocational training and mobility (wheelchair and calipers).

Partner Relationships: Patients and partners were counseled for the reasons of uncordial relationship.

Sleep disturbances: We advised the patients not to sleep during the day and advised psychologist consultation for depression / sleep disturbances.

Patients were re-evaluated after six months to see impact of these measures on psychosocial issues.
Statement of Ethics: "We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research."

Results

Seven (14%) patients were having psycho neurogenic problems in the form of altered attention span, concentration, memory, learning abilities, problem solving abilities and visuo-spatial perception difficulties. Psychologist's opinion, counseling and medical treatment were beneficial in 3(40%) of these affected patients.

Twenty (55.5%) patients were having normal erection functions. The ejaculation functions were normal or near normal in 14 (39.9%) out of 36 male patients. Erectile dysfunction in male SCI patients was observed in 16 patients (44.5%) and ejaculation dysfunction in 22 (60.1%) male patients. Four (24.9%) female patients were having sexual dysfunctions in the form of loss of libido and orgasms and never indulged in sexual activity after injuries. Improvement in the sexual functions was observed on 6 month follow up after use of remedial measures in the form of partner counseling, privacy at night and medications like sildenafil (Viagra).

The social adjustment was good in 29 patients, average in 10 and poor in 11 patients. Eleven (22%) patients were suffering from PTSD. Regular psychologist's counseling and necessary medical treatment were given. Subsequent follow up showed a decrease in the PTSD in 6 patients and 5 patients did not respond. Seventeen (34%) patients had severe burden on the family, 5 had moderate and 15 had mild burden on the family. Thirteen patients did not have any impact of the injury on their family. We advised various means of self dependence and mobility as by wheelchair and calipers to the patients. Twenty (70%) patients benefited from these measures in subsequent follow ups. Sixteen (32%) patients were having uncordial relationship to their partners. Patients were counseled for the reasons of uncordial relationship and 10(62%) patients responded with improvement in relationship, 5(31%) patients did not show any improvement and 1(7%) showed deterioration.

Regarding occupation, 17 (34%) patients were able to do their job or work at home. Rest were bed ridden or could not do their work even with mild ambulation. Regarding mobility, 26 (52%) patients were not able to move and they were bed ridden and 3 had restricted mobility. 21 patients were fully mobile. Twenty one (42%) patients were having full autonomy. Others were having either no autonomy (26 patients) or were only able to do the routine work (3 patients). Twenty patients had sleep disturbances but majority were not using any drug treatment. Sixteen patients were benefited with counseling and/or by changing their sleep schedule.

Discussion

Spinal cord injury is a devastating event that has not only physical but also social and psychological ramifications for the injured person. The psychosocial problems affecting SCI patients include sexual dysfunctions, problems of social adjustment, burden on family, strained partner relationships, and sleep disturbances. The frequent hospitalization, inability to return to pre-injury occupation, immobility and lack of autonomy can adversely affect the community reintegration and quality of life of SCI patients (Roth., et al, 1989; Kennedy & Rogers, 2000; Kennedy & Duff, 2000; Gill, 1999; Siosteen., et al, 1990; Phleps., et al, 1983; Franceschini., et al, 2003; Bonekat., et al, 1990). The present study was an attempt to understand these problems, taking remedial measures to minimize these problems and to observe the impact of these on psycho-social life of persons with SCI.

In the present series 14% patients were suffering from psycho-neurogenic complications in the form of altered attention span, concentration, memory, learning ability, problem solving abilities and visuo-spatial perception difficulties. The prevalence of neuropsychological abnormality on comprehensive motor free neuro-psychological test battery ranged between 10% and 40% in a study by (Roth., et al, 1989). Mean performance levels of patients were significantly more impaired than those of control subjects (Roth., et al, 19890. Rehabilitation after SCI requires the ability to attend, to concentrate on, understand, process, retain, retrieve, integrate and utilize the information, which have major implications for the design and implementation of SCI rehabilitation programme. Accurate analysis of specific neuro-psychological deficits in individual patients provides the opportunity for modification of each patient’s treatment programme and directs the therapeutic approach.

In the present study, 55% of patients were having normal erection after SCI which is comparable to 5-75% in a study by Biering-Sorensen & Sonksen (2001). The normal ejaculation functions in 39.9% of SCI patients in the present study are also comparable to 0-55% in a study by Sonksen & Biering-Sorensen (1992). The rates of dysfunction in erection and ejaculation in the present study are comparatively on the lower side to our previous study in 86 males in year 2006 (Sharma., et al,2006). In the study by White et al (1992) 67% males with SCI had a physical relationship in the past 12 months. Most concerning areas of sexual activity for the respondents were not satisfying a partner, getting or giving a sexual disease, urinary accidents, and not getting enough personal satisfaction (White., et al, 1992). Phelps et al reported that 42% of males with SCI were not satisfied with their sex lives, 50% had a weak sense of sexual adequacy and 20% judged their sexual desire to be weak or very weak (Phleps., et al, 1983).

Orgasm in SCI patients was comparatively low (64.4%) as compared to able bodied subjects having 100% orgasm (Sipski., et al, 2006). Mean time of the orgasm was also less in able bodied person as compared to SCI patients (Sipski., et al, 2006). 75% of the female patients in the present study were having normal sexual functioning and were indulging in sexual activity, which is comparable to the 62-80% patients reported in other series (Ferreiro-Velasco., et al, 2005; Kreuter., et al, 2008). It was also comparable to our previous study, which reported that 72.5% had interest in sex, 65% indicated decrease in desire in sex and 30% had never indulged in sexual activities (Singh& Sharma, 2005). Reasons for not wanting or not having the courage to be intimate and sexual were physical problems, low sexual desire, low self-esteem and feelings of being unattractive (Kreuter., et al, 2008). We agree with Ferreiro et al (2005) that variables such as age, neurological level, the ASIA grade, and the level of independence or the type of bladder did not influence the physical relationships. The paraplegic women were able to reach orgasm with more ease than tetraplegic women urinary leakage and difficulties with positioning were the most commonly problems during sexual intercourse. However, these can be solved by maintaining the position of that required minimum effort and emptying the bladder before intercourse and applying lubrications for the problems of dryness of the vagina. We observed that female patients claiming a drop in the libido and not indulging sexual activities related it to loss of sensitivity in the genital region and their prime focus on the injury and the depression.

From our previous experience and from the initial findings of the present study, we took measures to overcome these problems (Sharma., et al,2006; Singh& Sharma, 2005). Patients were counseled for that although, sexual intercourse is a part of sexual enjoyment but it is not only the one method. Patient and partners were advised to spend time together and use other methods of enjoyment like kissing, hugging etc. Attendants were advised to give them privacy. These interventions showed good results in subsequent follow-up. The present study showed that sexual adjustment after SCI was not solely explained by genital function and degree of physical impairment. General satisfaction with life, high self esteem and sexual behaviors characterized by mutual openness and experimentation would promote an active and satisfying sexual life. The present study also agreed with Siosteen et al that both general psychological and more specific sexual counseling would help to reduce fear, lack of confidence and self doubts concerning sexuality after injury which might have more negative influence on sexual adjustment than genital dysfunction itself (Siosteen., et al, 1990).

Twenty percent patients were having average social adjustment. These patients were having significant disability but were able to do their routine activities with the help of aids e.g. wheel chairs, orthotics etc. These patients were having adjustment difficulties when they have to go out of the home due to uneven streets, mud, non availability of ramps and lifts at public places. Twenty two percent patients were having poor social adjustment as they were mainly non-ambulatory. Patients were totally dependent on their caregivers and hospital staff. These patients were usually suffering from PTSD. This study was comparable to the study of Kennedy and Duff who reported that PTSD after SCI was about 10-40% (Kennedy & Duff, 2000). We should guide the caregivers, partners, family members and society to improve adjustment with SCI patients.

Sixteen patients (32%) were having uncordial relationship and 34 (68%) were having cordial relationship in the present study. The findings were not in agreement to the study of Franceschini et al who found that 63% patients told change in relationship as having detachment 32.9, more careful assessment of one’s friendship 13.4%, higher awareness of one’s feelings 12.2% and disruption of an important bond 6.1% etc. 89.9% were living with their families, 5.5% lived alone and 2.1% lived in institution. 48.6% were satisfied with their partners and 34.2% not satisfied (Franceschini., et al, 2003). This study was comparable to our previous studies (Sharma., et al,2006; Singh& Sharma, 2005). 42% of the patients reported that their partners were never satisfied with the sexual activity and 36% reported uncordial sexual relationship after SCI (Singh& Sharma, 2005). Majority of the women (80.6%) had cordial relationship with their partners and 64% of the women reported that their partners cooperated with them during sexual activity (Singh& Sharma, 2005). The present study was also comparable to the Kreuter (2000) study which showed that partner relationships seem to be affected by SCI, although not as much as is widely believed. Present study shows simple interventions directed towards factors impacting relationships can be quite useful in improvement of relationships as 62% of the patients having uncordial relations showed improvement in relationships at subsequent follow-ups.

In the present study 34% patients were having severe burden on the family. These patients were the sole earning person in the family or were the most responsible persons of that family. Ten percent patients were having moderate burden and 15 (30%) were having mild effects on the family. The persons having mild or none burden were usually having mild or no disability and that did not interrupt in the routine work of family. In the present study there was a male preponderance and their primary caregivers were mainly females (usually wives). Caregivers had to face the problems of immobility and physical dependence of the patient, financial burden of the treatment and problem with their routine activities as also reported by Unalan et al (2001). Present study emphasizes to make strategies of rehabilitation of SCI patients in a way to minimize the burden on the family and caregivers (Unalan., et al, 2001). Our strategies of early mobilization, self dependence and vocational training had good results in the long run.

Thirty four percent of patients could regain their working capability and only 42% patients were fully mobile & had full autonomy; while 6% were able to do routine activities independently. Sixty six percent had changed their jobs;

full autonomy was in 42% of patients. The present study differs from Franceschini et al (2003) who reported that 35.6% had changed the job. 61% left the home on daily basis. Regarding autonomy only 35.6% could leave home only with assistance and average autonomy score was 6.5 out of 10 (Franceschini., et al, 2003). In the present study 20% of patients were having sleep disturbances as compared to normal persons. These were mainly patients having severe injuries as ASIA I and II grades. These patients were mainly bed ridden and having history of sleeping during the day time. A small group of patients 10% were using tranquilizers on and off at night. In this study we found that there was no significant difference between the total hours of sleep to the normal persons. The SCI individuals had greater difficulty in falling asleep, described more frequent awakenings, slept subjectively less well, were more often prescribed sleeping pills, slept more hours, took more and longer naps, and snored more (Biering-Sorensen & . Biering-Sorensen, 2001). In particular, spasms, pain, paraesthesia, and troubles with voiding were claimed to be part of the sleep problems (Biering-Sorensen & . Biering-Sorensen, 2001).

In conclusion, the present study highlights that the effects of SCI on the areas like psychology, sexual functions, social adjustments, burden on family, partner relationships, and sleep disturbances are quiet evident. Observations of this study show that simple instructions and interventions can help a SCI patient to decrease these complications for a better reintegration into the family and society. Accurate analysis of specific problems faced by these individuals provides an opportunity for modification of each patient treatment programs and directs the therapeutic approach; thus enhancing psychosocial life of patients with SCI.

References:

1. North, N.T. (1999) The psychological effects of spinal cord injury: a review. Spinal Cord, 37, 671-679.

2. Devivo, M.J., Shewchuk, R.M., Stover, S.L., Black, K.J., Go, B.K. (1992) A cross-sectional study of the relationship between age and current health status for persons with spinal cord injuries. Paraplegia, 30, 820-827.

3. Kreuter, M., Siosteen, A., Erkholm, B., Bystrom, U., Brown, D.J. (2005) Health and quality of life of persons with spinal cord lesion in Australia and Sweden. Spinal Cord, 43, 123-129.

4. Roth, E., Davidoff, G., Thomas, P., Doljanac, R., Dijkers, M., Berent, S., Morris, J., Yarkony, G. (1989) A controlled study of neuropsychological deficits in acute spinal cord injury patients. Paraplegia, 27, 480-9.

5. Kennedy, P., Rogers, B.A. (2000) Anxiety and depression after spinal cord injury: a longitudinal analysis. Arch Phys Med Rehabil, 81, 932-937.

6. Kennedy, P., Duff, J. (2001) Post traumatic stress disorder and spinal cord injuries. Spinal Cord, 39, 1-10.

7. Gill, M. (1992) Psychosocial implications of spinal cord injury. Crit Care Nurs Q,22,1-7.

8. Siosteen, A., Lundquist, C., Blomstrand, C., Sullivan, L., Sullivan, M. (1990) Sexual ability, activity, attitudes and satisfaction as part of adjustment in spinal cord-injured subjects. Paraplegia, 28, 285-95.

9. Phleps, G., Brown, M., Chen, J., Dunn, M., Lloyd, E., Stefanick, M.L., Davidson. J.M., Perkash, I. (1983) Sexual experience and plasma testosterone levels in male veterans after spinal cord injury. Arch Phys Med Rehabil, 64, 47-52.

10. Franceschini, M., Di Clemente, B., Rampello, A., Nora, M., Spizzichino, L. (2003) Longitudinal outcome 6 years after spinal cord injury. Spinal Cord, 41, 280-5.

11. Bonekat, H.W., Andersen, G., Squires, J. (1990) Obstructive disordered breathing during sleep in patients with spinal cord injury. Paraplegia, 28, 392-8.

12. Maynard, F.M. Jr., Bracken, M.B., Creasey, G., Ditunno, J.F. Jr., Donovan, W.H., Ducker, T.B., Garber, S.L., Marino, R.J., Stover, S.L., Tator, C.H., Waters , R.L., Wilberger, J.E., Young, W. (1997) International standards for neurological and functional classification of spinal cord injury. American spinal injury association. Spinal Cord, 35, 266-274.

13. Biering-Sorensen, F., Sonksen, J. (2001) Sexual function in spinal cord lesioned men. Spinal Cord, 39, 455-70.

14. Sonksen, J., Biering-Sorensen, F. (1992) Fertility in men with spinal cord or cauda equina lesions: A review. Semin Neurol, 12, 106-14.

15. Sharma, S.C., Singh, R., Dogra, R., Gupta, S.S. (2006) Assessment of sexual functions after spinal cord injury in Indian patients. Int J Rehabil Res, 29, 17-25

16. White, M.J., Rintala, D.H., Hart, K.A., Young, M.E., Fuhrer, M,J. (1992) Sexual activities, concerns and interests of men with spinal cord injury. Am J Phys Med Rehabil, 71, 225-31.

17. Sipski, M., Alexander, C.J., Gomez-Marin, O. (2006) Effects of level and degree of spinal cord injury on male orgasm. Spinal Cord, 44, 798-804.

18. Ferreiro-Velasco, M.E., Barca-Buyo, A., de la Barrera, S.S., Montoto-Marques, A., Vazquez, X.M., Rodríguez-Sotillo, A. Sexual issues in a sample of women with spinal cord injury. Spinal Cord, 43, 51-55.

19. Kreuter, M., Siosteen, A., Biering-Sorensen, F. (2008) Sexuality and sexual life in women with spinal cord injury: a controlled study. J Rehabil Med, 40, 61-9.

20. Singh, R., Sharma, S.C. (2005) Sexuality and women with spinal cord injury. Sexual Disab, 2005, 23(1), 21-33.

21 Kreuter, M. (2000) Spinal cord injury and partner relationships. Spinal Cord, 38, 2-6.

22. Unalan, H., Gencosmanoglu, B., Akgun, K., Karamehmetoglu, S., Tuna, H., Ones, K., Rahimpenah, A., Uzun, E., Tuzun, F. (2001) Quality of life of primary caregivers of spinal cord injury survivors living in the community: controlled study with short from-36 questionnaire. Spinal Cord, 39, 318-22.

23. Biering-Sorensen, F., Biering-Sorensen, M. (2001) Sleep disturbances in the spinal cord injured: an epidemiological questionnaire investigation, including a normal population. Spinal Cord, 39, 505-13.

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 1
July 2011– June 2012

Implementing Empowerment Psychoeducation in a Psychosocial Rehabilitation Setting

Lindsay A. Phillips, Psy.D.
Assistant Professor
Albright College
lphillips@alb.edu
P.O. Box 15234
Reading, PA 19612

Danielle N. Schade, Psy.D.
Psychologist and Program Manager
Veterans Affairs Medical Center, Coatesville
danielle.schade@gmail.com
1400 Blackhorse Hill Road
Coatesville, PA 19320

Citation:
Phillips LA & Schade DN (2012). Implementing Empowerment Psychoeducation in a Psychosocial Rehabilitation Setting ***International Journal of Psychosocial Rehabilitation. Vol 16(1) 101-108***

Abstract

Topic. In this article, we address why empowerment psychoeducation may be beneficial for individuals participating in services in a Psychosocial Rehabilitation (PSR) setting.
Purpose: We provide a case example of how empowerment psychoeducation was implemented in a group at a recovery-oriented wellness center.
Sources: We review the published literature that informed this group, and provide an overview of the topics addressed in sessions, including applications of empowerment, motivation, “personal medicine,” overcoming stigma, and personal recovery process. We discuss our observations in implementing this tool.
Conclusions and Implications for Practice: Empowerment is a frequently discussed topic in the PSR literature, and discussion about empowerment in PSR settings is valuable for all parties involved. We strongly recommend that other providers in PSR settings consider implementing a psychoeducational group on empowerment.

Keywords: Empowerment, Psychoeducation, Psychosocial Rehabilitation, Psychiatric Rehabilitation

Introduction

This article addresses why empowerment psychoeducation may be beneficial for individuals participating in services in a Psychosocial Rehabilitation (PSR) setting, and we provide a case example of how empowerment psychoeducation was implemented in a recovery-oriented wellness center. PSR, by its very definition is, “a holistic approach that places the person- not the illness- at the center of all interventions" (Weinstein & Hughes, 2000, p. 35). Empowerment is a mechanism through which PSR services can be better focused on the individual and not on an illness. Cattaneo and Chapman (2010) define empowerment as "an iterative process in which a person who lacks power sets a personally meaningful goal oriented toward increasing power, takes action toward that goal, and observes and reflects on the impact of this action" (p. 647).

We saw this group as an important way to fill a gap in the available programs at the wellness center, since participants at the center were transitioning from a medical to a recovery model, and often needed encouragement to take an active role in their treatment and participation. Mental illness and traditional treatment models (i.e., those with power differentials between service providers and service users) have had disempowering effects on individuals (Oades & Deane, 2007). Recovery is an active process and for many, recovery-oriented treatment allows an individual to move from what was once a passive role in treatment to a role that is now active and empowered (Glover, 2007). Empowerment psychoeducation can explore how individuals can be more active in their recovery process and recovery center. Furthermore, an empowerment group that promotes active involvement, such as this one, leads to skill building that can be transferred to encourage individuals to actively participate in their treatment and in their communities.

While empowerment is a commonly discussed facet of PSR (Barton, 1999; Corrigan, 2004; National Empowerment Center, 2008; Substance Abuse and Mental Health Services Administration, 2006; Weinstein & Hughes, 2000), there is limited literature addressing engagement in psychoeducation and discussion on empowerment in PSR settings. We aim to address how all parties involved in PSR settings can actively engage in applied empowerment through psychoeducation, skill building, and discussion.

Why Empowerment?

Empowerment is a key facet of PSR and recovery-oriented values. The Substance Abuse and Mental Health Services Administration's (2006) statement on recovery identified empowerment as one of the ten "fundamental components of recovery" (p. 1). They define empowerment as the following:

Consumers have the authority to choose from a range of options and to participate in all decisions—including the allocation of resources—that will affect their lives, and are educated and supported in so doing. They have the ability to join with other consumers to collectively and effectively speak for themselves about their needs, wants, desires, and aspirations. Through empowerment, an individual gains control of his or her own destiny and influences the organizational and societal structures in his or her life. (Substance Abuse and Mental Health Services Administration, 2006, p. 1)

Although empowerment is widely discussed (Barton, 1999; National Empowerment Center, 2008; Substance Abuse and Mental Health Services Administration, 2006; Weinstein & Hughes, 2000), and services, such as clubhouses, supportive housing and employment, and peer support have been identified as empowering resources (Corrigan, 2004), there is limited discussion in the literature about engaging in psychoeducation and conversation with individuals about empowerment itself. Psychoeducation informs individuals on topics that are central to their recovery process and empowers individuals to be active in their recovery because they have knowledge and information (King & Lloyd, 2007). Empowerment psychoeducation, hence, utilizes an empowering modality to engage in education, discussion, and practice of this important element of PSR.

Since empowerment is the mechanism through which individuals realize their control (Substance Abuse and Mental Health Services Administration, 2006), engaging in active interventions that center on empowerment seems essential to recovery-oriented services. Empowerment psychoeducation should be included in the repertoire of groups and services in a PSR setting. The benefits of empowerment include improved self-image, self-efficacy, confidence, and hopefulness, as well as increase ability to cope with daily life, greater satisfaction with treatment, and higher likelihood of reaching treatment goals (Linhorst, Hamilton, Young, & Eckert, 2002).

Historical Significance of Empowerment

Over the past several decades, treatment for severe mental illness has evolved considerably due to a myriad of converging theoretical, political, social, and economic factors. By 1955, there were 559,000 individuals in the United States living in state psychiatric institutions (Lamb & Weinberger, 1998). The 1960s marked the beginning of deinstitutionalization, as new psychotropic medication enabled patients to improve and made medicating people on an outpatient basis a viable, less expensive alternative to long-term hospitalization. Consequently, public mental hospitals began to close. It was hoped that individuals with mental illness could receive treatment while living in the community via a comprehensive network of services, but inadequate funding and development prevented community-based services from providing adequate care of a large proportion of former patients (U.S. Department of Health and Human Services, 1999; McFarlane, 1995). A system that formerly placed individuals in a passive role as “consumer” of service, now expected individuals to integrate into the community at large. But how do these individuals make the transition successfully? What enables a person to move from the role of passive patient/service recipient to one of active community contributor? Empowerment is a key factor.

Implementation of Empowerment Psychoeducation

Philosophy Behind Implementation

The motivation for writing this article was our experience in implementing a weekly psychoeducational group in a recovery-oriented wellness center. The center provided services, including groups and activities, on weekdays for adults with a mental illness. The topic of empowerment was chosen as a group topic for this setting due to the emphasis on empowerment in PSR literature (Barton, 1999; Corrigan, 2004; National Empowerment Center, 2008; Substance Abuse and Mental Health Services Administration, 2006; Weinstein & Hughes, 2000), as well as our observation that the adults attending the center were relatively disempowered at the time. They would come to the center and socialize, however would not actively engage in the therapeutic activities. Additionally, while they knew some key PSR terms, including empowerment, they were seeking to find ways to apply these terms to their lives. Linhorst and Eckert (2003) discuss seven factors that promote empowerment. First, some degree of symptom control is needed so that individuals are able to engage in decision-making. Second, the individual must possess decision-making skills required to make meaningful, thoughtful, and deliberate decisions. Third, the individual needs access to resources (e.g., emotional support, advocates, logistical resources). Fourth, concrete incentives for participation in decision-making promotes empowerment. Fifth, the setting/environment must have structures and processes through which individuals can participate in decisions. Sixth, individuals should have meaningful and plentiful information about their options when making choices. Finally, a supportive culture that welcomes and nurtures involvement in decision-making promotes an individual’s empowerment.

We utilized psychoeducation in a collaborative and empowering manner. Social empowerment “must embody a co-equal interaction between individuals and social environments” (Neese-Todd & Pavick, 2000, p. 95). Although this psychoeducational group was facilitated by a staff member, participants were encouraged to engage in active discussion and social interaction. The facilitator’s role was to provide psychoeducation, but more importantly, to facilitate collaboration between all participants and the facilitator and to build rapport (Deane & Crowe, 2007). Corrigan (2004) asserts that collaboration and participant input are core ways to support empowerment for individuals with mental illness. Hence, empowerment psychoeducation is not just about empowerment; empowerment psychoeducation can actively empower individuals to participate in services. For example, we used discussion questions to generate participation, and pointed our similarities in responses to build rapport between participants. Additionally, we discussed other community and wellness center resources that could be used to help participants apply the facets of empowerment to their lives.

Similarly, a key demonstration of empowerment in facilities that operate with PSR principles is involvement of individuals in planning their own treatment (Neese-Todd & Pavick, 2000). Because of this, individuals who participated in this initial empowerment group were encouraged to suggest future topics or areas in which they believed the group will benefit. When participants suggested topics, this was acknowledged at the start of the session to demonstrate the value given to suggestions. For example, participants wanted to focus on their personal recovery process, so we included this topic. During our discussion, participants asked if we could make a list of healthy leisurely activities, so we made a list on a poster board that remained in the center, with all participants contributing ideas.

Practical Aspects of Implementation

In addition to philosophical principals followed, we delineated a specific format for the group, as well as objectives and an agenda for each session. Each group lasted about 45 minutes and focused on posing a topic related to empowerment. This group was initially implemented once a week for 11 weeks (the number of sessions was limited for logistic, scheduling-related reasons). The first half of each session was psychoeducational. The psychoeducational component of each session included discussion questions and occasionally used handouts and a white board with markers to highlight key concepts. The second half of the group engaged in active discussion of the topic and how to apply the topic to increase feelings of empowerment and recovery-oriented action. We thought it was especially valuable for participants to talk about the actions they could take to apply the topics to their lives.

Empowerment Topics

The empowerment group that inspired this article educated participants on the meaning of empowerment. Moreover, it helped individuals develop in key topic areas. We will now discuss this list of topics to encourage other individuals involved in PSR settings to consider how they can promote psychoeducation and discussion on empowerment. This is not an all-inclusive list. All participants in empowerment psychoeducation can consider what topics they wish to include when engaging in empowerment-related psychoeducation and discussion. The topics addressed in our implementation of an empowerment group included applications of empowerment, motivation, “personal medicine,” overcoming stigma, and personal recovery process. Our goal in is to promote using these or similar topics that help individuals engage in discussion and application of empowerment. We will share discussion questions we used for each topic, and we believe that these questions might also be valuable areas of discussion between peers, in individual treatment, and even as casual discussion topics for those family members and loved ones who read this article.

Applications of Empowerment

The first few meetings of the empowerment group focused on generally discussing empowerment. In these sessions, the facilitator defined empowerment (specifically as having power or the ability to accomplish) and provided a rationale for why an empowerment group was starting. Participants also provided their own personal definitions of empowerment. The discussions centered on questions such as:

- When have you felt empowered or disempowered?
- Can you think of a time when you felt disempowered?
- Can you think of a time when you felt empowered?
- How do we empower or disempower ourselves?
- What can you do to feel empowered or take charge of your life?

Participants also spent some sessions discussing “self talk,” exploring how what they say to themselves is either empowering or disempowering. Participants used a psychoeducational worksheet to explore this topic and developed phrases that they could use to empower themselves. We noticed that in the early sessions, participants could provide definitions of terms, like “empowerment,” but did not know how to actively apply the terms to their lives. The discussion questions and exploration of “self talk” seemed to be helpful in that participants began to provide examples of their challenges and goals for life improvement and empowerment.

Motivation

The next few meetings of the empowerment group focused on motivation and how it relates to empowerment. The facilitator used psychoeducational handouts on motivation and wellness. Additionally, the group applied the topic of motivation to the group participants' experience in the PSR setting in which the group was held. The discussions centered on questions such as:

- Why is it important to be motivated?
- Do you think that staying motivated here will help you in other areas of your lives? If so, where?

At their suggestion, participants also generated lists of how they stay motivated (for example, some shared about talking walks in the morning, and others discussed drinking mint tea). Future sessions addressed questions, such as:

- Did anyone try the suggestions we made for getting motivated/getting up and active?
- How did they work?
- If they did work, how can you keep this motivation and empowerment going?

"Personal Medicine"

Deegan (2004) noted, "I have learned that psychiatric medicine is not the only type of medicine that is important to recovery. Personal medicine, or those things that raise our self esteem and make life worth living are vital to recovery" (para. 2). The facilitator introduced this topic and linked "personal medicine" to empowerment by explaining that this is a part of empowerment and feeling that we can make changes in our lives that are completely under our control. Participants in this group discussed what they consider to be their "personal medicine."

Overcoming Stigma

Coping with stigma can be an important topic for individuals to address (Heijnders & Van Der Meij, 2006; Kirkwood & Stamm, 2006), especially as it relates to feeling empowered. Sessions on this topic focused on practical applications and addressed the following questions:

- What could/should we do if we hear a disempowering or stigmatizing statement?
- What would you do if you overhead someone with whom you were close saying something disempowering? What if it were someone you did not know?
- Are there times that you could assertively address and times you would not address with the person but instead would cope with your emotions on your own?
- What emotions might arise in such a situation? How would you cope with them?
- If you did decide to address a person who made such a statement, what would you do? Has this ever happened to you?

Participants also role-played situations in which they addressed stigma in the past and situations may face in the future. Most of the role-play situations were generated by members sharing some negative experiences they had in which they were the target of an inappropriate comment, or in which they wish they had better advocated for themselves with a treatment provider or other individual.

Personal Recovery Process

Finally, the closing sessions of this empowerment group addressed how individuals viewed their personal recovery process. They also employed what they learned about empowerment to their personal recovery process, addressing questions, such as

- How can feeling empowered help your recovery process?
- How can feeling disempowered hurt your recovery process?

The final session of this group focused on setting empowering, recovery-oriented plans for the future.

Conclusions

In closing, in this article, we provide a rationale for why interventions in PSR settings should have a direct focus on empowerment. Such interventions can provide education on empowerment, promote discussion on empowerment, and should most importantly, be provided in a manner that empowers individuals to actively participate.

We learned some valuable lessons from doing this group. Although we found that participants had heard about the terms and concepts we were discussing, they never previously considered active implementation (such as what they might do to cope with feeling disempowered). Because participants knew the terms but not the applications in their lives, we learned that we needed to discuss actions and behaviors that they could take, rather than just defining important terms. This also helped participants move from being passive in groups and discussions to exploring ways in which they can be more active. The topics we discussed are important in many settings beyond a psychoeducational group, and we encourage peers, family members, and treatment providers to explore these topics together.

Although the group discussed in this article was not subjected to any empirical evaluation, future systematic investigation of psychoeducational programs, such as the group described in this article, are needed. Additionally, the phenomenon of empowerment should be subjected to further empirical investigation. Barton (1999) has also suggested outcome studies on empowerment and this article echoes that suggestion, particularly in regard to whether services are empowering and which elements of PSR settings individuals find to be empowering. Empowerment is a key tenant of PSR, and future research, program development, and discussion should address this important facet of recovery.

References:

Barton, R. (1999). Psychosocial rehabilitation services in community support systems: A review of outcomes and policy recommendations. *Psychiatric Services, 50*(4), 525-534.

Cattaneo, L. B., & Chapman, A. R. (2010). The process of empowerment: A model for use in research and practice. *American Psychologist, 65*, 646-659. doi: 10.1037/a0018854

Corrigan, P. W. (2004, Autumn). Enhancing personal empowerment of people with psychiatric disabilities. *American Rehabilitation,* 10-21.

Deane, F. P., & Crowe, T. P. (2007). Building and maintaining a recovery focused therapeutic relationship. In R. King, C. Lloyd, & T. Meehan (Eds.) *Handbook of psychosocial rehabilitation* (pp. 57-70). Oxford, UK: Blackwell Publishing.

Deegan, P. (2004). *The importance of personal medicine.* Retrieved from http://www.patdeegan.com/blog/posts/importance-personal-medicine

Glover, H. (2007). Lived experience perspective. In R. King, C. Lloyd, & T. Meehan (Eds.) *Handbook of Psychosocial Rehabilitation.* Oxford, UK: Blackwell Publishing.

Heijnders, M., & Van Der Meij, S. (2006). The fight against stigma: An overview of stigma-reduction strategies and interventions. *Psychology, Health, and Medicine, 11*, 353-363. doi: 10.1080/13548500600595327

Kirkwood, A. D., & Stamm, B. H. (2006). A social marketing approach to challenging stigma. *Professional Psychology: Research and Practice, 37,* 472-476. doi: 10.1037/0735-7028.37.5.472

King, R., & Lloyd, C. (2007). Family psychoeducation. In R. King, C. Lloyd, & T. Meehan (Eds.) *Handbook of psychosocial rehabilitation* (pp. 102-114). Oxford, UK: Blackwell Publishing.

Lamb, H. R., & Weinberger, L. E. (1998). Persons with severe mental illness in jails and prisons: A review. *Psychiatric Services, 49,* 483-486.

Linhorst, D. M., & Eckert, A. (2003). Conditions for empowering people with severe mental illness. *Social Services Review*, *77*(2). 279-305. doi: 10.1086/373909

Linhorst, D. M., Hamilton, G., Young, E., & Eckert, A. (2002). Opportunities and barriers to empowering people with severe mental illness through participation in treatment planning. *Social Work, 47*(4), 425-434.

McFarlane, W. R. (1995). Families in the treatment of psychotic disorders. *Harvard Mental Health Letter, 12,* 4-6.

National Empowerment Center. (2008). *National Empowerment Center, Inc.* Retrieved from http://www.power2u.org/

Neese-Todd, S., & Pavick, F. (2000). Person-centered practices in Psychosocial Rehabilitation. In R. Hughes & D. Weinstein (Eds.) *Best practices in psychosocial rehabilitation.* Columbia, MD: International Association of Psychosocial Rehabilitation Services.

Oades, L. G., & Deane, F. P. (2007). The framework for Psychosocial Rehabilitation: Bringing it into focus. In R. King, C. Lloyd, & T. Meehan (Eds.) *Handbook of psychosocial rehabilitation* (pp. 43-56). Oxford, UK: Blackwell Publishing.

Substance Abuse and Mental Health Services Administration (2006). *SAMHSA issues consensus statement on mental health recovery.* Retrieved from http://www.samhsa.gov/news/newsreleases/060215_consumer.htm

U.S. Department of Health and Human Services. (1999). *Mental Health: A Report of the Surgeon General – Executive Summary.* Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.

Weinstein, D., & Hughes, R. (2000). What is Psychosocial Rehabilitation? In R. Hughes & D. Weinstein (Eds.) *Best practices in psychosocial rehabilitation.* Columbia, MD: International Association of Psychosocial Rehabilitation Services.

The International Journal of Psychosocial Rehabilitation

Building Community in Mental Health

Peter J. O’Brien, MSW,RSW
Shared Mental Health Care
Calgary Zone
Alberta Health Services
Sheldon Chumir Health Centre
1213 – 4th Street S.W.
Calgary, Alberta, T2R 0X7

peter.obrien@albertahealthservices.ca

Citation:
O'Brian, PJ (2012). Building Community in Mental Health.
International Journal of Psychosocial Rehabilitation. Vol 16(1) 109-116

Abstract

A project focused on building a sense of community in the broader mental health system is described. The accent is on taking the time and creating the conditions that will facilitate members joining together in the spirit of intentional collaboration. Participants are collectively creating an environment conducive to the goal of an integrated mental health system that is truly responsive to client and family needs.

Key Words: building community; integration; collaboration; mental health.

Introduction

Too often, a lament in mental health circles is that we are not a community, that particular challenges in the delivery of service to a client or family are “not my problem,” that, “this situation is outside our program mandate.” This article describes the Community Rounds project that has developed in Calgary, Alberta since 2006, amplifying our shared responsibility in the continuum of care of clients and families in the mental health system.

The Community Rounds project was stimulated by front-line staff sharing their frustration about how to access services within the mental health system for the Calgary region. Front-line staff were interested in doing something constructive in response to the experience of silos and barriers prevalent throughout the mental health system. At no time in the initial stages of developing this project was management consulted. Thus this project truly represents a grassroots approach to change.

The main focus of the Community Rounds project is to contribute to an integrated and collaborative mental health community by promoting alliances across the mental health sector, inclusive of personnel in other social service and agency settings.

Defining the terms

From the outset the Community Rounds project settled on the term community to capture the essence of the initiative. It seemed like a natural fit and was sufficiently encompassing of the values and principles reflected in the project.

Definitions of the term community include words and phrases such as a common or shared spirit and similarity or agreement of interests (Hanks, 1988). From the outset the term community has captured the spirit of the enterprise, connoting the friendly and inclusive intentions that Community Rounds strives for. The idea that a community is not static but will grow and evolve as the process of the project unfolds also reflects the premise of Community Rounds.

Other terms, such as partnership, coalition or integration, can also be considered as characteristic of the project, without suggesting a formal or sanctioned agreement between programs and agencies. These terms will be used interchangeably throughout this text, just as they are in Community Rounds sessions. The significance of intentional collaboration with one another is an important premise of the Community Rounds project.

Rationale

The ethos of Community Rounds - communicating respect, mutual trust and understanding - are each identified as significant factors in successful collaboration (Mattesssich & Monsey, 1992). The Community Rounds project transcends individual agency mandates and promotes collaboration as a life style “that is simultaneously flexible and responsive to others” (London et al., 2009, p.1).

There are many ways to actualize the African proverb – “it takes a village to raise a child” – and to honour the collective will to make a difference (Tourse, et al, 2008). Further, there is increasing recognition that partnerships among agencies and diverse organizations in the community generate opportunities to find new and creative ways to address complicated health care challenges (Lasker, Weiss & Miller, 2001).

The Mental Health Commission of Canada proposes that organizations need to work more closely to better coordinate and integrate programs and services, in order to break down silos that serve as barriers to the care of clients (Mental Health Commission Canada, 2009, p.6). Community Rounds contributes to altering traditional cultures in the mental health and social service systems that have fostered hierarchy, an accent on exclusion criteria, fixed boundaries (Poole, 1997), competition and less-than cohesive efforts to work cooperatively with other programs and agencies. When staff of various programs and agencies neither know one another nor understand respective perspectives or mandates, it is easy to be sensitized to boundary conflicts, competition for increasingly shrinking resources, tensions between agencies and concerns about sharing information due to confidentiality issues (Secker & Hill, 2001). Finding a forum to energize and engage in discussion about functioning more cooperatively is required.

Making new approaches a reality requires a major restructuring of how mental health systems and communities behave (Carling, 1995). It has been noted that staff from many training disciplines in mental health tend to focus on their relationships with clients and families, without understanding the significance of attending to relationships with colleagues (Robinson, 2005). By bringing people together in an informal way to discuss issues and activities of mutual interest, misunderstanding is reduced and relationships are fostered (Larkin & Callaghan, 2005). A culture of individuals, agencies and institutions viewing themselves as part of the broader mental health community is facilitated (Hall, 2005). The Community Rounds project is also consistent with suggestions in the Kirby Commission Report – “Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addictions Services in Canada” - (Kirby, 2006, p.51) that integration of services in mental health requires local input.

Not unlike the wisdom articulated in “The Tipping Point” (Gladwell, 2000), the Community Rounds process is an example of a small number of people behaving differently, with the intention of having an impact across the larger community.

The Community Rounds Process

The idea of Community Rounds began from what is a familiar scenario to many. An informal discussion, among staff from a few mental health programs at Foothills Hospital, focused on where to refer a particular client. The initial suggestion was disputed, on the grounds that the recommended program had recently changed its mandate and would decline the referral due to new exclusion criteria.

This led to a lively discussion and assertions of considerable frustration in remaining current with changing mandates and admission criteria for various programs. There was agreement that an accent on exclusion criteria was common among programs and made it difficult to access particular programs or to take seriously the idea of collaboration or a functioning continuum of care, or the belief that staff are all “in this together” in sharing the care of clients in the mental health system.

This discussion initially focused on programs within the Alberta Health Services (AHS) Adult Mental Health portfolio, Calgary region. The discussion expanded to include representatives of staff external to the health care system and produced even more emphatic expressions of frustration about how to work in a collaborative and integrated manner with the health care system in providing service to clients and families.

Staff of community agencies will despair over the fact that they offer ongoing care for a client until that client ‘disappears’ into hospital, after which the agency will receive no information whatsoever as to status or treatment, until the individual is discharged from the hospital and arrives back at the agency, with no accompanying discharge summary or consultation about assessment and treatment. Primary care physicians will similarly lament, with some perplexity, the complete lack of information they are able to obtain about their office patients when these individuals are admitted to hospital. The act of consulting community agency personnel about treatment steps, or involving them in the discharge process, is infrequent, though many individuals will comment on the potential value of standardizing such a practice. Similarly, staff of hospital programs will express the challenge in developing a discharge plan for a client due to the paucity of programs or outreach services available to the client in the community. In summary, whether working in an inpatient milieu or in the wider community, there is a recurring frustration with the lack of cohesion, integration and basic communication in the care of clients and their families.

Thus, rather than simply commiserating about the frustrations commonly shared in the mental health community, a small group of staff created an informal Committee to address this dilemma. The Community Rounds project, initiated in the summer of 2006, and organizing four presentations annually, commenced in November 2006. The vision for Community Rounds was to bring together like-minded people who share the view of having a collective responsibility to create a more integrated and cohesive continuum of care. The Community Rounds project makes no distinctions about which people, programs and agencies to include in the process. The idea is to invite staff of programs, agencies and institutions within the broader mental health and social service systems who express an interest in Community Rounds.

In the initial planning stage for this project it became clear that there were many ways to understand the meaning of the word “community”. This became the focal point for the first three Community Rounds sessions, occurring over a period of six months. These first three sessions included representatives of various programs and agencies from within the health care system, as well as the wider community, serving as Panel members in a discussion about “the meaning of community”.

The format developed in the first year of Community Rounds has served as a template. The designated subject being presented at the Community Rounds session involves a presenter(s) or Panel, with a moderator, assuming responsibility for the first half of the presentation. Following an intermission, the moderator assumes a more active role, typically facilitating interaction with the audience and presenter(s). The moderator invites audience observations, comments and questions and can choose to invite an immediate response from a presenter(s), or can first canvass others in the audience for a response. This potentially generates an ever-widening discussion of the presentation topic, thereby more fully engaging the audience. This is a departure from the more common lecture style involving a limited number of speakers that often occurs in educational gatherings.

The Community Rounds process is meant to facilitate a friendly and informal atmosphere, with an emphasis on building relationships. Registration prior to the presentation as well as a fifteen minute intermission half-way through the session allows participants to have an additional networking opportunity. This intermission offers a natural break in the proceedings, complementing the shift from the more formal presentation or Panel discussion to the audience participation in the latter portion of the session. Also contributing to the friendly atmosphere is a ticket draw for door prizes at the conclusion of the intermission. This practice has been supported, as has the provision of coffee, by mental health administration for the health region, and has added a sense of fun to the proceedings. It is these kinds of small details that have contributed to the success of this project.

The next phase of the Community Rounds process arose from audience feedback in the initial sessions, suggesting that Community Rounds serve as a forum for discussion of the Kirby Commission Report (Kirby, 2006). The emphasis in this document on integration of mental health services and the importance of programs and agencies working together in a more collaborative manner to ensure high-quality service delivery in mental health, punctuated the collective realization that more needed to be done to create a greater sense of community in the broader mental health system in the Calgary area. Several points made in the Kirby Commission Report serve as guidelines in the building of community in mental health. For example, time, leadership and money are described as key ingredients to the successful integration of mental health and addictions services. In other words, you cannot dictate integration or offer a template or timeframe for the successful merging of, and cooperation between, services in any region. Rather, you can articulate a vision for building community, provide leadership and then allow people to begin the process of meaningful collaboration. Promoting successful integration and collaboration requires attention to the history and particular circumstances of the local area in question (Kirby, 2006, p.51).

The early viewpoint of the Community Rounds process was to build slowly. In some instances, it was obvious that a particular agency or program be invited to participate in the Community Rounds process, by virtue of their involvement with clients and families in the mental health system. In other situations, invitations to participate in the Community Rounds process followed from suggestions offered in the evaluative feedback at the conclusion of each Community Rounds session. Alternately, staff of community groups simply expressed interest in attending Community Rounds. Invitations are extended to any program or agency personnel expressing such interest, based on the principle of inclusion.

Why is our specific “Community” the Focus of Community Rounds?

Simply put, we had to start somewhere, and it seemed sensible to start with our interactions most directly in relationship to one another in offering services in the mental health system as our community. Existing partnerships and working relationships in the community can help to develop and enhance a collaborative system of care (Naidoo, 2006). This summary report states that cross-agency meetings are a necessary component of building skills and capacities of service providers. Further, that any process that helps staff to gain familiarity with one another and promotes working together is to be encouraged. The Community Rounds project offers such opportunities.

A main goal of the Community Rounds project is to develop a stronger sense of commitment and expectation for collaborative behaviour throughout the mental health system. The idea that we all have a responsibility to share in the provision of care and services to consumers and their families cannot be stressed too greatly. An illuminating study by Geoffrey Nelson and colleagues (Nelson, et. al, 2001) emphasizes that change is saturated by values and principles and “… values provide the ‘compass’ or the ‘direction’ for all implementation” (p.222) of desired goals. Values do matter and the more they are lived by an organization the more meaningful they will become.

We are aware that there is a robust literature about building a sense of community and collaboration within the mental health system from a consumer perspective. In addition to the aforementioned study by Geoffrey Nelson and colleagues, the Canadian Mental Health Association has been a strong and effective proponent of consumer participation and incorporating the experiences of consumers and their families to create a more dynamic mental health system. For example, the Frameworks for Support (Trainor, 2004) can be accessed via the CMHA website and includes a focus on community and how to develop partnerships with consumers and their families, as well as engaging the wide-range of knowledge that has emerged in contributions of consumers and their families in the development of mental health services. The Mental Health Commission of Canada (www.mentalhealthcommission.ca) has been an equally strong proponent of creating a comprehensive and seamlessly integrated system in which people living with mental illness are at its centre and along with their families are fully engaged with the mental health system.

The hope is that the Community Rounds project will evolve to include the consumers and families engaged in the mental health system. Such a vision is consistent with the dynamic literature that can be found in consumer advocacy, self-help, community psychology and other disciplines with an interest in building a more comprehensive sense of community. However, in order to achieve the vision of being genuinely inclusive in all who are part of the mental health continuum, a collaborative system involving programs and agencies is a foundational step.

Barriers & Challenges to Building Community

In the earliest days of developing the Community Rounds project there was some debate about the legitimacy of a small, volunteer group of front-line staff creating an initiative without official sanction and mandate. In fact, these initial and arbitrary objections to the initiative almost derailed Community Rounds before the first session was held. This may just reflect human nature where a negative response to ideas can be their death-knell before they reach fruition. Fortunately, among the small group that coalesced to form the Community Rounds Committee there was sufficient energy and determination to overcome this negativity. And, at a management level within the AHS Mental Health portfolio, there was no attempt to meddle with the evolving project.

An ethos that embraces inclusion of all partners in mental health and accents collaboration – whether that means clients, family members or personnel of agencies that have traditionally been seen to be less sympathetic to some clients – takes time (Backer, 2003) and encouragement to seed. In addition to having a vision and energy to initiate the process of bringing together the staff of disparate community programs and agencies, the value of a core group of committed people serving as a Committee is critical. That core group can sustain and hearten one another through the early phase of uncertainty when maintaining confidence calls for considerable persistence.

We exist in a larger culture which frequently emphasizes values of competition at the expense of cooperation (O’Connor, 2001). Competition and turf (Backer, 2003) also exist in the mental health system and in the social service sector. Further, a culture and history of competitiveness is not easy to overcome (Norman, 2003). Worry over job security, ambitions related to career advancement and a personal inclination to interact with potential colleagues in an adversarial manner are rife in this culture. It is not uncommon for the same individual who espouses principles of collaboration and cooperation while working in a community not-for-profit agency to suddenly become circumspect and vigilant around program boundaries when they transfer to a “therapist” role in a program within the mental health system for AHS, demonstrating that the concepts of collaboration and cooperation are no longer part of their lexicon.

Sustaining collaborative efforts is a challenge, as they have a tendency to be short lived for a variety of reasons (Freeth, 2001). Maintaining energy in the Community Rounds project, as a focal point for building community, is required. Whether this is achieved by adding new members to the Committee overseeing Community Rounds, or through other methods, remains to be seen.

Some concern was expressed at the outset of the Community Rounds project about having presentation topics that were too general, or having a process at Community Rounds that was so informal that it would not galvanize participants. This concern about a too open-ended approach has been balanced with a desire to be non-directive, and to not attempt to predict what topics and opportunities for interaction might best suit the participants at Community Rounds. In a similar vein, there has been occasional debate about how widely to distribute the notices announcing Community Rounds presentations. The larger the community representation from programs, agencies and institutions, the greater the challenge to offer a forum that will satisfy so disparate a gathering. Concerns that interests be addressed in a mutually satisfying manner are a legitimate issue to account for when planning and advertising presentations. Topics for presentation at Community Rounds are largely drawn from the evaluative feedback that is provided at the conclusion of each presentation. In addition to requesting feedback about the specific presentation, the audience is canvassed for ideas about future topics and programs or agencies that should be invited to the Community Rounds. The Community Rounds Committee pays careful attention to this evaluative feedback (Francisco et al., 2003). Planning for subsequent presentations, as well as tweaking the process of each session, is a direct result of the audience feedback. This is also in keeping with the grassroots objective of audience participation in the Community Rounds process and in building the community. Although widely divergent impressions are provided via the feedback, main themes and suggestions for future topics do emerge.

There has been some debate within the Community Rounds Committee concerning composition of the Committee. This involves considering membership from the Adult Mental Health portfolio, AHS, and programs and agencies representative of the larger community. This can be a delicate matter, as appreciating the importance of finding a “fit” between Committee members with sufficient unity as to purpose and vision requires balancing with the principle of being inclusive and representative of the wider community. Almost fifty years ago, Robert Kennedy, as Attorney General of the United States, insisted that there be a strong representation of black lawyers in the Department of Justice if the administration was to promote civil rights (Schlesinger, 1978). In building a genuine mental health community there is a similar obligation to ensure broad representation from across the mental health community. The Committee has an opportunity to lead by example and to serve as a mirror for the fulfillment of the intended vision of building a comprehensive, representative mental health community.

Strengths & Benefits in Building Community

Gaining support from leaders and administrators in the mental health system is important, especially so with the multiple fiscal and staffing pressures that are being experienced throughout the health care system. The Community Rounds project has been fortunate to have consistent and informal support from the administrative group in the AHS Mental Health portfolio; for example, by providing a modest budget for coffee, muffins and door prizes at Community Rounds. As well, managers of various programs encourage their staff to attend the Community Rounds presentations. Such support from the formal leadership of any institution or agency is a key component of a successful project. Aside from offering this administrative support, the grassroots project has evolved with no outside attempts to guide or alter the process.

The topic for each presentation offers a subject for education and discussion. The accent on networking and audience participation in the presentations is designed to promote attention to relationships among all who are present. Feedback has included the observation that it is refreshing to join a forum where there is not a lot of highly critical, sharp or intimidating verbal exchanges during presentations. There is an emphasis on creating an atmosphere and an expectation that the Community Rounds process offers an opportunity to participate in friendly and informal exchange of ideas, to renew acquaintances or to meet staff from a diverse variety of agencies and programs.

The Community Rounds process provides immense opportunity to influence the nature of relationships that evolve in the mental health community. For example, on the basis of informal relationships formed at the Community Rounds, discussions arise as to how two or three staff of community agencies might collaborate with staff from an inpatient hospital program to facilitate a discharge from hospital. Included in such a plan are respective agency/program roles in providing follow-up care for the client and family. This standard of collaborative practice along the continuum of care is not necessarily as common as we might wish, but remains a goal for working relationships among staff of various programs, agencies and institutions in the mental health community.

The vision of the Community Rounds project is that it serves as a ‘touchstone’ where individuals and agencies can attend to renew energy and commitment to the broader goal of creating an environment conducive (Lasker, Weiss & Miller, 2001) to an integrated mental health system that is truly responsive to client and family needs. This, in itself, promotes change in professional practice (Robinson & Cottrell, 2005). The collective energy of staff attending Community Rounds can facilitate an attitude of openness to one another and respect for the shared enterprise, building community in mental health.

Future Directions

Two main directions are proposed as the Community Rounds project approaches its fifth year of existence. A more systematic evaluation with the participants to examine specific ways in which real and positive changes are accruing is envisioned. Although it may be difficult to evaluate whether an experience of an attitude and practice of respect and collaboration leads to concrete results with consumers and families, such examples can be solicited via the feedback forms that are distributed at the conclusion of each Community Rounds presentation. It is hoped that participants in the Community Rounds process are experiencing a collective recognition that intentional collaboration, shared values, respect for the mutual contributions and learning, and a shared responsibility for participating in service delivery enhances the well-being of consumers and families.

The second proposed direction is that the Community Rounds project makes an intentional effort to be more inclusive of consumers and families in the presentations. This likely involves greater collaboration and planning with some of the key agencies that advocate for consumers and families, as well as recruitment of individual consumers and families to be part of the planning process with Community Rounds. The more stressful economic climate and associated pressures in the health care system and social services network may contribute to making this step additionally challenging. Sustained reflection and dialogue may be imperative to address the apprehension that some staff, programs and agencies express when contemplating including consumer groups in the process. However, such ambitions are worthy of the Community Rounds project and the collective energy that can be harnessed to facilitate meaningful change in the mental health system.

Conclusion

It is hoped that this article has reached its goal of offering a model to create similar initiatives in systems that may be of significance to the reader. Outreach to communities is important, and more so when conducted with intentional collaboration. The vision of the Community Rounds project in Calgary, Alberta is to facilitate an integrated mental health system that is truly responsive to client and family needs, and I hope that this blueprint may serve the needs and aspirations of your own community.

References:

Backer, T. (2003). Evaluating community collaborations: An overview. In Thomas E. Backer (Ed.), Evaluating community collaborations (pp. 1-18). New York:Springer.

Carling, P. (1995). Return to community:Building support systems for people with psychiatric disabilities. New York:Guilford Press.

Francisco, V., Schultz, J. & Fawcett, S. (2003). Making sense of results from collaboration evaluations. In Thomas E. Backer (Ed.), Evaluating community collaborations (pp. 113-128). New York: Springer.

Freeth, D. (2001). Sustaining interprofessional collaboration. Journal of Interprofessional Care, 15(1), 37-46.

Gladwell, M. (2000). The Tipping Point: How little things can make a big difference. New York:Little, Brown & Company.

Hall, P. (2005). Interprofessional teamwork: Professional cultures as barriers. Journal of Interprofesional Care, May 2005 Supplement 1: 188-196.

Hanks, P. (chief editor). (1988). Collins Concise Dictionar:, Second Edition. Glasgow: William Collins Sons & Co. Ltd.

Kirby, M. (2006). Out of the shadows at last: Transforming mental health, mental illness and addiction services in Canada. The Standing Committee on Social Affairs, Science and Technology, Senate of Canada.

Larkin, C. & Callaghan, P. (2005). Professioals' perceptions of interprofessional working in community mental health teams. Journal of Interprofessional Care, 19(4), 338-346.

Lasker, R., Weiss, E. & Miller, R. (2001). Promoting collaborations that improve health. Education for Health, 14(2), 163-172.

London, S. Mexico, D., St. George, S. & Wuff, D. (2009). Guides for collaborating. International Journal of Collaborative Practice, 1(1),1-8.

Mattessich, P.W. & Monsey, B.R. (1992). Collaboration:What makes it work. St. Paul, MN: Amherst H. Wilder Foundation.

Mental Health Commission of Canada. (2009). Toward recovery and well-being(draft). Retrieved July 13, 2009 from www.mentalhealthcommission.ca

Naidoo, K. (2006). Building capacity:A framework for serving Albertans affected by addiction and mental health issues. Summary report of the concurrent disorders demonstration project evaluation. Alberta Alcohol and Drug Abuse Commission. Edmonton:AADAC Research Services.

Nelson, G., Lord, J. & Ochocka, J. (2001). Shifting the paradigm in community mental health:Towards empowerment and community. Toronto:University of Toronto Press.

Norman, A. (2003). Multicultural issues in collaboration:Some implications for multirater evaluation. In Thomas E. Backer (Ed.), Evaluating community collaborations (pp. 19-36). New York: Springer.

O'Connor, Richard. (2001). Active treatment of depression (pp.245-246). New York: W.W. Norton & Co. Inc.

Poole, D. (1997). The SAFE project: community-driven partnerships in health, mental health, and education to prevent early school failure. Health & Social Work, 22(4), 282-289.

Robinson, L. (2005). Promoting multidisciplinary relationships: a pragmatic framework for helping service providers to work collaboratively. Canadian Journal of Community Mental Health, 24(1), 115-127.

Robinson, M. & Cottrell, D. (2005). Health professionals in multi-disciplinary and multi-agency teams: Changing professional practice. Journal of Interprofessional Care, 19(6), 547-560.

Schlesinger, Jr. A. (1978). Robert Kennedy and his times. pp. 311-312. New York: Ballantine Books.

Secker, J. & Hill, K. (2001). Broadening the partnerships: experiences of working across community agencies. Journal of Interprofessional Care. 15(4), 341-350.

Tourse, R., Mooney, J., Shindul-Rothschild, J., Prince, J., Pulcinie, J., Platt, S. & Savransky, H. (2008). The university/community partnership: Transdisciplinary course development. Journal of Interprofessional Care, 22(5), 461-474.

Trainor, J., Pomeroy, E. & Pape, B. (2004). A framework for support (3rd ed.). www.cmha.ca retrieved 29 March 2011).

The International Journal of Psychosocial Rehabilitation

Inclusion of people with mental illness in Community Based Rehabilitation: need of the day

Dr. N. Janardhana & D.M. Naidu

Department of Psychiatric Social Work
National Institute of Mental Health and Neuro-sciences (NIMHANS)
Bangalore 560 029 India

Citation:
Janardhana, N & Naidu, DM (2012). Inclusion of people with mental illness in Community Based Rehabilitation: need of the day. ***International Journal of Psychosocial Rehabilitation. Vol 16(1) 117-124***

Abstract

Through out the world people with mental illness are denied their basic human rights, especially the right to access treatment, rehabilitation and appropriate mental health care (UN 2006, UN 1999). People with mental illness (PWMI) and their families experience discrimination and exclusion from economic and social activities. Due to stigma, PWMI and their families are often ridiculed and isolated, trapping them in a cycle of poverty. A lack of access to information about their rights and support to exercise these rights perpetuates and deepens this marginalization. People with disabilities also do experience stigma, discrimination and social exclusion. However, the situation, in the case of people with disabilities has improved in many countries through CBR initiatives. Including PWMI having psychosocial disabilities in CBR programme seems an ideal answer to address the needs and rights of PWMI along with other people with disabilities.

Introduction

Mental illness is not a personal failure, it happens to most of us at one time or the other in life. Mental, behavioural and social health problems are an increasing part of health problems in the world. The WHO estimates that mental and behavioural disorders constitute 12% of the global burden of disease. Worldwide, nearly 450 million people have mental or behavioural disorder (WHO 2001). The number of PWMI will increase substantially in the coming decades for the following reasons. Firstly the number of people living in the age groups of risk for certain illness is increasing because of the changes in the demographic features. Thus there has been increase in the number of person with mental illness in the age group of 15- 45 years. Secondly, there has been substantial increase in the geriatric population having mental health problems, as the life expectancy is increasing. Thirdly, there is an overall increase in the rate of depression seen in all age groups as an effect of the changing socio- cultural-economic and political situation of the modern world (Janardhan and Naidu, 2006; Janardhan and Naidu 2007).

Mental illness in certain cases leads to psychosocial disability (Tally and Murali 2001). Advances in behavioural science have proven that mental and behavioural disorders are treatable like any other physical illness (WHO 2001). Unfortunately, in most countries mental health and disorders are low priority, with no services in the community for treatment and well-being. Though the burden resulting from psychiatric, psychosocial, and behavioural disorders are enormous; it is grossly under represented by conventional public health statistics. Nearly 10% of Disability Adjusted Life Years (DALYs) across all age groups are due to depressive disorders, suicides and alcohol related problems. It is estimated by WHO that in 2020 the burden of mental disorders would increases to 15% and mental disorders will be among the leading cause of global disease burden by 2020, at which time, depression alone is expected to become the second highest cause of death and disability world wide (WHO 2001).

If a person is unable to perform an activity because of disease/illness or due to bodily impairment, the person is considered as disabled. Though psychiatric disorders do not cause any physical impairment, they can stop a person from doing many activities that are expected of them. The disability in psychiatric illnesses is dynamic being influenced by the nature of illness, phase of the illness, treatment status and social support network available to them. PWMI are treated as second-class citizens with no adequate facilities or provision from the government. As a result, they face chronic ill health and the families experience economic and social burden. In certain cases this leads to social destitution.

Goal of Inclusion of people with mental illness in the CBR programme:

PWMI participate in societal activities, having access to generic services as well as appropriate support and which they consent to.

Purpose of inclusion:

To enable development practitioners to include mental health issues in the existing CBR programmes through increased understanding of PWMI, recognising psychosocial disabilities, appreciating the similarity in approaches, cost effectiveness etc.

Basic Needs India (BNI), a resource group in mental health and development believes that mental health is a development issue; hence it can be included in the development activities of the organizations. BNI provides technical support to the CBOs and NGOs to include mental health issues in their existing programmes. BNI has been successful in including PWMI in 50 CBOs and NGOs, carrying out CBR work and other development activities. In the process, awareness has been created about the needs of PWMI in the communities and among local and district level government authorities. Many people recovering from mental illness and their family members have joined self- help groups of people with disabilities. While working with the CBR organizations in following activities PWMI can be included.

CBR and people with mental illness

Development and changes in the concept of CBR over the last two decades has influenced the thought of inclusion of mental health in CBR programmes. The CBR strategy shifts rehabilitation interventions to homes and communities of people with disabilities. Basic services are provided or facilitated by CBR workers who are minimally qualified non professionals but who are highly qualified change agents. The main goal of rehabilitation has become broader and focuses beyond the individual, to the family and communities in which people live. CBR recognizes that breaking down barriers to inclusion in society is as important to the mission of the CBR programme as is the functional rehabilitation of individuals with disabilities. Thus the universal mission of CBR is:

1. To enhance activities of daily life of disabled persons
2. To create awareness in disabled person's environment to achieve barrier free situations around him and help him in meeting all human rights.
3. To create a situation in which the community of the disabled persons, participates fully and assimilate ownership of their integration in to the society. The ownership lies with the affected persons. Maya Thomas and M.J Thomas 2003, Pritivish 2006).

The above mission is no exception for PWMI. CBR programmes can link with mental health professionals, users of mental health services, DPOs and SHGs to broaden its scope to include people with psycho social disabilities and to promote community mental health services

Indicators of readiness

In order to begin a mental health component in the CBR programme, the following readiness indicators should be demonstrated:

1. Organization's willingness to work with mental illness
2. Basic understanding of the mental health concept/problem
3. A match of context between current CBR activities and mental health and development needs
4. Resource stability of the organization (Shoba Raja 2005)

Inclusion of mental health in to CBR:

There are a number of reasons why mental health should be integrated into community based rehabilitation programmes:

- Community processes, full participation, equal opportunities, social inclusion, gender, diversity and a focus on rights are some of the key common elements of CBR work. Community mental health work is no different so the programmes integrate well together.
- The high prevalence of psychosocial disabilities emerging through mental illness and its impact on communities, societies and economies means that CBR workers are confronted with the issues in their work. CBR programmes can have a positive impact on the lives of PWMI, their families and on the situations in which people live by including people with psychosocial disabilities in their programmes (WHO 2010).
- there are a limited number of mental health professionals and mental health services in low-income countries, making a CBR strategy which empowers community level stakeholders to take action an important strategy
- the emerging trend away from vertical health programmes to integrated, multipurpose health programme models favours primary level services and community based strategies
- there is an increasing recognition of the importance of early detection and treatment of mental illness in order to prevent chronic conditions
- the goal of continuity of care and inclusion of people who are mentally ill into the community is more readily achieved when there is an existing community based strategy
- the prevalence of mental health problems among people with other disabilities means that a mental health component in the CBR programmes brings added value

The care for people with mental illness can be provided by :

- Family members providing care to PWMI starts from baring all the violent behaviour, to accompanying them for treatment, than administering medicines, helping to engage in gainful productive work.
- Community providing support for the well-being of PWMI. This is seen in the form of not labelling them as mad people, giving opportunities and advocating for the ensuring measures to meet the needs of PWMI.
- Rehabilitation workers providing care for the PWMI and their families. This starts with identification, assessment, follow up, home based support and linking them to existing groups and mainstreaming.
- Organization providing support to deal with other associated problems of PWMI and their caregivers. This is seen in the form of conducting camps, integrating them in to their existing programmes.
- Provided with the above support, the role of mental health professionals would be more meaningful.

Suggested Activities for inclusion of people with mental illness to be included in the existing CBR programmes:

1. Promote community based mental health services

The community based services should emphasize on community acceptance, family involvement, social integration and livelihood opportunities as a key component of interventions while rehabilitating people with disabilities. Similar approach is required for PWMI for integrating them in to the community. An approach, where in medical inputs are seen as a part of a larger whole including income generation and mainstreaming individuals with mental health problems into the full community.

The community based organization, SACRED, included mental health programme in their existing CBR programme. PWMI had to travel 100 kilometres to attend the mental health camp conducted by the National Institute of Mental Health And Neuro Science because there were no services available in that district. With the support of the federation of people with disabilities, PWMI were successful in sensitising the district authorities and advocating for the availability of mental health services with in the district. Of course the struggle took more than three years for the appointment of Psychiatrist in the District Hospital

Similar experience in Koppal and Raichur districts, PWMI and their caregivers were travelling 10-12 hours to reach Karnataka Institute of Mental Health, Dharwad for assessment, diagnosis and treatment services. Organizations of people with disabilities promoted by CBR programme of Samuha sensitised the authorities and were successful in getting the services with in their district. Awareness building among family members and community complemented the efforts.

2. Work with Disability people's organizations (DPOs)

and service users to advocate for access to treatment: Access to treatment as near as possible

3. Involve people with mental illness and their families in livelihood programmes

A tale of market

Mr. S a beneficiary of the mental health programme implemented by BasicNeeds India partner in Tamilnadu shares his experience. S suffered from mental illness but has now recovered sufficiently to be able to run a small enterprise selling cooking ingredients on his bicycle. He rides about 35 kilometres per day on a regular set of routes and has built up a network of established customers. At the outset, he spent a good deal of time working out the various ingredients that were likely to be in greatest demand, such as pepper and coriander, and the quantities required. He sells small packets tailored exactly to the needs of low-income customers who purchase their requirements daily and at affordable prices. He earns 2 US dollars a day.

Before he became mentally ill, Mr V worked for thirty years in the weaving industry. He gave it up and concentrated in overcoming his illness with the support of his family. Following treatment and ongoing assistance from an NGO, he decided to set up a small business supplying snacks to travellers using the bus shelter in his village. He starts preparing the food at 5.00am and sells from 8.00am until noon and than he rests. Trade has been consistently good and he earns 3 US dollars a day. This income although modest, is comparable to others in his village. He describes himself as having a completely new beginning. He is confident and contented, enjoying the relative freedom of the work that he does now. The local village council was instrumental in his success, allowing Mr V to use the bus shelter, which is a favourable location for his business

4. Promote community mental health services

Mental health professionals in several low-income countries are actively promoting Community Mental Health (CMH) and are attempting to influence their governments to initiate measures to bring mental health into the primary health care system. CBR programmes can work with mental health professionals, local health centre staff and users of mental health services to promote community mental health services. Many mental health problems can be effectively resolved by working together with people who experience mental illness in their own homes and communities, using resources and support networks that are available to them. Awareness raising campaigns and large-scale dissemination of knowledge and skills would help in reducing the stigma attached to illness. Building knowledge and awareness among families can make the real difference, in ensuring that PWMI are integral members of the family and community, participating in all social and cultural activities.

Street Theatre

Street theatres play a major role in generating awareness in the community. Some organizations also have formed puppet shows troops. Street plays can provide knowledge on causes, treatments and symptoms of mental illness. The purpose is to demystify the subject and to raise the awareness of the public on mental health issues. Street theatres can also highlight the important roles and responsibilities of families and the community, which could go long way in rehabilitating PWMI. The street theatre performances can be followed by question and answer sessions, where people can ask specific questions.

Self help groups

Self-help groups are a common feature of CBR and development work. A self-help group of women were clearly working hard to be strong in the face of personal tragedy and unrelenting poverty. Comprising twelve members, they came together with the support of CBR worker to promote savings of Rs.100 per month per person so that individuals can accumulate enough to buy a buffalo. This would then be a source of regular income, the milk being sold to a cooperative at a guaranteed rate per litre. One of the women had lost her husband to snakebite the previous week and so the group was rallied around to support her and her three children.

The link comes from the member living with schizophrenia, who has been accepted as treasurer for her literacy skills (despite only having stabilised her schizophrenia during the previous year). And she also derives benefit as any other marginalized member of the group. Together the group advocates for meeting the individual, group and community needs.

This way they play an important role in integrating PWMI in main stream and provide mutual support to people in crisis.

5. Seek out alliances for training and mutual support

Local community organizations staff like community rehabilitation workers/field staffs, coordinators of self-help/user groups and other programmes, lay volunteers/ animators, nurses, and health workers; who are not professionals in mental health or health care provide a variety of services. Many of these informal community-care providers have little or no formal mental health care training, but in many low income countries they are the main source of community mental health provision. They are usually accessible and generally well accepted in local communities. They can help with the integration of people with mental disorders into community activities and the other developmental activities of their own organizations, and thus play an supportive role in meeting the treatment needs of PWMI.

Caregivers Associations

PWMI and their caregivers are encouraged to form an association of their own. This provides a platform for them to discuss various problems they share and find solutions. For example, Mr B’s, family experienced unwelcome reactions of neighbours towards their son. Mr B was wandering in the streets and his parents had to find him and bring him back. The caregivers’ association in the village took the responsibility to explain the illness to others. Mr B has now returned to work as a labourer and is maintaining full-time employment.

Another caregivers association took the decision to advocate for their right to treatment. The association members met the district authorities, explained to them the need for treatment to be made available at their block level. PWMI and their families decided to voice their needs rather than depending on the local organizations. This resulted in the deputation of a psychiatrist to conduct mental health camps in the local health care centres on a monthly basis, with medicines being distributed during these camps..

Some of the important roles of the CBR and the community development work force are:

- awareness creation and dissemination of information;
- identification of people with mental health problems and referral to health services;
- crisis support;
- home based support - supportive care, including basic information and counselling;
- helping in the activities of daily living skills and community reintegration;
- formation of caregivers groups/associations;
- advocating for the rights of PWMI;
- preventive and promotive services;
- Organising affected people to advocate for meeting their needs.

Mr M, a young volunteer from a youth group in Jalahalli, took initiative in supporting a woman who is mentally ill and destitute in his village. He witnessed a shop keeper physically abusing (pushing) her for entering his restaurant. Mr M took this abuse seriously. With the help of an NGO he took her to the mental hospital for treatment, following guidelines of mental health act for the involuntary admission. After her discharge, he spoke with the woman's relatives and made arrangements for her stay and for her livelihood. People like Mr M, volunteer to support NGOs in their work. NGOs also experience stabilised people playing the role of volunteers and advocates. Always people inspired by good work voluntarily offer assistance.

Advantages of inclusion of people with mental illness in the existing CBR programmes:

1. Meeting the needs of most disadvantaged group.
2. This promotes faster integration of PWMI into the mainstream societal activities.
3. Promotes good mental health in the community and leads to early identification.
4. Inclusion of PWMI in CBR programme would be cost effective.
5. CBR strategies and approaches very much fit in meeting the needs of PWMI.
6. Encourages innovative use of the resources that already exist (for example street theatre troops, advocacy groups, etc.)
7. Inclusion would ensure coverage of all people with disabilities.
8. Mental health problems of people with disabilities are addressed, which adds value to the existing CBR programme.
9. An environment would be built where in all disadvantaged groups including PWMI fully participate in their own development and the community in which they live in.

CBO

The project head during one of the meeting expressed that because of inclusion of the mental health programme, the credibility of the organization has increased, the organization got more recognition in the community and also in the district administration. The organization leaders were invited to become members of the government constituted boards. District authorities were appreciative and requests were received to extend mental health services to other parts of the district.

Broaden understanding of the issues

Development practitioners need basic understanding of mental disorders. It is essential to consult PWMI and their family members to listen to their experiences, and needs aspirations to understand that particular individual and the family. Training can be provided in basic competencies, such as counselling- listening and communication skills and need to maintain confidentiality, managing conflict of interests while dealing with individuals as well as their families, maintaining a neutral stance and dealing with disturbing emotions.

Outcomes expected from inclusion:

By including PWMI in CBR programmes, the following outcomes can be achieved:

- PWMI advocate for their rights and entitlements as equal and full participants in the disability movement
- PWMI participate in their own development and the development of communities in which they live
- PWMI are listened to and are able to consent to or refuse treatment in circumstances that are not life-threatening.
- PWMI have access to appropriate community-based treatment and support.
- Families of PWMI are provided with the support
- PWMI and their families are able to earn their livelihoods.
- Community health workers include mental health issues as an integral aspect of their work
- PWMI are able to access health care and educational services within and outside of the community
- PWMI participate in the social, cultural and religious life of their communities as they choose.
- PWMI fulfil their roles as community members, family members, parents and citizens

Conclusion:

It has been tested and proved that inclusion of mental health issues in CBR programmes is possible, cost effective and help building an environment where in people with all disabilities access their entitlements and enjoy equal opportunities for full participation in their own communities. A different and better world for all people, including PWMI can be created through community based mental health services, where in the communities understand issues related to mental health, resulting in positive response to the issues. In this scenario the families of people who are mentally ill are vitally involved in bringing change in the attitude of the community. Through these an environment of mutual understanding can be built, where in PWMI enjoy their rights.

References:

Janardhan and Naidu(2006), Community Mental Health and Development model evolved through consulting PWMI in Mental health by the people Edited by Murthy 2006.

Janardhan and Naidu (2007) Mental Health in India: an over view, CHC publication, circulated during national assembly on health of Janaarogya Andolona.

Maya Thomas and M.J. Thomas (2003) Manual for CBR planners, Asia pacific Disability Rehabilitation Journal.

Mental Health Atlas 2005, World Health Organization, Geneva - 2005

Prathima Murthy (1998) Manual of mental health care for women in custody, Department of psychiatry, National Institute of mental health and Neuro sciences

S Pruthvish (2006) Community Based Rehabilitation of persons with Disabilities, Jaypee publishers

Shoba Raja, Director Policy & Practice, BasicNeeds – CBR MH success indicators research study report - 2005

Taly and Murali (2001) Foundations and Techniques in Psychiatric Rehabilitation, manual for CBR workers and caregivers, National Institute of mental health and Neuro sciences,

UN Convention on the Rights of people with disabilities, New York UN 2006

UN Convention on the Rights of people with disabilities, New York UN 2006, UN resolution 46/119, principles for protection of persons with mental illness and the improvement of mental health care (1991)

UN Standard rules on Equalization of opportunities for people with disabilities (Resoultion 48/96) New York, Geneva, UN 1997

World Health Report 2001, Mental health: New Understanding New Hope Geneva, WHO 2001

World Health Report 2006, working together for health Geneva, WHO

WHO (2010) Community Based Rehabilitation CBR Guidelines, WHO

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 1
July 2011– June 2012

Abstinence Predictors among Substance Dependents Treated in a Brazilian Psychosocial Care Center

Maiko Marini, RN, MSc
Graduate Program in Nursing
Federal University of Rio Grande do Sul (UFRGS)
Porto Alegre (RS). City Department of Health of Caxias do Sul (RS), Brazil.

Giovana Bertassi Brandalise
Undergraduate Program in Psychology
University of Caxias do Sul (UCS)

Taciana Madruga Schnornberger
Undergraduate Scientific Research Program
CNPq-UFRGS, Porto Alegre (RS), Brazil

Elizeth Heldt, RN, PhD
Graduate Program in Nursing
Federal University of Rio Grande do Sul (UFRGS)
Porto Alegre (RS), Brazil
Graduate Program in Medical Sciences: Psychiatry, UFRGS
Porto Alegre, RS, Brazil

Citation:
Marini M, Brandalise GB, Schnornberger TM & Heldt E. (2012) Abstinence Predictors among Substance Dependents Treated in a Brazilian Psychosocial Care Center. ***International Journal of Psychosocial Rehabilitation. Vol 16(1) 125-135***

Correspondence:
963 São Manoel St. Porto Alegre
Rio Grande do Sul, Brazil. Zip Code: 90620-110
Email: maikomarini@gmail.com

Abstract

PURPOSE: To identify predictors of abstinence in users of Psychosocial Care Center for Alcohol and Other Drugs (CAPSad, by its initials in Portuguese). METHOD: The sample consisted of individuals with diagnosis of substance dependence being treated at a CAPSad for more than 6 months. The outcome factors - abstinence and substance use - were obtained based on the Addiction Severity Index (ASI6). Abstinence was defined as no substance use within 30 days or 6 months preceding the interview. FINDINGS: Seventy-seven individuals participated in the study. Most of them were men (n = 65; 84%), with mean age of 43.84 (SD=11.25) years. The sample was grouped into substance use (n = 27; 35%) and abstinence (n= 50; 65%). We identified significant associations between the abstinence group and lower severe problems in the areas of drugs, alcohol and social-familial. Higher psychiatric comorbidity and individual treatment with a psychiatrist were associated with the group that remained abstinence. However, the independent predictive variables for abstinence were psychiatric comorbidity ($p = 0.041$) and severity of alcohol dependence ($p = 0.024$). CONCLUSIONS: Our data indicate that individuals with psychiatric comorbidities and lower severity in the alcohol area treated at CAPSad are more likely to achieve abstinence.

Keywords: Mental Health Services; Substance Dependence; Abstinence; Alcohol and Drugs; Comorbidities.

Introduction

Substance dependence (SD) is a significant and growing public health problem worldwide. It is a chronic and recurrent disease (Kelly, Stout, Zywiak, & Schneider, 2006; National Institute on Drug Abuse [NIDA], 2009) that is associated with negative consequences in different life domains (Laudet, Becker, & White, 2009). Population-based studies estimate that 18 to 38 million people in the world abuse or have substance dependence (United Nations Office on Drugs and Crime [UNODC], 2009). In Brazil, a study conducted in the main cities found that 2.1% of individuals had substance dependence, except for alcohol and tobacco. In addition, this study demonstrated a growth of around 3% in the number of individuals who used substance in four years. In relation to alcohol and tobacco dependence, respectively, 12.3% and 10.1% of individuals were considered addicted (Carlini et al, 2007).

Despite the advances in pharmacology and current knowledge of the psychopathology of the disease, SD treatment remains a challenge. Studies have shown that there are high rates of noncompliance (Elbreder, Silva, Pillon, & Laranjeira, 2011) among alcohol-dependent individuals. A compliance rate (individual's bond with the program, regardless of abstinence) of 30% with a multidisciplinary outpatient program at a university hospital (Garcia & Macieira, 2003).

In this context, the current Brazilian public policy "Integral Attention to Users of Alcohol and Other Drugs" recommends that the SD treatment considers the individual as a whole, respects the individuals' specific characteristics and the need to make patients comply with the treatment (Brasil, 2004a). This policy states that the treatment should be based on harm reduction (HR) (Brasil, 2004a, 2004b, 2008), which consists of policies, programs, and practices primarily aimed at reducing adverse consequences in terms of health, social and economic aspects caused by the use of legal and illegal drugs (International Harm Reduction Association [IRHA], 2011), trying to alleviate suffering and promote individual or collective well-being (Marinho, 2005).

This policy is focused on psychosocial rehabilitation model whose axis is the Psychosocial Care Center for Alcohol and Other Drugs (CAPSad, by its initials in Portuguese) (Brasil, 2004a, 2004b). This type of health care facility is an open and community health center of the Brazilian Unified Health System (SUS, by its initials in Portuguese) to which patients are referred for the treatment of problems arising from improper substance use, whose severity and/or persistence indicates the need for continuing care (Brasil, 2004b).

The public policies are managed at the CAPSad through the Therapeutic Project (TP) (Mângia & Barros, 2009). This project is characterized by a set of articulated practices focused on individuals or groups of patients. Such practices are defined by an interdisciplinary team, which results is an integrated performance of the team, valuing the different dimensions of the user under treatment, in addition to psychiatric diagnosis and medication (Brasil, 2009). The activities that may be included in the TP are: individual care (e.g., medication, psychotherapy), group care, therapeutic workshops, home visits, and detoxification (Brasil, 2004b).

TP interventions should be specific for each patient, covering the social and familial context, promoting independence and social inclusion (Cunha, 2005). Thus, broadening the interventions focused strictly on the treatment of symptoms, and offering a treatment that encompasses the other dimensions of the individual's life in a way that there is interaction with his context. This practice would also involve the support network, the individual's participation in the treatment, continued care, and dialogical actions (Mângia & Muramoto, 2006).

There is an increasing number of CAPSad in Brazil (approximately 262 units) (Brasil, 2011). However, there is no consensus on the effectiveness of this model (Alves, 2009; Diehl A, Cordeiro, & Laranjeira, 2011). Indeed, there are few recent studies evaluating the impact of current health policies on the efficacy of these centers (Gastal et al, 2007). In addition, among those studies investigating the effectiveness of psychosocial interventions, abstinence has been used as an outcome (Dutra et al, 2008).

Considering that individuals respond differently to treatment for SD (NIDA, 2009), as a consequence not everyone benefits from the TP proposed at CAPSad. However, there is a lack of studies assessing the outcomes in this therapeutic model. Therefore, the objective of the present was to identify demographic, clinical and psychosocial predictors related to abstinence in individuals treated at CAPSad in order to contribute to create guidelines regarding actions and strategies of the treatment for SD.

Methods

This is a retrospective study comparing data regarding the 30 days prior to an assessment interview with the last six months during which the user attended the CAPSad. The study was approved by the Research Ethics Committee at Universidade Federal do Rio Grande do Sul (no. 17886) and all participants signed an informed consent form.

Participants

Participants were being treated at the CAPSad Reviver, located in the south region of Brazil, from May 2010 to April 2011. Inclusion criteria were: being older than 18 years, both sexes, having a diagnosis of SD recorded on the medical record; attending the CAPSad for at least 6 months; having completed the initial group assessments with reference professionals to determine the need for treatment at the CAPSad. According to these initial visits, the interdisciplinary team discussed a proposal of TP for each user. The team working at this CAPSad includes the following reference professionals: social workers, nurses, and psychologists. General practitioners and psychiatrists, nursing technicians, as well as music therapist, visual artists, and art therapists - who offer therapeutic workshops and do not perform the role of reference professionals. Exclusion criteria were: having severe mental deficiency, presence of psychotic symptoms, or being intoxicated at the time of interview.

A total of 285 users of the CAPSad met the inclusion criteria, and 150 individuals were randomly invited to participate in the study based on the order of visits to the CAPSad.

Procedures

Participants were interviewed using the sixth version of the Addiction Severity Index (ASI6) at a private office located at the CAPSad by two researchers previously trained in the use of the instrument - administration manual (Kessler &Pechansky, 2006a) and DVD (Kessler &Pechansky, 2006b). Data collectors made two different interviews with the same user in order to ensure interrater reliability. After that, the data collected were qualitatively compared for a final agreement.

The ASI6 is a semi-structured interview that characterizes and quantifies the problems commonly associated with SD (Kessler et al 2007; McLellan, Cacciola, Alterman, Rikoon, & Carise, 2006). It is considered the current gold standard in evaluations of SD (Murphy, Hser, Huang, Brecht, & Herbeck, 2010). The ASI6 weighs the severity of the problems in seven areas: medical, employment, legal, social-family, psychiatric, alcohol use, and use of other drugs. Therefore, it is a multidimensional instrument that enables an overall assessment of the individual (Cacciola, Alterman, Habing, & McLellan, 2011; Kessler et al, 2010; McLellan et al, 2006). The ASI6 is the most widely used instrument in research and the outcome indicator most commonly used in SD treatments (Ahmadi, Kampman, & Dackis, 2006; Dutra et al, 2008). It is also used to evaluate the effectiveness of the SD treatment (McLellan et al, 2006), as well as to identify relapse and abstinence predictors (Haraguchi et al, 2009).

The ASI6 was culturally adapted and validated for the Brazilian context (Kessler et al 2007, 2010). This version includes objective questions: number, severity, and duration of symptoms throughout the individual's life, within 30 days and 6 months prior to the interview; as well as subjective data: the individual's perception of the severity of

current problems and the need for treatment in each area (Cacciola et al, 2011; Kessler et al 2007).
The outcome factors -- abstinence and substance use -- were obtained based on the ASI6 questions. Abstinence was defined as no substance use within 30 days to 6 months. Individuals currently using substance were those who had used substance in the 30 days preceding the interview.
Data on activities attended during the 6 months preceding the interview, psychiatric diagnoses, and medications being used were collected from the individuals' medical records.

Statistical Analysis

The ASI6 composite scores were calculated based on combinations of the items in each area (Kessler & Pechansky, 2006a). We used the Student's t test for independent samples and the nonparametric Mann-Whitney test to compare the parametric quantitative variables between the groups. The chi-square test was used for the analysis of the categorical variables between the groups. Logistic regression analysis was used to identify the independent variables with $p < 0.05$.

The statistical analyses of the variables were performed using the statistical computer program Statistical Package for the Social Sciences (SPSS) version 18.0. The significance level was set at 0.05 with a confidence interval of 95%.

Results

Of the 150 selected CAPSad users, 77 (51.3%) participated in the study: 13 (8.6%) refused to participate, and 60 (40%) did not attend the scheduled interviews. The mean age (standard deviation) of the sample was 43.84 (SD = 11.25) years. There was a predominance of male participants (n = 65; 84%). They had less than 8 years of schooling (n = 55; 72%). Most of them did not have a partner (n = 45; 58%) and were unemployed (n = 49; 64%). Clinical data indicate that the most frequent SD diagnosis was alcohol dependence (n = 41; 53%); whereas among the comorbidities, mood disorders were the most common (n = 17; 22%). Most individuals (80%) used medications (n = 62) and 65% met the abstinence criterion (n = 50).

Regarding the degree of concern about alcohol-related problems, need for treatment, and importance to achieve or maintain abstinence, there was moderate to extreme intensity (mean = 3.03; SD = 1.44 to 3.45; SD = 1.44). The degree of concern about problems related to the use of other drugs, need for treatment, and importance to achieve or maintain abstinence ranged from moderate to extreme intensity (mean = 3.71; SD = 0.66 to 3.80; SD = 0.52).
Characteristics of users of CAPS and abstinence.

The association between sociodemographic and clinical characteristics with abstinence is shown in Table 1. We only found significant association between presence of psychiatric comorbidity and being abstinent (p = 0.002).

Table 1 Association between sociodemographic and clinical characteristics with abstinence in users of CAPSad.

Characteristics	Total n = 77	Use 27 (35%)	Abstinence 50 (65%)	P
Sociodemographic				
Age (years) *	43.84 ± 11.25	44.63 ± 12.95	43.42 ± 10.33	0.656
Sex**				

Male	65 (84)	25 (39)	40 (80)	0.197
Race ***				
White	42 (54)	12 (44)	30 (60)	0.461
Brown	18 (23)	8 (30)	10 (20)	
Black	10(13)	5(19)	5(10)	
Other	7(9)	2(7)	5(10)	
Educational level**				
≥ 8 years	21 (28)	8 (30)	13 (27)	0.772
<8 years	55 (72)	19 (70)	36 (73)	
Marital Status **				
Without a partner	45 (58)	12 (44)	33 (66)	0.067
With a partner	32 (41)	15 (56)	17 (34)	
Employment **				
Unemployed	49 (64)	16 (59)	33 (66)	0.557
Employed	28 (36)	11 (41)	17 (34)	
Clinical				
Substance Dependence**				
Alcohol	41 (53)	13 (48)	28 (56)	0.633
Multiple Substance	36 (47)	14 (52)	22 (44)	
Psychiatric comorbidities	**29 (38)**	**4(15)**	**25 (50)**	**0.002**
Use of medication	62 (81)	20 (74)	42 (84)	0.294

[*] Continuous variable, expressed as mean and standard deviation, was analyzed using the Student's *t* test.

[**] Categorical variables are presented as absolute and relative frequency (%) and were analyzed using the chi-square test.

*** Categorical variable analyzed with the chi-square test and adjusted residuals.

$p < 0.05$

Severity of dependence, participation in the activities of the CAPSad and abstinence

The analysis of the severity dependence and the outcome revealed a significant association between abstinent individuals and lower severity in the areas alcohol ($p = 0.012$), other drugs ($p = 0.033$), and social-family ($p = 0.006$).

The other areas assessed by the ASI6 did not show significant associated with the outcome (Table 2).

Table 2 - Association between substance use and severity of dependence in users of CAPSad

ASI6*	Total n= 77	Use 27(35%)	Abstinence 50 (65%)	p
Alcohol	**49.84 ± 6.98**	**52.51 ± 8.40**	**48.40 ± 5.65**	**0.012**
Other drugs	**38.96 ± 8.24**	**41.66 ± 9.92**	**37.50 ± 6.84**	**0.033**
Psychiatric disorders	44.62 ± 8.16	44.62 ± 7.91	44.96 ± 8.36	0.867
Clinical problems	46.53 ± 9.42	48.37 ± 9.71	45.54 ± 9.20	0.211
Legal problems	46.52 ± 2.23	46.74 ± 2.66	46.40 ± 1.97	0.527
Employment/income	35.86 ± 5.65	36.40 ± 4.72	35.56 ± 6.11	0.533
Family	52.45 ± 7.05	53.25 ± 7.82	52.02 ± 6.64	0.466
Social-Family Support	39.38 ± 7.94	39.22 ± 7.19	39.46 ± 8.38	0.901
Social-Family Problem	**47.40 ± 7.37**	**50.51 ± 7.00**	**45.72 ± 7.07**	**0.006**

Notes: ASI6 - 6th edition of the Addiction Severity Index
* The variables are expressed as mean and standard deviation and were analyzed with the Student's *t* test.
p <0.05

Regarding the TP, we compared the type of activities attended between the abstinent group and the group of individuals who continued to use substance (Table 3). We found associations of intensive treatment (p = 0.025) and individual treatment with a psychiatrist (p = 0.010) with the group that remained abstinent. The other activities and types of care were not significantly associated. However, when compared on an ongoing basis, the total number of participations in the activities showed significance between the groups (p = 0.024), i.e., abstinent users participated in a larger number of the activities defined in the TP.

Table 3 - Association between abstinence and treatment project at CAPSad.

	Total n = 77	Use 27(35%)	Abstinence 50(65%)	p
Variables of treatment				
Model*				
Intensive	20 (26)	3 (11)	17 (34)	**0.025**
Semi-Intensive	56 (73)	24 (89)	32 (64)	
Reference professional*				
Social worker*	35 (45)	11 (41)	24 (48)	0.542
Nurse	22 (29)	7 (26)	15 (30)	0.706
Psychologist	20 (26)	9(33)	11 (22)	0.279
Participation in activities				
Groups$^{\#}$				
User	45 (58)	18 (67)	27 (54)	0.282
Family	12 (16)	3 (11)	9 (18)	0.524
Workshops$^{\#\#}$	33 (43)	8(11)	25 (50)	0.085
Individual care				
Reference Technician	67 (87)	25 (93)	42 (84)	0.479
Psychiatrist	**41 (53)**	**9(33)**	**32 (64)**	**0.010**
General Practitioner	58 (75)	22 (81)	36 (72)	0.357
Psychotherapy	12 (16)	2(7)	10 (20)	0.197
Number of participations**				
Groups	3(0-9)	5(0-9)	2(0-8,25)	0,513
Workshops	0(0-19)	0(0-15)	0.5(0-31.7)	0,070

Individual care	8(4-12)	7(4-10)	9(4-13)	0,231
Reference Technician	3(1-5.5)	3(2-5)	3(1-6)	0,914
Medical Care	3(2-6)	3(2-5)	4(2-6)	0,235
General Practitioner	2(0.5-3)	2(1-3)	2(0-3)	0,948
Psychiatrist	1(0-4)	0(0-3)	2(0-4.2)	0,071
Total	**22 (14-40.5)**	**16 (13-28)**	**24 (16-48.2)**	**0.024**

Notes

* Categorical variables are presented as absolute and relative frequency (%) and were analyzed using the chi-square test*

** Continuous variables, expressed as median and interquartile range, were analyzed using the Mann-Whitney test.

p <0.05

[#] Relapse Prevention, Motivational, Experiences, Feelings and Women;

[##] Music therapy, Painting, Body expression, Recreation, Cooking, Nutritional education, Culture of Peace, Physical Activity, Integration, Self Care, Texts and Chatting, Jewelry, Income Generation, Carving, Wall Paintings, Posters and Cards, Reuse of Materials, Art Therapy, Biodance, Needlework, Mosaic, Drawing, Newspapers, Threads, Crafts and Gardening.

Abstinence predictors at the CAPSad

We used logistic regression analysis to identify independent predictors of abstinence. Because of the small size of the sample and to select the relevant variables ($p < 0.05$), regression was performed separately between clinical characteristics (comorbidity, severity of alcohol dependence, other drugs, and social-family problems) and the characteristics related to the TP of the CAPSad (treatment model, full participation in the activities, and individual care with a psychiatrist). The selected variables that maintained their significance and entered the final model were: presence of comorbidity ($p = 0.009$), severity of alcohol dependence ($p = 0.033$), and individual care with a psychiatrist ($p = 0.021$). Among these factors, being seen by a psychiatrist was no longer significant (OR = 1.47 [0.41-5.32], $p = 0.549$), whereas presence of psychiatric comorbidity (OR = 4.78 [1.06-21.14], $p = 0.041$) and severity of alcohol dependence remained significant (OR = 1.10 [1.01-1.20], $p = 0.024$).

Discussion

Results showed that the presence of comorbidity was an abstinence predictor. This finding may indicate that SD is secondary to psychiatric disorders and that the continued use of psychotropic medications - which was frequent in our sample (80%) - stabilizes the symptoms of underlying disease and thus contributes to achieving and maintaining abstinence. Previous studies have also found that when comorbidities are properly treated, alcohol or other drugs abuse tend to be controlled (Schuckit, 2006). In addition, the extent of abstinence often involves the remission of the psychiatric disorder (Lejoyeux & Lehert, 2011). Furthermore, another study has demonstrated that the presence of comorbidities is associated with worse prognosis (Drake, O'Neal, & Wallach, 2008). The findings of this study indicated that being treated at a CAPSad promotes the achievement of positive results in substance abusers with psychiatric comorbidity.

The significant association between maintenance of treatment and presence of comorbidity in substance addicted individuals has been identified in a previous study. The authors included alcoholics treated in a service for SD that had a multidisciplinary team treating SD and psychiatric comorbidity at the same time. They found that had evaluated the therapeutic setting had appropriate complexity to meet the needs of individuals with this clinical picture, and thus contributed to improve their prognosis (Ribeiro et al, 2008, 2009). Therefore, the results of the present study support this consideration, bearing in mind that the association was identified with abstinence and not only with higher frequency or maintenance of treatment.

Lower severity of alcohol dependence was identified as a predictor of abstinence. Thus, this finding is in agreement with a previous study that evaluated the efficacy of a psychosocial intervention using the EuropASI (Garcia-Fernandez et al, 2011).

The demographic characteristics of our sample were similar to those of previous studies. The prevalence of males is consistent with that expected in studies involving clinical samples, whose sex ratio is 4.5:1 male/female, as well as the percentage of men seeking treatment at CAPSad (Monteiro et al, 2011; Peixoto et al, 2010). We also found prevalence of low educational level, unemployment, and not having a partner. These characteristics were similar to the sample of the study mentioned above (Peixoto et al, 2010). However, these variables were not associated with abstinence. This result was also demonstrated in a European study that did not identify a significant association between sociodemographic variables and abstinence in individuals treated for SD (Garcia-Fernandez et al, 2011).

The high frequency of alcohol dependence identified in the present study was also observed in the sample of studies conducted in other CAPSad (Monteiro et al, 2011; Peixoto et al, 2010). However, the type of substance used did not show significance, which indicates that this characteristic -alcohol dependence - is one of characteristics of the individuals who attend the CAPSad and remain in treatment, and this characteristic is not related to better outcomes. It is possible that the prevalence of this disorder in individuals being treated in this model of service is a reflection of the data of population surveys, which suggest that alcohol is the most used substance and with the largest number of dependent individuals (Carlini et al, 2007).

Most individuals of our sample (65%) were included in the study group that remained abstinent, indicating that treatment at CAPSad achieved good results when compared with different psychosocial interventions, which showed abstinence rates in about a third of the individuals treated (Dutra et al, 2008). However, these data should be analyzes with caution because the inclusion criteria of our study, such as: being treated for at least 6 months, having completed the initial assessment and medical evaluation, in addition to agreeing to participate and attending the interview, we included individuals who had better health status. Therefore, randomized trials are needed to confirm this finding.

The current policies regarding the care of individuals with abuse of alcohol and other drugs do not consider the extent of abstinence as the primary goal of treatment. However, these policies emphasize the participation of individuals in the treatment (Brasil, 2004a, 2004b, 2008) and the present sample attributed high importance to the achievement and maintenance of abstinence. Thus offering this group of subjects a treatment focused on reducing consumption would be inconsistent, considering that these individuals really want to achieve abstinence. This goal is evident, because substance dependent individuals, who keep using the drug they are addicted to, will hardly be able to control their impulsiveness of use, given that this is an inherent characteristic of SD (NIDA, 2010) Therefore, it is necessary that public policies cover the severity of the disorders related to the substance use, focusing on the need and motivation of those seeking treatment.

The present study has some limitations such as small sample size, retrospective design, and the fact that it does not have an initial assessment using the ASI6 for comparisons. Another limitation is the lack of evaluation and control of the confounding variables (e.g., individual motivation, encouragement from family and care team). However, often attending the visits indicates the individual's motivation. Nevertheless, to the best of our knowledge, this is the first study conducted at CAPSad assessing results and, at the same time, using a multidimensional assessment instrument (ASI6) at CAPSad.

Based on the results, it is possible to conclude that further studies assessing abstinence predictors at CAPSad and the effectiveness of this health services in the care of SD prospectively are needed. However, the Brazilian version of the ASI is not available yet. In the present study, the severity scores on the ASI6 were associated with the outcome. This finding suggests that assessment tools should be continuously used in research and clinical practice to help treat addicted individuals.

Currently, the adoption of CAPSad as a strategic service has been promoted. However, the use of this device alone does not meet the complex demands involving the substance use. Thus, it is necessary to consider other treatment models, such as specialized outpatient clinics, Primary Care Units, Family Health Strategies, or non-governmental institutions (therapeutic communities, Alcoholics Anonymous, Narcotics Anonymous), for individuals with single diagnosis of SD (Diehl et al, 2011).

References:

Ahmadi, J., Kampman, K., & Dackis, C. (2006). Outcome predictors in cocaine dependence treatment trials. *American Journal on Addictions,* 15(6):434-9.

Alves, V.S. (2009) Modelos de atenção à saúde de usuários de álcool e outras drogas: discursos políticos, saberes e práticas. *Cadernos de Saúde Pública*, 25(11):2309-19.

Brasil. (2004a). Ministério da saúde. Secretaria Executiva. Secretaria de Atenção à Saúde. Coordenação Nacional DST/Aids. *A Política do Ministério da Saúde para atenção integral a usuários de álcool e outras drogas*. (2nd ed.). Brasília: Author.

Brasil. (2004b). Ministério da saúde. Secretaria de Atenção à Saúde. Departamento de Ações Programáticas Estratégicas. *Saúde mental no SUS: os Centros de Atenção Psicossocial*. Brasília: Author.

Brasil.(2008). Lei n. 11.343 de 23 de agosto de 2006 : institui o Sistema Nacional de Políticas Públicas sobre Drogas 10 ed. Brasília: Câmara dos Deputados.

Brasil. Ministério da saúde. (2009). *Clínica ampliada e compartilhada*. (Série B. Textos Básicos de Saúde). Brasília: Author.

Brasil. (2011). Ministério da Saúde. *Saúde Mental em Dados 8*. Ano VI, nº 8, Informativo Eletrônico. Retrieved, 2 jun 2011, from http://bvsms.saude.gov.br/bvs/periodicos/saude_mental_dados_v8.pdf.

Cacciola, J. S., Alterman, A. I., Habing, B., & McLellan, A. T. (2011). Recent Status Scores for Version 6 of the Addiction Severity Index (ASI-6). *Addiction*, 106(9):1588-602.

Carlini, E. A., Galduróz, J. C., Noto, A. R., Carlini, C. M., Oliveira, L. G., Nappo, S. A., Moura, Y. G., & Sanchez, Z. V. D. M. (2007). II *Levantamento Domiciliar sobre o Uso de Drogas Psicotrópicas no Brasil: estudo envolvendo as 108 maiores cidades do país, 2005*. São Paulo: Páginas & Letras.

Cunha, G. T. (2005) *A construção da clínica ampliada na atenção básica*. São Paulo: Editora Hucitec.

Diehl, A., Cordeiro, D. C., & Laranjeira, R. (2011). *Dependência Química: prevenção, tratamento e políticas públicas*. Porto Alegre: Artmed.

Drake, R. E., O'Neal, E. L., & Wallach, M. A. (2008). A systematic review of psychosocial research on psychosocial interventions for people with co-occurring severe mental and substance use disorders. *Journal of Substance Abuse Treatment,* 34(1):123-38.

Dutra, L., Stathopoulou, G., Basden, S. L., Leyro, T. M., Powers, M. B., & Otto, M. W. (2008). A Meta-Analytic Review of Psychosocial Interventions for Substance Use Disorders. *American Journal of Psychiatry,*165(2):179-87.

Elbreder, M. F., Silva, S. R., Pillon, S. C., & Laranjeira, R. (2011). Alcohol dependence: analysis of factors associated with retention of patients in outpatient treatment. *Alcohol and Alcoholism,* 46(1):74-6.

Garcia, M. L. T., & Macieira, M. S. (2003). Adesão ao tratamento entre alcoolistas. *Arquivos brasileiros de psiquiatria, neurologia e medicina legal,*(83-84):13-8.

Garcia-Fernandez, G., Secades-Villa, R., Garcia-Rodriguez, O., Alvarez-Lopez, H., Sanchez-Hervas, E., Fernandez-Hermida, J. R., & Fernández-Artamendi, S. (2011). Individual characteristics and response to contingency management treatment for cocaine addiction. *Psicothema*, 23(1):114-8.

Gastal, F. L., Leite, S. O., Fernandes, F. N., Borba, A. T., Kitamura, C. M., Binz, M. A. R., & Amaral, M. T. (2007). Reforma psiquiátrica no Rio Grande do Sul: uma análise histórica, econômica e do impacto da legislação de 1992. *Revista de Psiquiatria do Rio Grande do Sul*, 29(1):119-29.

Gentil, V. (2011). Principles that should guide mental health policies in low-and middle-income countries (LMICs): lessons from the Brazilian experiment. *Revista Brasileira de Psiquiatria*, 33(1):2-3.

Haraguchi, A., Ogai, Y., Senoo, E., Saito S., Suzuki, Y., Yoshino, A., Ino, A., Yanbe, K., Hasegawa, M., Murakami, M., Murayama, M., Ishikawa, T., Higuchi, S., & Ikeda, K. (2009). Verification of the addiction severity index Japanese version (ASI-J) as a treatment-customization, prediction, and comparison tool for alcohol-dependent individuals. *International Journal of Environmental Research and Public Health*, 6(8):2205-25.

IRHA - International Harm Reduction Association. (2010). *The global state of harm reduction 2010:key issues for broadening the response.* London: Author.

Kelly, J. F., Stout, R., Zywiak, W., & Schneider, R. (2006). A 3-year study of addiction mutual-help group participation following intensive outpatient treatment. *Alcoholism:Clinical & Experimental Researchm,* 30(8):1381-92.

Kessler, F., Cacciola, J., Faller, S., Souza-Formigoni, M. L., Cruz, M., Brasiliano, S., & Pechansky F. (2007). Adaptação transcultural multicêntrica da sexta versão da Escala de Gravidade de Dependência (ASI6) para o Brasil. *Revista de Psiquiatria do Rio Grande do Sul*, 29:335-6.

Kessler, F., Faller, S., Souza-Formigoni, M. L. O., Cruz, M. S., Brasiliano, S., Stolf, A. R., & Pechansky F. (2010). Avaliação multidimensional do usuário de drogas e a Escala de Gravidade de Dependência. *Revista de Psiquiatria do Rio Grande do Sul*, 32(2):48-56.

Kessler, F., & Pechansky, P. (2006a).*Vídeo de aplicação da Sexta Versão da Escala de Gravidade de Dependência - ASI 6*. Porto Alegre: Secretaria Nacional Antidrogas.

Kessler, F., & Pechansky, P. (2006b). Manual *de aplicação da Sexta Versão da Escala de Gravidade de Dependência – ASI6*. Brasília: Secretaria Nacional Antidrogas.

Laudet, A. B., Becker, J. B., & White, W. L. (2009). Don't wanna go through that madness no more: quality of life satisfaction as predictor of sustained remission from illicit drug misuse. *Substance Use & Misuse Subst Use Misuse,* 44(2):227-52.

Lejoyeux, M., & Lehert, P. (2011). Alcohol-use disorders and depression: results from individual patient data meta-analysis of the acamprosate-controlled studies. *Alcohol and Alcoholism,*46(1):61-7.

Mângia, E. F., & Barros, J. O. (2009). Projetos Terapêuticos e serviços de saúde mental: caminhos para a construção de novas tecnologias de cuidado. *Revista de Terapia Ocupacional da Universidade de São Paulo,* 20(2):85-91.

Mângia, E. F., & Muramoto, M. (2006). Integralidade e construção de novas profissionalidades no contexto dos serviços substitutivos de saúde mental. *Revista de Terapia Ocupacional da Universidade de São Paulo,* 17(3):115-22.

Marinho, M. B. (2005). O demônio nos paraísos artificiais: considerações sobre as políticas de comunicação para a saúde relacionadas ao consumo de drogas. *Interface- Comunicação, Saúde, Educação,* 9(17):343-54.

McLellan, A. T., Cacciola, J. C., Alterman, A. I., Rikoon, S. H., & Carise C. (2006). The Addiction Severity Index at 25: Origins, Contributions and Transitions. *American Journal on Addictions*, 15(2):113-24.

Monteiro, C. F. S., Fé, L. C. M., Moreira, M. A. C., Albuquerque, I. E. M., Silva, M. G., & Passamani, M. C. (2011). Perfil sociodemográfico e adesão ao tratamento de dependentes de álcool em CAPS-AD do Piauí. *Escola Anna Nery Revista de Enfermagem*, 15(1):90-5.

Murphy, D. A., Hser, Y. I., Huang, D., Brecht, M. L., & Herbeck, D.M. (2010). Self-report of longitudinal substance use: a comparison of the UCLA natural history interview and the Addiction Severity Index. *Journal of Drug Issues*, 40(2):495-516.

NIDA - National Institute on Drug Abuse. (2009). *Principles of drug addiction treatment: a research-based guide.* 2nd ed. Bethesda (Maryland): Author.

NIDA - National Institute on Drug Abuse. (2010). Comorbidity: addiction and other mental illnesses. Research Report Series. Retrieved, 08 Aug 2011, from http://www.nida.nih.gov/ResearchReports/comorbidity/treatment.html.

Peixoto, C., Prado, C. H. O., Rodrigues, C. P., Cheda, J. N. D., Mota, L. B. T., Veras, A. B. (2010). Impacto do perfil clínico e sociodemográfico na adesão ao tratamento de pacientes de um Centro de Atenção Psicossocial a usuários de Álcool e Drogas (CAPSad). *Jornal Brasileiro de Psiquiatria,* 59:317-21.

Ribeiro, M. S., Ribeiro, L. C., Garcia, M. A., Souza, G. F., Sousa, K. D. C., & Nogueira RB. (2008). Fatores associados à adesão a um programa de tratamento de alcoolistas. *Jornal Brasileiro de Psiquiatria,* 57(3):203-11.

Ribeiro, M. S., Ribeiro, L. C., Souza, G. F., Antunes, M. G., Nogueira, R. B., & Sousa, K. D. C. (2009). Aplicabilidade da classificação de alcoolismo tipo A/tipo B. *Jornal Brasileiro de Psiquiatria,* 58:17-25.

Schuckit, M. A. (2006). Comorbidity between substance use disorders and psychiatric conditions. *Addiction*, 101Suppl. 1:76-88.

UNODC - United Nations Office on Drugs and Crime. (2009). *World Drug Report 2009*. Austria: Author.

End of Volume 16, Number 1

IJPR Volume 16, Number 2
July 2011 - June 2012

Feature Articles

Feature Articles

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 2
July 2011– June 2012

The International Journal of Psychosocial Rehabilitation

The Impact of Forensic Peer Support Specialists on Risk Reduction and Discharge Readiness in a Psychiatric Facility

A Five-Year Perspective

Robert Short, MA

Karen Woods-Nyce, LISW, CCFC

Susan L. Cross, MSEd, PC

Mark A. Hurst, MD

Lisa Gordish, PsyD

James Raia, PhD

Twin Valley Behavioral Healthcare, Columbus, Ohio
A regional psychiatric hospital of the Ohio Department of Mental Health for approximately 200 civil, forensic, and maximum-security forensic consumers.

Citation:
Short R, Woods-Nyce K, Cross SL, Hurst M, Gordish L, Raia J (2012).The Impact of Forensic Peer Support Specialists on Risk Reduction and Discharge Readiness in a Psychiatric Facility A Five-Year Perspective. ***International Journal of Psychosocial Rehabilitation. Vol 16(2) 3-10***

Correspondence to:James Raia, Ph.D., Psychology Director
Research and Education Committee Chair
Twin Valley Behavioral Healthcare
2200 West Broad Street, Columbus, Ohio, 43223, USA.
E-Mail: James.Raia@mh.ohio.gov

Abstract

This article describes the successful five-year employment of specialized forensic peer supports in a state regional psychiatric hospital, with a focus on the hospital's unique forensic community re-integration program, "The Community Living, Education and Recovery Program (CLEAR).” The hospital, Twin Valley Behavioral Healthcare (TVBH), located in Columbus, Ohio is an Ohio Department of Mental Health (ODMH) psychiatric treatment facility for approximately 200 civil, forensic, and maximum-security consumers. Although the TVBH peer supporters interact with both forensic and non-forensic TVBH consumers, this article focuses on their unique, risk management services with TVBH forensic consumers, who encounter complex legal issues and community placement challenges as they near conditional release and discharge.

Key Words: Mental Health, Peer Support Services, Inpatient Mental Health Care, Psychosocial Rehabilitation, Psychiatric Care, Inpatient Mental Health Treatment, Specialized Mental Forensic Services

Overview

One of the key recommendations in the 2003 President’s New Freedom Commission on Mental Health report, “Achieving the Promise: Transforming Mental Health Care in America”, is “to involve consumers and families fully in orienting the mental health system toward recovery” (Hogan, 2003).

Since the publication of the Commission’s report in 2003, mental health care has witnessed a wide increase in effective programs to involve consumers in the recovery process as “peer supports” to work with persons having serious mental illness, including those with forensic and criminal justice system involvement. The working definition of a “peer support” identifies a consumer who is recovering from mental illness and providing support to other consumers who can benefit from their life experiences. Peer support differs from other types of support in that the experience of “having been there” and having made progress in one’s own personal recovery comprises a major part of the support and guidance provided. Peer support consumers include non-professionals, paraprofessionals, and licensed professionals, depending upon their educational levels and credentials. Research has shown that peer support programs are cost effective and advance the treatment culture and therapeutic outcomes (Minyard, 2006). Health and Human Services Secretary, Katherine Sebelius, has been encouraged by Members of the U.S. Congress to include trauma survivor and mental health consumer leadership in publicly funded programs (Sebelius, 2010).

Recovery-oriented peer supports are provided employment with treating facilities by consulting with consumer-run agencies, or they volunteer or work independently as providers in a variety of psychosocial rehabilitative and residential settings, including mental health facilities. Consumers who work as peer supports are able to expand the quality, range and availability of services which professionals may not be able to offer (Dihoff, 2009).

Thirty states have developed criteria for the training and deployment of “peer specialists,” and at least 13 states have initiated a Medicaid waiver option that provides reimbursement for specialized peer-delivered mental health services. One area of “peer specialists” is “forensic peer supports” which involves support from peers with histories of mental illness as well as forensic or criminal justice involvement. This type of forensic peer support provides treatment interventions to meet the needs of people with mental illness who are involved in the justice system; this treatment includes an understanding of the impact of forensic mental hospitalization and/or incarceration on the recovery process. Understanding, recognizing and treating trauma and posttraumatic stress disorders, prevalent among this population, is additionally critical to the specialized services of the forensic peer supporters (Davidson & Rowe, 2008).

The authors of the current article describe the successful five-year employment of specialized forensic peer supporters in a state regional psychiatric hospital, with a focus on the hospital’s unique forensic community re-integration program, “The Community Living, Education and Recovery Program (CLEAR).” The hospital, Twin Valley Behavioral Healthcare (TVBH), located in Columbus, Ohio, is a treatment facility for approximately 200 civil, forensic, and maximum-security forensic consumers of the Ohio Department of Mental Health (ODMH). Although the TVBH peer supporters interact with both forensic and non-forensic TVBH consumers, this article focuses on their unique risk management services with TVBH forensic consumers, who encounter complex legal issues and community placement challenges as they near conditional release and discharge.

Forensic Peer Support Services

The CLEAR program services are provided on a uniquely managed TVBH unit, designed to facilitate the earliest possible discharge and appropriate residential placement for forensic residents while simultaneously identifying and managing risk factors. CLEAR services are individually planned for all forensic consumers who are working towards a conditional release, or are nearing discharge with an expired forensic commitment status. CLEAR consumer forensic statuses include Incompetent-to-Stand Trial, Unrestorable-to-Competency, Not-Guilty-by-Reason-of-Insanity (NGRI), and NGRI-on- Conditional Release. The CLEAR program provides these consumers with an opportunity to live in a more independent hospital living arrangement compared to the other hospital units. In addition to ongoing medical and mental treatment, CLEAR consumers have the opportunity to engage in work programs within the hospital, hold community jobs, participate in weekday community educational and leisure activities, and weekend supervised community events.

The CLEAR forensic residents participate in a quarterly “Consumer Care Satisfaction Survey” to assess and assure that their personal needs and treatment goals are being fulfilled to their satisfaction. Each CLEAR consumer is additionally assigned a TVBH professional staff member as a “mentor” to facilitate the quality of their care, and to assist in the continuity of their services and their preparation for discharge. This Survey helps consumers identify and relate their individual special needs to all staff. Copies of the CLEAR program, and the Consumer Care Satisfaction Survey, are available in PDF upon request; request contact is Lori.Bowsher@mh.ohio.gov.

The TVBH forensic peer supporters consist of former, forensic consumers within the TVBH treatment system; therefore, they have “first hand” experience dealing with the specific challenges of managing forensic risks in the hospital and, upon discharge, in a Columbus, Ohio residential placement. The peer supporters are staff who were hired for their demonstrated competency skills in the area of providing peer services; the TVBH clinical and administrative managers provide peer staff supervision.

The forensic peer supporter’s work to help each forensic resident manage risk is paramount for each consumer’s mental stabilization, completion of the CLEAR program, and for the most expedient discharge. A forensic consumer’s continuous recovery in the community with a lasting residential placement, and without future criminal activities, or legal involvement, or re-hospitalization, is dependent upon his or her risk management abilities. Peer supporters can provide residents with durable forensic risk management skills. Preparing community placement for forensic consumers upon discharge is often difficult as providers of residences such as group homes, supervised apartments or independent apartments are characteristically prejudiced or fearful of tenants with a past mental-criminal history. Therefore, careful attention to minimizing risk factors for recidivism, including maximizing treatment adherence, is operative to securing each TVBH consumer a successful community placement.

Forensic Peer Support Function and Roles

Peer supporters have defined office space in the consumer care areas. They greet all hospital admissions with a description of TVBH’s peer support services and attend consumer treatment planning meetings to assist in the development of each consumer’s personalized recovery objectives and goals. After the treatment plan is completed, peer supporters meet individually with the consumers to guide them in the achievement of the treatment plan’s recovery targets. Peer supporters often can answer questions and process issues that residents may not feel comfortable discussing with a professional staff or with their mentor or in a group treatment meeting. Peer supporters also assist consumers, who may have reading or writing problems during their completion of forms or the usage of computer formats. Peer supporters hold meetings on the consumer care units offering teaching materials on various mental health topics, physical wellness, self-empowerment, legal issues, risk containment, education and employment opportunities and community adjustment skills. Peers involve consumers in social and recreational activities. Peers coordinate their support work with the other members of the consumer’s treatment team, the consumer’s mentor and family members. The peer supporters are directly supervised by the TVBH Clients’ Rights Specialist, a full-time employee of the hospital.

Additionally, peers supporters are active members of TVBH’s standing committees, such as Research and Education, Behavior Therapy, Cultural Competence, Coercion Free, and Ethics. They are involved in the planning and execution of special activities, for example, the completion of consumer satisfaction surveys, the TVBH newsletter, the TVBH professional publications, the "Speak-up Program", the hospital health fairs and the staff-consumer respect initiatives. These activities are in keeping with the U.S. Congress' request to include "mental health consumer leadership" in publicly funded programs and services (Sebelius, 2010).

When performing the above peer functions, supporters serve as

A) Role models for risk free effective behaviors both in the hospital and upon residential placement,
B) Unique communicators between consumer and the professional staff during sensitive treatments such as trauma related care,
C) Identifiers and innovators for improved consumer care procedures within the hospital culture, and in the local, state and federal systems,
D) Mediators during complaint or grievance resolutions between consumers and family members with hospital staff or community resources,
E) Mentors and teachers for self-advocacy skills for the attainment of treatment, housing, education, employment and economic recovery goals.

Specific Forensic Risk Management Interventions

A. Role Models for Risk Free Effective Behaviors

As role models for risk free effective behaviors, peer supporters are able to relate to consumers through their own experiences when they were consumers at TVBH, and were successful to overcome various risky situations or challenges that could have put their stability in jeopardy. Treatment sessions involving peer-to-consumer role-playing, drawing on the experiences of peers, can provide consumers with effective solutions for avoiding risk in the hospital and in the community. The peer supporter can describe risky situations they have encountered, explore with the consumer what they would do or did to remain risk free, and then work with the consumer on understanding the best risk free resolutions. This type of peer-consumer role-playing enables a consumer to practice coping strategies and empowers them with hands-on behavior skills.

Peer supporters provide role modeling through interacting with consumers in a variety of situations. In addition to hospital work, they take the residents out of the hospital for outings to restaurants, stores, parks, ball games, and cultural events, where they can engage in open discussions about a variety of community life issues and problems, including how to get their needs met and how to negotiate services in the community. The peer supporters provide their perspectives of maintaining responsibility for oneself in the community as they navigate within a complicated community mental health system. Peer supporters share experiences how to use personal skills to keep community mental health treatment schedules, and thus maintain medication compliance, and how to refrain from drug and alcohol abuse when other people around them are using and abusing substances.

The peer supporters at TVBH also provide role model commentary to other consumers in training DVD they created and star in "Making a Difference through Hope and Respect." In this DVD, they detail the history of their own recovery. This DVD is played on the in-hospital TV closed circuit, which is used to educate staff and newly admitted consumers.

B. Unique Communicators between Consumers and the Professional Staff

Peer supporters can share unique communications with consumers and staff since they are able to use language or "lingo" which can be closely representative to a consumer's idiosyncratic thoughts and emotions. TVBH consumers relate they perceive their peer supporters as providing unique insights from a perspective of "real life knowledge" rather than "second hand professional training." This perception of a peer's "real life knowledge" can facilitate the consumer's acceptance and practical use of treatment advice and enable the consumer to unify cognitions and feelings seamlessly in a solidified pathway to recovery. This is especially true during sensitive therapies such as post-traumatic stress disorder treatment; for example, when a peer has suffered a similar trauma event, such as a mugging or sexual assault. These types of unique communications, such as defining a trauma in the framework of peer supporter's experience, can provide a bond between the consumer and the peer supporter that can be a crucial agent for therapeutic change.

A young TVBH consumer with a diagnosis of schizophrenia was struggling to accept this diagnosis and the explanation of his related symptoms from his treatment team members. He saw the team members as authority figures who were trying to keep him in the hospital, and thus rejected their attempts to educate him on the symptoms of his schizophrenic illness. However, this consumer's insight improved significantly after engaging with his peer supporter in an educational meeting and hearing the peer supporter's lead discussion about his own schizophrenic disorder and the symptoms he experienced. The following day, the consumer expressed to his treatment team, "I think I have a schizophrenic mental illness" and he was willing to explore the various symptoms he was having in relation to needed treatment. This example emphasizes the peer supporter's communication role as teacher and coach in the recovery process. Residents repeatedly say that when they arrived at the hospital they knew nothing or little about mental illness, and everything they learned about it came from the staff. TVBH consumers remark and emphasize that their recovery journey would not have been possible without this understanding of their mental illness, and the specific symptoms of their mental illness. When consumers understand the nature of their mental illness, they recognize the rationale for psychiatric treatment and the need for complying with psychiatric medication.

Overall, the peer supporters have the unique opportunity to be able to relate their own life story of recovery so that the TVBH consumers feel comfortable, and, in turn, to tell their own life stories. The residents feel that the peer supporters can truly understand the problems they are experiencing which make for a more open sharing of feelings. This appears to build trust and provides hope across all recovery experiences. The peer supporters are able to "meet the consumers where they are mentally and emotionally" given their own hospital experiences.

C. Identifiers and Innovators for Improved Consumer Care Procedures

Peer supporters are able to recall and assess experiences when they were consumers in terms of what "worked" or "did not work" for them. At the time when peer supporters were TVBH residents, their energies were occupied with their own treatment, thus they may not have been able to become active as identifiers and innovators for changes, which could improve mental care. When they were residents, peer supporters may have recognized the need for improvements, and discussed these with their treating sources, but at that time, their focus was inward on their own recovery. However, now employed as peer supporters, their identified mental care improvements can be addressed as one of the special goals of their work. At TVBH, peer supporters are included on organizational committees, and thus have a voice and direct input for improvements at all levels. In addition to their own ideas for change, peers supporters can survey TVBH consumers and bring the consumer's valued ideas for changes forward for institutional consideration and action. Positive results of consumer care improvements at TVBH can then be shared to activate broader systemic changes at the state and federal level. Such sharing can take place by peer supporters when they attend state and federal committees or when they participate on the academic and professional communities.

TVBH peer supporters interview residents who have had an incident of seclusion or restraint and then provide feedback to the hospital administration about the consumer's point of view and experience. Such feedback is related directly to various hospitals committees, which, in turn, enables the committee members to develop and introduce seclusion and restraint strategies to reduce traumatic experiences to the consumer and improve training for the staff.

D. Mediators during Complaint or Grievance Resolutions

Peer supporters can be mediators between consumers and treatment staff during complaint or grievance resolutions, since complaints are a sensitive or difficult topic for residents to address themselves directly with staff. Without this mediation, residents may never express dissatisfaction and staff would not have the opportunity to assess the complaints and improve hospital procedures accordingly.

Consumer dissatisfaction or complaints can be obstacles or deterrents to their recovery process. There is a tendency for residents to "live with" dissatisfaction and not to complain to professional staff since they perceive professionals as "authorities who know what they are doing." "The staff knows better than me" and "I should just be quiet and follow what is provided to me" are found to be common coping devices among residents as a means to manage dissatisfaction. In addition, TVBH consumers have expressed fears that if they complain to professionals, they believe that this could negatively affect their therapeutic relationship with the treatment staff, and affect the overall quality of their care, or prolong their discharge date, or the staff's interest in finding them the best possible community, residential placement.

On the other hand, residents express that they are less fearful and more trusting with their peer supporters in terms of disclosing their discontent and complaints. Residents relate that they believe their peer supporters are closer to them in overall identity, and thus will be empathic listeners to complaints or grievances. When peer supporters facilitate the completion of the Consumer Care Satisfaction Surveys, consumers are informed that they can document dissatisfaction on the survey to be discussed later confidentially with their peer supporter. The Consumer Care Satisfaction Survey has proven to be an effective bridge for beginning the process whereby consumers can work with peer supporters on their concerns. Since the peer supporters report to the TVBH Clients' Rights Specialist, they can bridge communication between the consumer with this clients' rights specialist who oversees all consumer complaints and grievances.

E. Mentors and Teachers for Self-Advocacy Skills

Forensic peer supporters, during the course of their own recovery, learn strategies to advocate for themselves in the community. Peer supporters recognize that self-advocacy strategies are important survival skills, which have enabled them, on their own, to obtain or utilize community resources for treatment, to secure and maintain housing, and to achieve education and employment opportunities. Upon discharge, consumers often begin to feel isolated and deserted when they do not have daily contact with treatment staff. They realize that they have to fend for themselves and draw on their own strengths to meet their physical and emotional needs. The success to which consumers can meet these physical and emotional needs post-discharge depends largely on the adequacy of their survival skills. Therefore, one of the essential functions of the peer support staff is to work as mentors and teachers for self-advocacy skills. Peer supporters can uniquely impart or teach the lessons they learn about self-advocacy to consumers utilizing their experiences in the community after their own discharge from the hospital.

By way of example, the peer supporters indicate that they help the consumers to feel empowered to speak up if they feel their rights are being violated. The TVBH peer supporters are involved in an initiative in the hospital called the “Speak Up” program. The goal of this program is to educate the residents on the various appropriate means of speaking up and discussing any concerns they have about their care or the facility. The “Speak Up” initiative begins early in the admission process when peer supporters meet with newly admitted consumers to review their client's rights. The peer supporters also attend community meetings on the direct care units, and encourage residents to speak up to the treatment staff about any concerns they may have, ranging from their treatment, to the behavior of other consumers on the unit, or to facility and safety concerns.

Since the peer supporters have administrative, working relationships with staff, they can often help solve consumer-staff problems in an expedient and collaborative manner. The peer supporters' input can help to formulate advocacy policies that are more sensitive to the consumers' needs, concerns, and worries. The peer supporters are in a unique situation of knowing the TVBH environment and “seeing” both sides (consumer vs. treating source).

Conclusion

Treatment facilities can be viewed as a care system of complex people communicating and interacting with each other across multifaceted formats. Each person in this system has the opportunity to uniquely influence each other's thinking, behaving, performing and ability to change or improve. Medical and administrative staff has traditionally dominated the information exchange in most treatment systems. By contrast, the formal introduction and addition of peer support services into the care processes at TVBH has significantly enhanced its therapeutic options and cultural attributes. TVBH peer supporters and consumers can communicate and support each other in distinctive ways not available by the traditional medical and administrative personnel. TVBH recognizes the worth and respects the effectiveness of peer supporters as providers of mental health care, especially in the areas of forensic risk reduction and discharge preparedness. The addition of peer supporters at TVBH has expanded the range of services to the consumers and improved the overall quality of recovery for its residents. The presence and services of the peer supporters imply "hope" to the TVBH consumers. Hope that they do not have to live in the state hospital all their lives and hope that they can live successfully and independently in the community.

Implications for Psychiatric Rehabilitation Services

A. Peer supporters can be role models for risk free effective behaviors. They are able to relate to consumers through their own experiences when they were consumers and were successful to overcome various risky situations or challenges that could have put their stability in jeopardy. Treatment sessions involving peer-to-consumer role-playing, drawing on the experiences of peer supporters, can provide consumers with effective solutions for avoiding risk in the hospital and in the community.

B. Peer supporters can share unique communications with consumers and treatment staff since they are able to use language or “lingo” which can be closely representative to a consumer’s idiosyncratic thoughts and emotions. Consumers relate they perceive their peer supporters as providing unique insights from a perspective of “real life knowledge” rather than “second hand professional training.” This perception of a peer supporter’s “real life knowledge” can facilitate the consumer’s acceptance and practical use of treatment advice, and enable the consumer to unify cognitions and feelings seamlessly in a solidified pathway to recovery.

C. Peer supporters are able to recall and assess experiences when they were residents in terms of what “worked” or “did not work” for them during treatment at TVBH. At the time when peer supporters were residents, their energies were occupied with their own treatment, thus they may not been able to become active as identifiers and innovators for changes, which could improve care. When they were residents, peer supporters may have recognized the need for improvements, and discussed these with their treating sources, but at that time, their focus was inward on their own recovery. However, now employed as peer supporters, their identified care improvements can be addressed as one of the special goals of their work to provide feedback to the hospital administration, and to the various consumer care committees.

D. Peer supporters can be mediators between consumers and treatment staff during complaint or grievance resolutions, since complaints or grievances can be a sensitive or difficult topic for residents to address themselves directly with staff. Without this mediation, residents may never express dissatisfaction and staff would not have the opportunity to assess the consumer’s concerns and thereby improve hospital procedures related to a concern.

E. Peer supporters, during the course of their own recovery, learn strategies to advocate for themselves in the community. Peer supporters recognize that self-advocacy strategies are important survival skills, which have enabled them, on their own, to obtain or utilize community resources for treatment, to secure and maintain housing, and to achieve education and employment opportunities. Peer supporters can teach the lessons they learn about self-advocacy to other consumers, to help them feel empowered, and to speak up if they feel their rights are being violated. The peer supporters have been involved in an initiative in the hospital named the “Speak Up” program, which begins at the time of admission.

References:

Davidson, L., & Rowe, M. (2008) Peer Support within Criminal Justice Settings: The Role of Forensic Peer Specialists. The CMHS National GAINS Center. Retrieved July 1, 2011, From http://gainscenter.samhsa.gov/pdfs/integrating/Davidson_Rowe_Peersupport.pdf

Dihoff, D. (2009) Peer Support/Recovery Task Force Report, August 2009. Prepared by the Peer Support/Recovery Task Force NAMI NC. Subcommittee of the Coalition for Persons Disabled by Mental Illness. Retrieved July 1, 2011, from http://nationsnet.com/naminc/peer_support_task_force/Peer%20Support%20Report%208%200 9%20Entire.doc

Hogan, M. F. (2003) President's New Freedom Commission on Mental Health; Achieving the Promise: Transforming Mental Health Care in America. Retrieved July 1, 2011, from http://www.mentalhealthcommission.gov/reports/FinalReport/toc.html

Minyard, K. J. (2006) The Effect of Peer Support on Recidivism Rates for Mental Health Hospital Admissions and Crisis Stabilization Episodes. Georgia Health Policy Center. Retrieved July 1, 2011, from http://aysps.gsu.edu/ghpc/long_term_care/reports/Final%20Peer%20Support%20Report%209- 27-06.pdf

Sebelius, K. (2010) Public Policy Update May 13, 2010. Congress of the United States, House of Representatives, Letter to the U.S. Department of Health and Human Services, Retrieved July 1, 2011, from http://www.thenationalcouncil.org/cs/public_policy_update_newsletter/may_13_2010

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 2
July 2011– June 2012

Study on the association between severity/recovery of depression and severity/recovery of gross motor retardation

J Knapen. 1, 2

E Coppens 1

D Vancampfort 1, 2

P Minquet 1, 2

A Schueuremans 2

A De Herdt 1

M Probst 1, 2

Faculty of Kinesiology and Rehabilitation Sciences

1. Katholieke Universiteit Leuven, Tervuursevest 101, 3001 Leuven, Belgium
2. University Psychiatric Centre K.U.Leuven, Campus Kortenberg, Leuvensesteenweg 517, 3070 Kortenberg, Belgium

Citation:
Knapen, J., Coppens, E., Vancampfort, D., Minguet, P., Schueuremans, A., De Herdt, A., Probst, M. (2012). Study onthe Perceived Exertion during a Graded Exercise Test in Patients with Depressive and Anxiety Disorders International Journal of Psychosocial Rehabilitation. Vol 16(2) 11-19

Corresponding author:
Jan Knapen
University Psychiatric Centre K.U.Leuven, Campus Kortenberg
Leuvensesteenweg 517
3070 Kortenberg,
Belgium
Mail: jan.knapen@faber.kuleuven.be

Acknowledgements:
The authors thank the patients who participated in the study and staff members of the University Psychiatric Centre Katholieke Universiteit Leuven, Campus Sint-Jozef Kortenberg for their help during data collection.

Abstract

Purpose: To examine the associations between severity/improvement of depression and severity/changes of psychomotor retardation (PR). Previous research on these topics was mainly conducted within the cognitive or fine motor domain of PR. This study focuses on the gross motor retardation.
Method: Twenty-three hospitalized patients performed a six-minute walk test, a plate tapping test and a cycle ergometer test. Total walking distance (TWD), average amount of steps per 50 meter (SFM), time to complete the plate tapping test (PT) and average cycle speed (ACS) were measured. Average walking speed (AWS) was calculated from TWD, average stride length (ASL) estimated from SFM. Severity of depression (IDS) was assessed with the self-rated Inventory of Depressive Symptomatology (IDS-SR). After a treatment period of 8 weeks all tests were repeated as well as the IDS measurement. Differences between T1 and T2 results were calculated.
Results: IDS, AWS, ACS, PT improved but not ASL. Only AWS and PT scores were significantly correlated with IDS. No relationships were found between improvement in depression and gross motor parameters.
Conclusions: The relationship between recovery of depression and PR does not seem transferable to the gross motor domain of PR (walking, cycling and arm movement). More homogeneous samples are needed in further research.

Introduction

Psychomotor retardation (PR) is an important feature of depression (1). Through the literature, PR is defined as ‘motor slowing’, ‘psychomotor slowing’, ‘psychomotor impairment’, ‘psychomotor disturbance’, ‘motor retardation’, or just ‘slowing’. A description of what exactly these terms imply, is in most articles not given. Some reviews tried to summarize all characteristics of PR (1 - 5), but a clear definition is still absent. The Diagnostic and Statistical Manual for Mental Disorders, 4th edition, text revision (DSM-IV-TR) defines PR in its glossary as ‘a visible generalized slowing of movements and speech’ (6).

Psychomotor retardation in depressed patients is considered to be the result of two types of slowing: cognitive and motor (7). Most studies on PR focussed on fine motor movements like drawing or finger-tapping, therefore, how exactly PR manifests itself in gross motor activities like walking, cycling or gross movements of the upper limbs, is less known. The few studies that have investigated gait/walking in depressed patients revealed that compared to controls, depressed patients show a specific, slowed ‘Parkinsonian-like’ (8) gait. Bader and colleagues (9) examined various gait characteristics in 20 moderately to severely depressed inpatients. The results were compared with those of 20 matched healthy controls. The depressed group differed significantly from the control group in terms of step length (shorter) and average walking speed (slower) during a 3-minute walking test. Hergueta and colleagues (10) performed quantitative video-analyses of gait in 26 depressed inpatients and 26 healthy controls. They observed lower heel propulsion velocity and shorter stride length in the depressed group compared to the healthy control group. In another study (11) spatiotemporal gait parameters were measured during over ground walking at self-selected walking speed. Compared to controls, 16 depressed patients showed significantly lower gait velocity, reduced stride length, double limb support and cycle duration. Other studies showed similar results (4, 12). Depressed patients tend to move their upper limbs less frequent and more slowly in comparison with healthy persons. Not many studies were performed on this subject, and they were all observational studies. To the authors’ knowledge, cycling has even never been investigated in the context of PR in depressed patients.

For diagnostic purpose, a fundamental question regarding PR is in which subtype of depression this symptom occurs and in which it doesn’t. Studies showed that the manifestation of PR is highly unlikely in non-melancholic depression and highly probable in the melancholic subtype (1, 4). Research demonstrated that bipolar depressed patients are very likely to have the melancholic subtype with the according psychomotor retardation (13). Moreover, several authors have suggested that PR may represent a marker for bipolarity in patients with MDD (14). Thus, PR is considered a main feature of melancholia. Nonetheless, not all melancholic depressed patients have PR, and sometimes PR has been found present in patients with another subtype of depression (4). This can be partly explained by another possible determinant for the presence of PR within the clinical state of depressed patients, the severity of depression. Schotte and colleagues introduced in 1997 an integrated threshold model (15). According to this model, melancholic symptoms and PR appear above a certain severity of depression. Several other studies have demonstrated that the presence of PR is associated with severity of depression (1, 4).

Not only presence, but also degree of PR and depression severity are thought to be related (1). Most research results on this association were obtained by the use of cognitive or fine motor tasks. In a review concerning visuomotor tasks (16) the authors pointed out the possibility that melancholic depressed patients were slower because they were more depressed. Visuomotor tasks such as copying tasks, the Digit Symbol Substitution Test and the Fitts' task are frequently used in PR research examining this association. They combine both fine motor (movement time, velocity) and cognitive measures (reaction time). Reaction time and velocity (2, 7) were found to be related to severity of depression. The Salpêtrière Retardation Rating Scale (SRRS), a symptom severity scale specific to psychomotor retardation, includes items related to motility, speech and cognition (18). Research showed positive correlations between this scale and depression severity (1). As regard the gross motor aspect, one study (19) found that more severely depressed patients were more likely to be less active during 24h.

Related to the association severity of depression/degree of PR, is the question whether recovery of depression (total or partial) is associated with improvement in psychomotor slowing, or whether PR is an indicator of treatment response in depressed patients. Schrijvers and colleagues (4) summarized previous research results on this topic, concluding that treatment with antidepressants during 3 to 12 weeks resulted in total or partial improvement of psychomotor functioning, mostly due to clinical recovery. A more recent review (5) made similar conclusions. The above-mentioned disbalance between cognitive and motor research and between fine motor research and gross motor research continues to apply within this research topic. In cognitive/fine motor research partial or total recovery of depression was found to be related to recovery of slowed movement time during drawing tasks (20). There is no consensus regarding reaction time (21, 22). However fewer studies were conducted, stronger evidence on this association was found in research focussing on the gross motor domain. In the study of Bader and colleagues (9) patients improved in terms of stride length, maximal walking distance and maximal walking speed after 3 weeks of inpatient treatment and significant symptomatic improvement. In the study of Hergueta and colleagues (10), heel propulsion velocity returned to normal when patients with depression were discharged after 3 weeks of inpatient treatment, however length of stride remained shorter. The study of Lecrubier (8) showed that stride length only significantly improved after 3 months of venlafaxine treatment, where heel propulsion velocity already improved after 2 or 3 weeks. The combined data of these studies reveal the possibility that not all psychomotor retardation improves at the same rate.

The aims of the present study were to examine the association between severity of depression and severity of PR, and secondly between (partial) recovery of depression and changes in PR, hereby focussing exclusively on the gross motor aspect. Gross motor disturbance was assessed by average speed of walking and step length during a 6-minute walk test, arm movement speed during the plate tapping test and average cycle speed during a 10-minute submaximal test on a bicycle ergometer. To the authors' knowledge, the present study is the first to evaluate the association between PR and severity/recovery of depression through cycle speed and speed of upper limbs. As previous mentioned, speed of walking and step length has been the subject of such research before, but these parameters were never measured with the 6-minute walk test (although the 3-minute walk test in the study of Bader was very similar to the 6-minute version). Based on the above-mentioned research results, we hypothesized that severity of depression is positively associated with degree of gross motor disturbance and secondly that (partial) recovery of depression is positively associated with improvement in gross motor functioning. In order to answer these research questions, an 8-week longitudinal study design was set up.

Method

Subjects

The depressed patients were recruited from December 2010 until March 2011 from two different treatment units of the University Psychiatric Centre Katholieke Universiteit Leuven, Campus Sint-Jozef Kortenberg in Belgium. All patients who were diagnosed by trained psychiatrists according to the DSM-IV-TR (23) with depressive disorder, bipolar I or II disorder (in the depressed phase), adjustment disorder with depressed mood or adjustment disorder with mixed anxiety and depressed mood and who had observed PR were asked to take part in the study. Patients were excluded if they were agitated or if they had clinically significant co-morbidities likely to affect motor functioning and test performance/results including severe orthopaedic problems, severe cardiopulmonary diseases, neurological diseases, schizophrenia and chronic fatigue syndrome. Patients who were treated with electroconvulsive therapy were also excluded because this treatment has a greater effect on PR than drug therapy (1). All included patients received a similar multi-dimensional treatment consisting of 3 or 4 psychomotor therapy sessions per week, different forms of psychotherapy and occupational therapy and drug therapy. At time of their inclusion, all patients were using different types of antidepressants: tricyclic antidepressants (TCA's, n=16), selective serotonin reuptake inhibitors (SSRI's, n=6), monoamine oxidase inhibitor (MAO, n=1) and lithium (n=1). Twenty patients were treated with with a combination of antidepressant wth antipsychotics and benzodiazepines. This medication was changed as little as possible during the testing period. If major changes in medication use occurred during the test period, those patients were excluded from further testing.

Instruments and procedures

In this 8-week longitudinal study, patients were tested twice. T1 refers to the first testing moment; T2 refers to the second series of tests after 8 weeks treatment. During each test moment, patients carried out 3 tasks containing gross motor movements: the Six-Minute Walk Test (6MWT), a 10-minute submaximal test on a bicycle ergometer (CET) and the plate tapping test (PT). They also filled in the self-rated Inventory of Depressive Symptomatology (IDS-SR) so the severity of their depression could be determined.

Six-Minute Walk Test

The 6MWT is a well described functional exercise capacity test. This test is used in different rehabilitation settings, mostly to evaluate patients with cardiopulmonary disorders. To conduct the 6MWT in a standardized manner, a practical guideline concerning indications, factors that influence results, interpretation of results and a step-by-step protocol has been set up by the American Thoracic Society (24). For the present study, patients were told to walk a distance as large as possible in 6 minutes. They had to walk up and down a hallway over 25 meters. Total walking distance (TWD, in meters) and the average amount of steps per fifty meters (SFM) were measured. From TWD, average walking speed (AWS, in km/h) could easily be calculated and logged per patient. The average amount of steps per fifty meters is associated with the average step length (ASL). When a patient takes sixty steps over fifty meters, we can say he takes bigger steps then when he would have taken 70 steps over fifty meters. For safety reasons, heart rate and blood pressure were measured just before and after the test (blood pressure meter type OMRON). Before the test, all examinees had to fill in a questionnaire concerning orthopaedic problems that could interfere with their performance.

The bicycle ergometer test

The CET was performed on an electronically braked bicycle ergometer (Ergo 2000, Ergo-Fit, The Netherlands). All patients were told to cycle 10 minutes at a self-selected intensity, meaning they were free to choose the workload and cycle speed, as long as it felt comfortable and they would not exert themselves. During the test 4 parameters were obtained: average workload (AW, in Watt), average cycle speed (ACS, in rotations/min). Also the saddle height was measured. For safety reasons, all patients' heart rates were constantly monitored.

Plate Tapping Test

Plate Tapping is a test to assess speed and coordination of upper limb movement. This test is part of the Eurofit Physical Fitness Test Battery (25), originally devised by the Council of Europe for children of school age. In 1995 a similar test battery was published for adults (26). Two discs were placed on a table with their centres 60 cm apart. Examinees were asked to place their non-dominant hand on a rectangle that is placed equidistant between both discs.

They had to move their dominant hand back and forth between the discs over the hand in the middle. This was repeated for 25 full cycles (50 taps). Patients were asked to perform the test as quickly as possible. To control for learning bias, the test was performed twice with an interval of 1 minute. Only the faster of the two scores (in seconds) was used for statistical analysis.

Severity of depression

Severity of depression was assessed by the Inventory of Depressive Symptomatology Self Report (IDS-SR) total score (27, 28). IDS-SR is a widely used 30-item questionnaire, developed by Rush in 1985, that has to be filled in by the patient. The total score of the questionnaire can vary between 0 and 84. A score between 0 and 13 should be interpreted as not depressed, between 14 and 25 as mildly depressed, between 26 and 38 as moderate, between 39 and 48 as severe, between 49 and 84 as very severe. Patients filled in the Dutch translation of this questionnaire right before the CET. The questionnaire has been shown adequately reliable and valid to rate the severity of depression in patients with mood disorders (27, 28).

Test 2

During T2, patients had to fill in the IDS-SR again and the 6MWT test and PT were performed in the same way as T1. However, during CET2, the patients were asked to cycle at approximately the same workload they had chosen themselves during T1. A deviation of 2 Watt was accepted. In this way, both test performances could be easily compared. Besides this adjustment, CET2 was performed in standardized conditions: on the same bicycle, with the saddle at the same height as it was during T1. Because PR can fluctuate during the day (3), patients performed the second tests at approximately the same hour of day as the first tests. In between the two test periods, patients continued to follow their treatment program as described above.

Statistical analysis

Statistical analysis was performed using Statistica 9 (29). A two-tailed t-test for dependent samples was used to determine if T1 results differ significantly from T2 results. The relationship between severity of depression (IDS scores) and PR (results on the gross motor functioning tests) and between recovery of depression (ΔIDS) and changes in PR was examined by calculating the Pearson product-moment correlation coefficients. For all analyses, a p-value < 0 .05 was adopted as the level of significance.

Results

Subject characteristics

Initially 30 patients took part in the study. Seven of them dropped out due to early discharge from the hospital (n=5) or because they were not willing to take part in the study any longer (n=2). Eventually, 23 patients completed test2. Three patients were not able to perform the 6MW at T2 because of overuse injuries at the foot. All subjects were adults with a mean age of 40.5 (SD 12.8) years and a mean body mass index of 26.9 (SD 4.6). Fourteen of the subjects were diagnosed with depressive disorder, two had bipolar I disorder (in the depressed phase) and seven suffered from adjustment disorder with mixed anxiety and depressed mood.

Changes in severity of depression and gross motor functioning after 8 weeks treatment

Performances on gross motor functioning tests and the IDS-SR scores at the time of T1 and T2, as well as differences before and after 8 weeks treatment (Δ = T2 – T1) are presented in table 1.

Depression severity

In accordance to the IDS-SR interpretation criteria, 3 patients could be categorized as mildly, 5 as moderately, 8 as severely and 7 as very severely depressed at the time of T1. The groups mean score at this time was 41.3, meaning the group as a whole was severely depressed. After 8 weeks treatment, 83% of the patients had a lower score on the questionnaire. Three patients had a higher score and one patient stayed status quo. The group mean was now 34.9, indicating the group of patients partially recovered and became moderately depressed. The group thus had an average improvement of 6.4 scale points or 15,6% improvement.

Gross motor functioning

As regards the 6MWT, patients walked more distance and thus faster during test 2, compared to T1. At the time of T1 the patient group covered a mean distance of 580.3 meters at an average walking speed of 5.8 km/h. During T2 AWD and AWS were respectively 633.2 meters and 6.3 km/h, meaning a group improvement of 52.9 meters and 0.5 km/h. The average amount of steps per fifty meters did not significantly differ between the 2 testing periods, so we can assume that the average step length did not improve.

Sixteen subjects (70%) performed better on the second plate tapping test compared to the first. On average the group significantly improved by 1.13 seconds
Of all gross motor functioning parameters, the most significant improvement was on ACS. Patients cycled 10.8 rotations/minute faster during the second test at the same work load. Only 4 patients (17%) did not improve.

Summarized, the patients improved on every gross motor parameter except for SFM after 8 weeks of treatment.

Association between severity of depression and degree of gross motor retardation

As indicated by the direction of the correlation coefficients (table 2), higher IDS-SR scores tend to relate with worse performance on the gross motor tasks. However, the relationships before treatment are weak and not significant. The strongest relationships were found after 8 weeks treatment. Moderate to good significant associations were observed between IDS2 and TWD2, AWS2 and PT2.

Association between changes in severity of depression and gross motor functioning

The correlation coefficients were not signifuicant (varied from -0.08 to -0.14), indicating that there is no association between patients' improvement on gross motor functioning and recovery of depression.

Discussion

As expected, patients became less severely depressed after 8 weeks treatment and with the exception of stride length, they improved on every gross motor parameter. Stride length of patients did significantly improve in other longitudinal studies (8, 9). The discrepancy between their finding and the result of the present study could be due to different measurement methods (25-meter walk test at self selected pace and video-analysis versus 6MWT), composition of the sample in terms of subtype of depression (see below: limitations) and different drug treatment. The patients in one study Lecrubier (8) only received venlafaxine, where patients in this study used different types of antidepressants in combination with antipsychotics and benzodiazepines. However, it is possible that stride length will improve in the weeks or months following the last measurements, because previous research suggested that stride length recovers more slowly than speed related parameters of walking (8).

Although there is a lot of evidence that severity of PR and severity of depression are related, these associations might only account for some aspects of PR. Previous research (2, 7, 16, 17) showed associations between severity of depression and degree of impairment on cognitive and fine motor parameters. In the gross motor domain only 24h activity level was studied and found to be related to severity of depression (19). Results of the present study could only find significant associations between severity of depression and degree of TWD, AWS and PT impairment.

Based on our results, the hypothesis that (partial) recovery of depression is associated with improvement in gross motor functioning could not be confirmed. Significant improvement of depression, TWD, AWS, PT and ACD were observed, but little to no relationships was found between these parameters. The lack of associations suggests that different factors are responsible for recovery of depression and improvement in gross motor retardation.

Limitations of the study

The most important limitation of the present study is the heterogeneity of the sample in terms of subgroups of depression. Presence of melancholia, comorbid anxiety and personality disorders may affect both the profile of PR and the speed and completeness of response to treatment (5). Because of the relatively small sample, we did not distinguish between melancholic and non-melancholic depression. Moreover, 7 patients were diagnosed with adjustment disorder with mixed anxiety and depressed mood. Therefore results may be difficult to interpret.

Subjects of the present study had different diagnoses but they were only included if they had clinically observed PR. This observation however was not confirmed by further standardized subjective (such as the SRRS) or objective measurements (comparison to healthy controls). Research indicate that gait and upper/lower limb movement are slowed in depressed patients compared to controls, but these findings were not based on performance on the 6MWT, the plate tapping test or a cycle ergometer test. Reference values of 6MWT and plate tapping performance do exist for a healthy Flemish population, but only for younger adults (PT) or older adults (6MWT) (31).

Another limitation is that the sample of the present study was also heterogeneous in terms of medication. Research suggests that some types of medication have a better effect on PR than others (4). Some types of medication can negatively interfere with motor functioning (7). Patients participating in this study took different types and combinations of antidepressants, antipsychotics and benzodiazepines. These types of drugs act on the nervous system and possible side-effects are sedation, fatigue and extrapyramidal symptoms (32). It would have been unethical and impossible to deprive all patients from this medication for the purpose of this study, but perhaps a more homogeneous group in terms of medication could have resulted in stronger associations between recovery of depression and recovery of PR.

Further directions

Further research is necessary to determine whether slowed limb movement in depressed patients with PR manifests itself during the 6MWT, the plate tapping test and a submaximal cycle ergometer test and to determine whether the relationship between severity of depression and severity of PR also applies to other aspects of gross motor retardation than the amount of activity during 24h. Longitudinal studies have begun to clarify the relationship between recovery of depression and changes in gross motor retardation but also on this topic more research is needed. Such research should preferably use a homogeneous sample in terms subgroup of affect disorder and medication use.

References:

1) Buyukdura JS, McClintock SM, Croarkin PE. Psychomotor retardation in depression: Biological underpinnings, measurement, and treatment. Progress in Neuro-Psychopharmacology & Biological Psychiatry 2011; 35:395-409.

(2) Caligiuri MP, Ellwanger J. Motor and cognitive aspects of motor retardation in depression. Journal of Affective Disorders 2000;57:83-93.

(3) Sobin C, Sackeim HA. Psychomotor symptoms of depression. The American Journal of Psychiatry 1997;154:4-17.

(4) Schrijvers D, Hulstijn W, Sabbe BGC. Psychomotor symptoms in depression: A diagnostic, pathophysiological and therapeutic tool. Journal of Affective Disorders 2008;109:1-20.

(5) Douglas KM, Porter RJ. Longitudinal assessment of neuropsychological function in major depression. Australian and New Zealand Journal of Psychiatry 2009;43:1105-1117.

(6) First MB, Frances A, Pincus HA. DSM-IV-TR handbook of differential diagnosis. Washington DC: American Psychiatric Publishing, Inc.; 2002. p 101.

(7) Sabbe B, Hulstijn W, van Hoof J, Tuynman-Qua HG, Zitman F. Retardation in depression: assessment by means of simple motor tasks. Journal of Affective Disorders 1999;55:39-44.

(8) Lecrubier Y. Physical components of depression and psychomotor retardation. The Journal of Clinical Psychiatry 2006;67:23-26.

(9) Bader JP, Bühler J, Endrass J, Klipstein A, Hell D. Muskelkraft und Gangcharakteristika depressiver Menschen. Der Nervenarzt 1999;70:613-619.

(10) Hergueta T, Delgado F, Lecrubier Y. Quantitative video-analysis of gait in depressed inpatients [abstract]. European Neuropsychopharmacology 1996;6:91.

(11) Lemke MR, Wendorff T, Mieth B, Buhl K, Linnemann M. Spatiotemporal gait patterns during over ground locomotion in major depression compared with healthy controls. Journal of Psychiatric Research 2000;34:277-283.

(12) Hausdorff JM, Peng C, Goldberger AL, Stoll AL. Gait unsteadiness and fall risk in two affective disorders: a preliminary study. BMC Psychiatry 2004;4:39.

(13) Parker G, Roy K, Wilhelm K, Mitchell P, Hadzi-Pavlovic D. The nature of bipolar depression: implications for the definition of melancholia. Journal of Affective Disorders 2000;59:217-224.

(14) Calugi S, Cassano GB, Litta A, Rucci P, Benvenuti A, Miniati M, Lattanzi L, Mantua V, Lombardi V, Fagiolini A, Frank E. Does psychomotor retardation define a clinically relevant phenotype of unipolar depression?. Journal of Affective Disorders 2011;129:296-300.

(15) Schotte CK, Maes M, Cluydts R, Cosyns P. Cluster analytic validation of the DSM melancholic depression. The threshold model: integration of quantitative and qualitative distinctions between unipolar depressive subtypes. Psychiatry Research 1997;71:181-195.

(16) Pier MP, Hulstijn W, van Hoof J, Sabbe BGC. Psychomotorische vertraging bij depressie, gemeten met visuomotorische taken. Overzicht en plaatsbepaling van tien jaar onderzoek. Tijdschrift voor Psychiatrie 2006;48:95-106.

(17) Pier MP, Hulstijn W, Sabbe BGC. Differential patterns of psychomotor functioning in unmedicated melancholic and nonmelancholic depressed patients. Journal of Psychiatric Research 2004;38:425-435.

(18) Dantchev N, Widlöcher DJ. The measurement of retardation in depression. The Journal of Clinical Psychiatry 1998;59:19-25.

(19) Iverson GL. Objective assessment of psychomotor retardation in primary care patients with depression. Journal of Behavioral Medicine 2004;27:31-37.

(20) Sabbe BGC, van Hoof J, Hulstijn W, Zitman F. Depressive retardation and treatment with fluoxetine: assessment of the motor component. Journal of Affective Disorders 1997;43:53-61.

(21) Sabbe BGC, van Hoof J, Hulstijn W, Zitman F. Changes in fine motor retardation in depressed patients treated with fluoxetine. Journal of Affective Disorders 1996;40:149-157.

(22) Hasler G, Drevets WC, Manji HK, Charney DS. Discovering endophenotypes for major depression. Neuropsychopharmacology 2004;29:1765-1781.

(23) American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision. Washington, DC: American Psychiatric Publishing Inc.; 2000.

(24) American Thoracic Society. ATS Statement: Guidelines for the Six-Minute Walk Test. American Journal of Respiratory and Critical Care Medicine 2002;166:111-117.

(25) Committee of Experts on Sports Research. EUROFIT: Handbook for the Eurofit tests of physical fitness, 2nd ed. Strasbourg: Council of Europe, Committee for the Development of Sports; 1993.

(26) Oja P, Tuxworth W. Eurofit for adults. Tampere: Council of Europe Publishing; 1995.

(27) Rush AJ, Gullion CM, Basco MR, Jarrett RB, Trivedi MH. The Inventory of Depressive Symptomatology (IDS): psychometric properties.Psychological Medicine 1996;26:477-486.

(28) Trivedi MH, Rush AJ, Ibrahim HM, Carmody TJ, Biggs MM, Suppes T, Crismon ML, Shores-Wilson K, Toprac MG, Dennehy EB, Witte B, Kashner TM. The Inventory of Depressive Symptomatology, Clinician Rating (IDS-C) and Self-Report (IDS-SR), and the Quick Inventory of Depressive Symptomatology, Clinician Rating (QIDS-C) and Self-Report (QIDS-SR) in public sector patients with mood disorders: a psychometric evaluation. Psychological Medicine 2004;34:73-82.

(29) Statsoft, Inc. Statistica for Windows [computer program]. Tulsa: Statsoft, 2009.

(30) Daley A. Exercise and depression: A review of reviews. Journal of Clinical Psychology in Medical Settings 2008;15:140-147.

(31) Wijndale K, Matton L, Duvigneaud N, Thomis M, Philippaerts R, Duquet W, Lefevre J. Fysieke activiteit, fitheid en gezondheid in Vlaanderen. In: Steens G, editor. Moet er nog sport zijn? Sport, beweging en gezondheid in Vlaanderen 2002-2006 Volume 1. Antwerpen: F&G Partners; 2006. p 61.

32) Belgisch Centrum voor Farmacotherapeutische Informatie [Internet]. Gecommentarieerd Geneesmiddelenrepertorium 2011 – [cited 2011 Apr 20]; Available from: http://www.bcfi.be

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 2
July 2011– June 2012

Creation of the Pillars of Peer Support Services: Transforming Mental Health Systems of Care

Emily A. Grant Ph.D.
(Corresponding Author)
Wyoming Survey and Analysis Center
University of Wyoming
1000 E. University Ave.
Laramie, Wyoming 82071
egrant3@uwyo.edu

Allen S. Daniels, Ed.D.
Healthcare Consultant

Ike G. Powell CPRP
Director of Training
Appalachian Consulting Group, Inc.

Larry Fricks
Vice President of Peer Services
Depression and Bipolar Support Alliance
email@larryfricks.org

Lisa Goodale M.A.
Director of Peer Services
Depression and Bipolar Support Alliance

Sue Bergeson MBA
Vice President, Consumer Affairs
OptumHealth Public Sector
Susan.bergeson@optumhealth.com

Citation:
Grant EA, Daniels AS, Powell IG, Fricks L, Goodale L & Bergeson S (2012).Creation of the Pillars of Peer Support Services Transforming Mental Health Systems of Care. ***International Journal of Psychosocial Rehabilitation. Vol 16(2) 20-27***

Acknowledgements:
The Pillars of Peer Support Services Summit was supported by: Substance Abuse and Mental Health Services Administration (SAMHSA) and Center for Mental Health Services (CMHS), National Association of State Mental Health Program Directors (NASMHPD), Depression and Bipolar Support Alliance (DBSA), Wichita State University Center for Community Support and Research, Appalachian Consulting Group (ACG), Carter Center, OptumHealth, and Georgia Mental Health Consumer Network. Special acknowledgements are also due to Peggy Clark, MSW, MPA, Technical Director Center for Medicaid State Operations at the Center for Medicare and Medicaid Services, and the participants from each of the represented states.

Abstract

The Pillars of Peer Support Services Summit convened in November 2009, to examine the multiple levels of state support necessary for a strong peer support workforce. Summit participants developed and agreed upon a set of Pillars of Peer Support Services. Twenty five “pillars” of peer support services propose a framework for states interested in developing or expanding peer support programs.

Key Words: Peer Support, Program Development, Mental Health Workforce

Introduction

Peer support is becoming an established role in the spectrum of mental health care (Salzer, Schwenk, & Brusilovskiy, 2010; Grant, 2009). In general, peer support occurs when people share common concerns or problems and provides emotional support and coping strategies to manage problems and promote personal growth (Davidson, Chinman, Kloos, Weingarten, Stayner, D, & Tebes, 1999). Peer support has demonstrated productive outcomes in areas of substance abuse, parenting, loss and bereavement, cancer, and chronic illnesses (Kyrouz, Humpherys & Loomis, 2002; White, 2000), and has now being implemented in mental health systems of care.

Peer support can be an integral part of the behavioral health workforce (Morris, Hoge, Morris, Adams, & Daniels, 2009). Settings for care include mental health centers, inpatient /outpatient settings, emergency rooms, and crisis centers (Salzer et al, 2010; Fricks, 2005). Certified Peer Specialists (CPSs) work with consumers assisting in regaining balance and control of their lives and supporting recovery (Chinman, Young, Hassel & Davidson, 2006; Sabin & Daniels, 2003; Orwin, Briscoe, Ashton & Burdett, 2003). A key differentiating factor in the CPS role from other existing mental health services is that, in addition to traditional knowledge and competencies, the CPS operates out of their lived experience and experiential knowledge (Mead, Hilton & Curtis, 2001). The CPS works from the context of recovery, utilizing language based upon common experience rather than clinical terminology, and person-centered relationships to foster strength based recovery (Davidson et al., 1999).

Multiple studies document favorable results from inclusion of peer supporters on treatment teams (Mead & MacNeil, 2006; Davidson et al., 2003; Felton, Stastny, Shern, Blanch, Donahue, Knight & Brown, 1995). Information provided by peers who have the lived experience often appears more credible than that provided by mental health professionals who do not have firsthand experience with this issue (Woodhouse & Vincent, 2006). When CPSs are part of hospital-based care, inpatients have shorter stays, decreased re- admissions, and subsequent reduction in overall treatment costs (Chinman, Weingarten, Stayner & Davidson, 2001). Other studies also suggest use of peer support can reduce need for more formal mental health services over time (Simpson & House, 2002; Chinman, et. al, 2001; Klein, Cnaan, & Whitecraft, 1998).

The formal role of peer support in the mental health system is still relatively new. Center for Medicaid Services deemed mental health peer support a reimbursable service beginning in 2001 (Fricks, 2005). To be eligible for Medicaid reimbursement, training, continuing education, supervision, and care coordination requirements must be established and met (Smith, Centers for Medicaid and Medicare Services, 2007). Certification is defined at the state level, contingent on completing necessary training and demonstration of core competencies. As of yet, national standards for practice or training have not been established.

Method and Results

Pillars of Peer Support Services Summit

As a first step in creation of standards for peer support services, representatives from all U.S. states that had a Medicaid recognized peer support program (23 states) were brought together to discuss essential components of peer support programs. Information gathered during this summit, as well as a set of recommendations that was created are detailed in this report to answer the following questions:

1) What is the current state of Peer Support Services across the United States?
2) What supports must be in place for a successful peer support program?

To answer the first question, each state was asked to complete a survey on peer support services in their state. The survey was sent out via email to be completed and submitted before attending the summit. Surveys were returned by 22 of 23 participating states (some states did not provide information on all questions). The survey consisted of eight questions about number of CPS, certification particulars and reimbursement rates. Three additional questions were asked on the unique experiences of each state. Survey results provide a comprehensive accounting for how states are using peer support, their roles, and the opportunities and challenges they face.

Peer Support Specialists Employed in State Systems and Rates of Reimbursement

The range of consumers employed in each state varied widely from 9 to 500. Of the 21 respondents, 10 states currently employ at least 50 CPSs. The range for reimbursements was between \$3.00 and \$19.00 per 15 minute billable unit. The average rate of reimbursement was \$10 per 15 minute unit. One state reported reimbursement on a monthly basis of \$150.00. Tracking billable services is an essential aspect of billing for peer support services. Twenty states indicated that they track by billing codes and one state reported using service logs.

Training and Certification of Peer Support Specialists

Most states (n = 14) reported a minimum number of training hours required for certification. However, six states have module-based training. Of the states requiring a minimum number of training hours, the range is 40 to 80 hours, with typical trainings of 40 hours. All but 2 of the 17 states who responded to the question regarding certification indicated they had standard certification processes. The most common certifying agent is the state department of mental health (n = 17). Some states use other entities including advocacy groups (n = 2) and academic institutions (n = 2).

Barriers to Implementation of Peer Support Services at the State Level

All states (n = 22) reported experiencing barriers to implementing peer support services. The most common barriers reported were acceptance of CPSs at mental health centers, financial issues, overall understanding of the CPS role, and individual CPS issues. Individual CPS issues include: dual role stress; loss of disability benefits due to income; fear to ask for help; fear of job loss; lack of anonymity; misunderstanding own role; burn out and turn over.
Pillars of Peer Support Services

To answer the second question: “What supports must be in place for a successful peer support program?” three qualitative questions were posed to each state:

1. What do you think are the strengths, unique qualities or innovations of your program?
2. What infrastructure do you believe must be in place at the state level to run a successful peer support program?
3. What recommendations would you make to states attempting to set up this kind of program for the first time?

During the summit, each state had a few moments to answer these questions by describing their program characteristics and their recommendations to the other participants. Afterwards, Appalachian Consulting Group and the Summit planning committee proposed a potential set of standards for the implementation of successful peer support programs. This list was drafted based on experiences of the Appalachian Consulting Group (who has developed a model of peer support training that is reportedly used by several states) and the planning committee. The states were split into work groups to examine this proposed list and modify it based on what their own experiences implementing CPS programs, as well as they experiences the shared from all other participating states. Proposed changes were then assimilated by the summit work groups and a new list immerged. There was consensus for the list and support for adoption from all participating states. This list, titled the Pillars of Peer Support Services, is to be a resource for states in their work with the CPS workforce, as well as a tool for states beginning or expanding their programs.

The Pillars of Peer Support Services

Created by State Representatives at the Carter Center: Pillars of Peer Support Services Summit November, 2009

A state's Peer Support Specialist Certification Program is strengthened when…

1…there are Clear Job and Service Descriptions that define specific duties that allow Certified Peer Support Specialists to use their recovery and wellness experience to help others recover.

2 …there are Job-Related Competencies that relate directly to the job description and include knowledge about the prevalence and impact of trauma in the lives of service recipients as well as trauma's demonstrated link to overall health in later life.

3…there is a Skills-Based Recovery and Whole Health Training Program which articulates the values, philosophies, and standards of peer support services and provides the competencies, including cultural competencies and Trauma Informed Care, for peer support specialist duties.

4…there is a Competencies-Based Testing Process that accurately measures the degree to which participants have mastered the competencies outlined in the job description.

5…there is Employment-Related Certification that is recognized by the key state mental health system stakeholders, and certification leads directly to employment opportunities that are open only to people who have the certification.

6…there is Ongoing Continuing Education, including specialty certifications, that exposes the peer support specialists to the most recent research and innovations in mental health, Trauma Informed Care and whole health wellness, while expanding their skills and providing opportunities to share successes, mentor and learn from each other.

7…there are Professional Advancement Opportunities that enable Certified Peer Support Specialists to move beyond part-time and entry level positions to livable wage salaries with benefits.

8…there are Expanded Employment Opportunities that enable Certified Peer Support Specialists to be employed in a variety of positions that take into account their own strengths and desires.

9…there is a Strong Consumer Movement that also provides state-level support, training, networking and advocacy that transcends the local employment opportunities and keeps Certified Peer Support Specialists related to grassroots consumer issues.

10…there are Unifying Symbols and Celebrations that give Certified Peer Support Specialists a sense of identity, significance and belonging to an emerging profession or network of workers.

11…there are ongoing mechanisms for Networking and Information Exchange so that Certified Peer Support Specialists stay connected to each other, share their concerns, learn from one another's experiences, and stay informed about upcoming events and activities.

12…there is Media and Technology Integration that connects Certified Peer Support Specialists with the basic and innovative information technology methods needed to do their work effectively and efficiently.

13…there is a Program Support Team that oversees and assists with state training, testing certification, continuing education, research, and evaluation.

14…there is a Research and Evaluation Component that continuously measures the program's effectiveness, strengths and weaknesses and makes recommendations on how to improve the overall program.

15…there are opportunities for Peer Support Workforce Development that help identify and prepare candidates for participation in the training and certification process.

16… there is a Comprehensive Stakeholders Training Program that communicates the role and responsibilities of Certified Peer Support Specialists and the concepts of recovery and whole health wellness to traditional, non-peer staff (peer specialist supervisors, administration, management and direct care staff) with whom the Certified Peer Support Specialists are working.

17…there are Consumer-Run Organizations that operate alongside government and not-for-profit mental health centers that intricately involve consumers in all aspects of service development and delivery and provide value-added support to the peer support workforce.

18…there are regularly-scheduled Multiple Training Sessions that demonstrates the state's long-range commitment to training and hiring Certified Peer Support Specialists to work in the system.

19…there is a Train-the-Trainer Program for Certified Peer Support Specialists that demonstrates the State's commitment to developing its in-state faculty for the on-going training.

20…there is Sustainable Funding that demonstrates the State's commitment to the long-term success and growth of the program.

21…there is Multi-Level Support across all levels of the government, with champions at all levels, that demonstrates the State's commitment to the program and continually promotes the valuable role of Certified Peer Support Specialists in the system

22…there is a Peer Support Specialist Code of Ethics/Code of Conduct that guides peer support service delivery.

23…there is a Culturally Diverse Peer Workforce that reflects and honors the cultures of the communities served.

24…there is Competency-Based Training for Supervisors of Certified Peer Support Specialists which reinforces fidelity to the principles of peer support and emphasizes the role of peer support specialists in building culturally competent and trauma informed systems of care that take into account the overall health and wellbeing of persons served.

25…there is opportunity for Certified Peer Support Specialists to receive training in and deliver Peer Support Whole Health Services to promote consumer recovery and resiliency.

These Pillars of Peer Support Services are intended as a set of guiding principles for the development of state based programs. They are also directly applicable to other organizations and roles that utilize the resources of Peer Support Specialists.

Discussion and Conclusion

The result of the Pillars of Support Services Summit was an active and lively review of peer support in state based mental health systems of care. As a part of the summit, data was collected and reported on the current status of peer support services. To date this is the most comprehensive review of CPS in these systems. This information will be useful in a variety of settings to endorse and expand peer support services across diverse systems of care.

This study demonstrates that peer support has gained an important and effective role in state systems of mental health care. While there are ongoing challenges, it is clear that participating states have been successful in integrating peer support in their workforces and overall systems of care. In order for long term viability and success, a set of common principles for strategic development, implementation, promotion, and maintenance of peer support services in state systems of care is needed.

The Pillars of Peer Support Services are intended to be both guidelines and resources providing a framework for future services to be built upon. They have been adopted by a consensus group and can serve as tools to help move the field forward. Recognition is due to the forward thinking states that participated in this summit to foster the evolving transformation of mental health services and strength based recovery. In the future, success and barriers to implementation of the Pillars should be studied. This is a promising start to understanding the current state of CPS and also creating a set of standards for program implementation. Efforts should be made to continue the advancement of the Pillars of Peer Support Services to foster the growth and evolution of the peer support workforce.

References

Center for Medicare and Medicaid Services (2007). Letter to state Medicaid directors, http://www.cms.hhs.gov/SMDL/downloads/SMD081507A.pdf (accessed 1/2010).

Chinman, M.J., Weingarten, R., Stayner, D., and Davidson, L. (2001). Chronicity reconsidered: Improving person-environment fit through a consumer run service. Community Mental Health Journal, 37(3) 215-229.

Chinman, M., Young, A.S., Hassell, J., Davidson, L. (2006). Toward the implementation of mental health consumer provider services. Journal of Behavioral Health Services & Research, 33(2) 176-195.

Daniels, A., Adams, N., Carroll, C., Beinecke, R. (2009). A conceptual model for behavioral health and primary care integration: emerging challenges and strategies for improving international mental health services. International Journal of Mental Health, 38(1), 101– 113, Spring.

Davidson, L., Chinman, M., Kloos, B., Weingarten, R., Stayner, D., and Tebes, J.K. (1999). Peer support among individuals with severe mental illness: A review of the evidence. Clinical Psychology: Science and Practice, 6(2) 165-187.

Felton, C.J., Stastny, P., Shern, D.L., Blanch, A., Donahue, S.A., Knight, E., & Brown, C. (1995). Consumers as peer specialists on intensive case management teams: Impact on client outcomes. Psychiatric Services, 46, 1037-1044.

Fricks, L. (2005). Building a foundation for recovery: a community education guide on establishing Medicaid-funded peer support services and a trained peer workforce. DHHS Pub. No. (SMA) Administration, 2005.

Grant, E. (2009). An examination of the integration of certified peer specialists into community mental health centers. Unpublished manuscript. Wichita State University, Wichita.

Grant, E.A., Swink, N., Reinhart, C., and Wituk, S. (2010). The development and implementation of a statewide certified peer specialist program. Brown, L.D. & Wituk, S. (Eds.). Mental health self-help: Consumer and family initiatives. New York: Springer.

Institute of Medicine, (2006). Improving the quality of health care services for mental and substance abuse conditions: quality chasm series. Washington, DC: National Academies Press.

Institute of Medicine, (2001). Crossing the quality chasm: a new health system for the 21st century. Washington, DC: National Academies Press.

Klein, A.R., Cnaan, R.A., and Whitecraft, J. (1998). Significance of peer social support with dually diagnosed clients: Findings from a pilot study. Research on Social Work Practice, 8(5) 529-551.

Kyrouz, E.M., Humphreys, K., and Loomis, C. (2002). A review of research on the effectiveness of self-help mutual aid groups. In B.J. White and E.J. Madara (Eds.), American self – help clearinghouse self-help group source book (7 ed, pp 71-85). Cedar Knolls, NJ; American Self-Help Group Clearing House.

Mead, S., Hilton, D., & Curtis, L. (2001). Peer support: A theoretical perspective. Psychiatric Rehabilitation Journal, 25, 134-141.

Mead, S., & MacNeil, C. (2006). Peer support: What makes it unique? International Journal of Psychosocial Rehabilitation, 10, 29 – 33.

Morris, G. W.; Hoge, M. A.; Morris, J. A.; Adams, N.; & Daniels, A.S. (2009). The Annapolis Coalition Report on the Behavioral Health Workforce Needs of the United States. International Journal of Mental Health. 38(1) 46 – 60.

New Freedom Commission on Mental Health (2003). Achieving the Promise: Transforming Mental Health Care in America. Final Report. DHHS Pub. No. SMA-03-3832. Rockville, MD.

Orwin, D., Briscoe, J., Ashton, L., and Burdett, J. (2003). Reflections on a pilot peer support service. The mind and body research and development team. 1-9.

Report to the President from The President’s Commission on Mental Health. (1978). Volume One. U.S. Government Printing Office, Washington, DC.

Sabin, J.E. and Daniels, N. (2003). Strengthening the consumer voice in managed care: VII the Georgia peer specialist program. Psychiatric Services. 54(4) 497-498.

Salzer, M. S.; Schwenk, E.; Brusilovskiy, E. (2010). Certified Peer Specialist Roles and Activities: Results from a national survey. Psychiatric Services, 61, 520 – 523.

SAMHSA (2004). National consensus statement on mental health recovery. U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration; Center for Mental Health Services, www.samhsa.gov.

Simpson, E. L. and House, A.O. (2002). Involving users in the delivery and evaluation of mental health services: Systematic review. British Medical Journal, 325, 1-5.

U.S. Department of Health and Human Services (1999). Mental Health: A Report of the Surgeon General-Executive Summary. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.
U.S. Department of Health and Human Services (2003). Emerging New Practices in Organized Peer Support: National Technical Assistance Center.

Woodhouse, A. and Vincent, A. (2006). Mental health delivery plan—development of peer specialist roles: A literature scoping exercise. Scottish Recovery Network and the Scottish Development Centre for Mental Health, Edinburgh.

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 2
July 2011– June 2012

Quality of Life and Social Support in Spouses of Patients With Depression

Jikun Wang, MD
PhD candidate
Institute of Psychosomatic Medicine
Shanghai East Hospital
Tongji University
School Medicine
Shanghai, China

Xudong Zhao, MD
Chief of the Psychiatry Department
Institute of Psychosomatic Medicine
Shanghai East Hospital
Tongji University
School of Medicine
Shanghai, China

Citation:
Wang J. & Zhao X. Quality of Life and Social Support in Spouses of Patients With Depression ***International Journal of Psychosocial Rehabilitation. Vol 16(2) 28-35***

Correspondence: Jikun Wang, liwangjk@gmail.com
244 P.O. Box, Tongji University
1239 Siping Road, Shanghai 200092
China

Abstract

Background: There was strong association between depression and caregiver burden. However, there are few studies about the quality of life and social support in the spouses of depressed patients in China. The aim of the present study was to explore the quality of life and social support perceived by the partners of depressed patients in China.

Methods: Using a cross-sectional design, fifty-nine participants with a depressed partner according to a DSM-Ⅳ diagnosis of major depressive disorder and fifty-nine married normal controls participated in the study. All participants completed MSPSS and QLESQ. The data collected was analyzed to compare the quality of life and social support between the depressed patients' spouses and married normal controls, and the relationship between social support and the quality of life in the two groups.

Results: There were significant differences in the quality of life ($p < 0.01$) and perceived social support ($p < 0.01$) between the two groups. The spouses of depressed patients, who were younger than fifty years, employed and role as a wife in the family reported better quality of life than those older than fifty years, unemployed and role as a husband. There was positively correlation between the quality of life and social support from friend in the spouses of depressed patients.

Conclusions: It is very important to provide the social support with a person with a depressed partner so that improving their quality of life.

Key Words: Quality of Life, Depression, Social Support, Caregiver Burden

Introduction

Mental disorders such as depression can result in enormous economic burden (Wang., et al, 2003), and caregiver burden (Baronet, 1999) including a serious of psychological, emotional, social, physical and financial problems. Caregiver burden consists of subjective and objective burden according to the definition (Idstad., et al, 2010). For example, subjective burden refers to psychological distress such as stigma and embarrassment while objective burden includes financial problems (Idstad., et al, 2010). Family members of depression such as partners reported much burden. There was strong association between depression and marital relationship (Ayotte., et al, 2010). Additionally, having a spouse with depression also increases the risk of depression for the partner (Townsend., et al, 2001). For example, one person suffered from depression may lead to changes in his/her partner (Siegel., et al, 2004). Lessening the burden of spouses of depression may help the improvement of depressed patients (Meyler., et al, 2007).

Previous research has shown family members of a depressed patients especially living with the patients were exposed to high risk of psychological distress and suffered from marital conflict (van Wijngaarden B., et al, 2004; Scazufca., et al, 2002; Highet., et al., 2005; van Wijngaarden., et al, 2009). Some research proposed that elderly caregiver may better deal with illness due to more experience (Baronet, 1999). It is well established that women tend to be vulnerable to depression than men (Idstad., et al, 2010), so that female spouses of mentally ill husbands tend to report more caregiver burden (Dudek ., et al, 2001).

Although caregiver burden are receiving attention, it is still in strong need to study spouse's burden of mental illness, particularly depression and anxiety (Idstad., et al, 2010). For example, there is a dearth of research about partner resemblance in mental health, such as assertive mating, effects of marital quality, and dynamic relationship between depression and mental health of partner.

The research about caregiver burden of mood disorders tended to overlap with the literature on spousal health (Idstad., et al, 2010). For instance, a recent review showed that affective contagion could be one explanation (Rehman., et al, 2008), because people tended to choose their partner whose characteristics are similar with them. Moreover, there was strong association between depression in spouses and marital distress (Rehman., et al, 2008).
Considerable research have reported family members and caregivers of persons with mental disorders seldom seek mental health services, while they may suffer from significant stress and burden (Saunders, 2003; Lua and Bakar, 2011). Depression influences family functioning, marital quality and parenting style. Family members exhibit dysfunction and bad emotion. Some research has demonstrated that there was an association between mental disorders such as depression in one partner and subjective burden in the spouse (Idstad et al., 2010).

Consequently, paying attention to spouses of depression may improve quality of life and social support in depression. The quality of life includes physical health, psychological health, social relationship and so on proposed by the World Organization Quality of Life (WHOQOL) Group (Sales, 2003). Past research has demonstrated lower quality of life for depressive patients were associated with the caregivers' reduced quality of life.

There is growing awareness on quality of life for depressive patients. However, not so much emphasis has been put on the research about the quality of life and social support for spouses of depressed patients. Previous studies about family members of depressed patients have shown improvement the quality of life for caregivers help depressed patients recover. This is very important in depression because depression is related with family functioning. Hence, assessing the quality of life and social support for caregivers is significant in the treatment of depression. By measuring and understanding the quality of life and social support of caregivers, clinicians can provide proper interventions with family caregivers and improve their quality of life and reduce their burden. The present study focused on the quality of life and perceived social support including from family, friend and significant others by the spouses of depressed patients.

Methods

Subjects

This was a cross-sectional study. The sample consists of 59 spouses of depressed married outpatients from the Psychiatry Department, Shanghai East Hospital of Tongji University in Shanghai, China, and the married normal controls recruited from the neighbor community. Participants completed written consent form after a careful explanation of the study. The study was approved by the institutional review board (IRB) of Tongji University School of Medicine.

Sociodemographic characteristics

Participants completed a sociodemographic survey form including gender, age, marital status, relationship with the patient and level of education. These items were selected based on the literature associated with family caregivers (Lua and Bakar, 2011).

Quality of Life

The quality of life was measured by Quality of Life-Enjoyment and Satisfaction Questionnaire (Q-LES-Q) (Endicott et al, 1993).The QLESQ consists of 14 items which is a self-reported questionnaire assessing subjective satisfaction and enjoyment (Hope, Page, and Hooke, 2009). High scores mean high quality of life ranging from 0 (very poor satisfaction) to 4 (very good satisfaction). The version of 14 items QLESQ has been demonstrated to possess good psychological properties, including high test-retest reliability (interclass correlation coefficient = 0.86) and high internal consistency (Cronbach's α= 0.90) (Rapaport, Clary, Fayyad, and Endicott, 2005).

Social Support

The social support was assessed by the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1990) which is a 12item self-reported measure assessing social support from three aspects including family, friends and significant others. Each item is rated between 1 (very strongly agree) and 7 (very strong disagree), high scores suggesting lower perceived social support. The psychometric properties of the MSPSS were previously investigated in a Chinese sample in Hongkong (Chou, 2000).

Data analysis

Data were analyzed using the statistical package, SPSS 16.0. Sociodemographic data were presented using descriptive statistics. The QLESQ scores and MSPSS scores were presented as median and mean for each dimensions. The value of $P<0.05$ was considered statistically significant for group differences.

Results

Sociodemographic characteristics of participants

The sample consisted of 59 depressed patients' spouses and 59 community controls. The overall mean age of spouses for depressed patients was 47.2 years (SD=14.4), and the range was from 18 to 70 years; the mean educational years was 10.8 years (SD=2.9); the mean marital years was 19.5 years (SD=12.9). The overall mean age of spouses for community controls was 43.9 years (SD=11.5), and the range was from 22 to 71 years; the mean educational years was 11.8 years (SD=3.3); the mean marital years was 16.0 years (SD=12.2). Table 1 shows there were no significant differences of age, education and marital years between the two groups.

Table 1. Sociodemographic Characteristics of Participants (n=59)

Characteristics	Spouses of patients	Spouses of controls	t

	Mean(SD)	Mean(SD)	
Mean age	47.2(14.4)	43.9(11.5)	1.388
Mean educational years	10.8(2.9)	11.8(3.3)	1.838
Mean marital years	19.5(12.9)	16.0(12.2)	1.520

Quality of life and social support

There were significant differences of social support and quality of life between the spouses of depressed patients and community controls (Table 2). Community controls reported better perceived social support including family, friend and significant others than the spouses of depressed patients. Also, the spouses of depressed patients reported poorer quality of life than the community controls.

Table 2. Quality of life and social support of Participants (n=59)

Characteristics	Spouses of patients Mean(SD)	Spouses of controls Mean(SD)	t
MSPSS	45.8(11.5)	27.2(10.8)	8.982**
Family	13.2(4.3)	8.5(4.0)	6.031**
Friend	20.1(5.2)	10.1(4.3)	11.284*
Significant others	12.5(5.1)	8.5(3.3)	4.987**
QLESQ-14	25.5(7.4)	38.1(5.1)	10.707**

**p＜0.01

Quality of life and social support: Univariate sociodemographic comparisons

Older people, not employed reported poorer quality of life than people younger than 50 years. Women reported higher quality of life than men.

Table 3. Quality of life and social support: Univariate sociodemographic comparisons

Socioldemographic Characteristics	MSPSS	Family	Friend	Significant others	QLESQ-14
＜50 years Mean(SD)	46.6(12.0)	14.0(4.3)	19.5(5.7)	12.8(4.9)	28.3 (6.8)
＞50years	44.5(1	12.7(4.	20.3(	11.	24.0

Mean(SD)	0.8)	7)	4.8)	6(5.1)	(6.5)
P	0.49	0.28	0.60	0.38	0.01
Employed Mean(SD)	46.5(12.2)	13.5(4.7)	20.4(5.1)	12.3(4.8)	28.3 (6.3)
Not employed Mean(SD)	44.0(10.1)	13.2(4.1)	18.9(5.5)	12.2(5.4)	23.0 (1.5)
P	0.42	0.80	0.29	0.93	0.003
Husband Mean(SD)	45.1(12.0)	12.9(4.7)	20.3(5.4)	12.0(5.3)	25.0 (6.1)
Wife Mean(SD)	46.4(10.6)	14.2(3.9)	19.1(5.0)	12.6(4.5)	28.7 (7.8)
P	0.67	0.29	0.42	0.65	0.03

Correlation between quality of life and social support in two groups

Table 4 shows that the quality of life for the spouses of depressed patients was negatively associated with the perceived social support from their friends, but not their family and significant others. While the quality of life for the community controls was negatively associated with the perceived social support from their friends, their family and significant others.

Table 4. Correlation between Quality of life and social support in two groups

Correlation (r)	Spouses of patients Quality of life	Spouses of controls Quality of life
MSPSS	-0.226	-0.454**
Family	-0.057	-0.506**
Friend	-0.322*	-0.373**
Significant others	-0.179	-0.404**

**p＜0.01

Discussion

In general, the spouses living with depressed patients encounter enormous emotional burden when their spouses suffer from depression. Some research has shown the quality of life for the family members and caregivers was influenced by mental disorders such as depression and schizophrenia (Lua and Bakar, 2011) and the quality of life for the partner could play a significant role in the prognosis of depression (Lua and Bakar, 2011). Considerable research has demonstrated there was strong association between depression and marital relationship. When one family member suffers from depression, the quality of life for the spouses was influenced. Our results showed the quality of life and social support for the spouses of depressed patients were poorer than the married community controls, consistent with previous study in mood disorders (Heru., et al, 2004). Obviously, when one family member suffered from depression, the spouse of depressed patients needed to take care of the patient and bear more emotional and economic burden, less social support especially from the family.

Additionally, our findings also showed the quality of life for spouses of depressed patients was positively associated with the social support from their friends, not from their family and significant others, which suggests when one person suffered from depression, the major supportive sources of the family caregiver is from their friends. While the quality of life for the community controls was positively with social support from their family, friend and significant others, which suggests they have enough supportive sources.

Sociodemographic characteristic also plays an important role in the quality of life for family caregivers of chronic disease (Haltermann., et al, 2004; Lim and Zebrack, 2004). Older family caregivers reported poorer quality of life than people younger than 50 years. The results suggest all the family members, including the spouses of depressed patients, were vulnerable because they needed to be exposed to the emotional burden of their depressive spouses. It is very important to realize that, because the treatment including the family members such as patients' spouses could improve the prognosis of depressed patients.

In addition, employment was another significant impact factor of quality of life for people with a depressed partner. In the present study, the spouses of employment showed better quality of life that those with unemployment. One possible reason could be that employment makes them earn money and reduce the economic burden. Also, they could communicate with more people and decrease the emotional burden. Therefore, employment could satisfy their economic and emotional needs. Some research showed that the family burden was related with unemployment13, resulting in lower quality of life. Some research showed there was a strong association between the quality of life and employment for the caregiver of schizophrenic patients, because employment was strongly associated with the income of the family (Lua and Bakar, 2011; Sales, 2003). Previous studies have demonstrated that household income was negatively associated with caregiver burden of schizophrenic patients (Vaddadi., et al, 2002; Li., et al, 2007).

Additionally, women reported better quality of life than men (Pinquart and Sorensen, 2006) which suggests when wife in the family suffered from depression, their husbands were exposed to higher burden and showed lower quality of life. One possible explanation could be women tend to seek more support and more social networks. Some research (Kung, 2002) proposed that Chinese family caregivers of mental disorders such as schizophrenia are usually exposed to highly family burden, because they possess strong obligation to patients, which leads them to be vulnerable to shame, stigma, guilt and anxiety (Li., et al, 2004).

The social support from friend perceived by the spouses of depressed patients was positively associated with the quality of life of them. The quality of life for the community married controls was positively associated with the perceived social support from family, friend and significant others. Our findings suggest perceived social support is very important to the quality of life for the spouses of depressed patients, especially the support from their friends, because when one family member suffered from depression, the other family member was lack of the social support from their family.

There are some limitations in the present study. The sample size is limited. Therefore, future studies need to be replicated in a larger sample size. Further, more influencing factors of quality of life should be considered such as the health problems.

However, our results could extend the understanding the quality of life for the family members of depressed patients in China. The quality of life and social support for the spouses of depressed patients were lower than that of the community controls. Better quality of life was observed in the family caregivers with these characteristics: female, younger than 50 years and employed. These information helps clinicians to understand the family burden caused by depressed patients and improve the prognosis of depression.

References:

Wang, P. S., Simon, G., and Kessler, R. C. (2003). The economic burden of depression and the cost-effectiveness of treatment. International Journal of Methods in Psychiatric Research, 12(1), 22-33.

Ayotte, B.J., Yang, F.M., and Jones, R.N. (2010). Physical health and depression: a dyadic study of chronic health conditions and depressive symptomatology in older adult couples. Journal of Gerontology: Psychological Sciences, 65B (4), 438–448.

Baronet, A. M. (1999). Factors associated with caregiver burden in mental illness: A critical review of the research literature. Clinical Psychology Review, 19(7), 819-841.

Chou, K. L. (2000). Assessing Chinese adolescents' social support: the multidimensional scale of perceived social support. Personality and Individual Differences, 28(2), 299-307.

Dudek, D., Zieba, A., Jawor, M., Szymaczek, M., Opila, J., Dattilio, F. M. (2001). The impact of depressive illness on spouses of depressed patients. Journal of Cognitive Psychotherapy, 15(1), 49-57.

Endicott, J., Nee, J., Harrison, W., and Blumenthal, R. (1993). Quality of Life Enjoyment and Satisfaction Questionnaire: a new measure. Psychopharmacological Bulletin, 29(2), 321-326.

Heru, A. M., Ryan, C. E., and Vlastos, K. (2004). Quality of life and family functioning in caregivers of relatives with mood disorders. Psychiatric Rehabilitation Journal, 28(1), 67-71.

Hope, M. L., Page, A. C., and Hooke, G. R. (2009). The value of adding the Quality of Life Enjoyment and Satisfaction Questionnaire to outcome assessments of psychiatric inpatients with mood and affective disorders. Quality of Life Research, 18(5), 647-655.

Highet, N., Thompson, M., and McNair, B. (2005). Identifying depression in a family member: The carers’ experience. Journal of Affective Disorders, 87(1), 25-33.

Idstad, M., Ask, H., and Tambs, K. (2010). Mental disorder and caregiver burden in spouses: the Nord-Trøndelag health study. BMC Public Health, 10, 516-521.

Kung, W. W. (2002). The illness, stigma, culture, or immigration? Burdens on Chinese American caregivers of patients with schizophrenia. Families in Society, 84(4), 547-557.

Lua, P. L., and Bakar, Z. A. (2011). Profiles among family caregivers of patients with schizophrenia. Family and Community Health, 34(4), 331-339.

Li, L., Young, D., Xiao, S., Zhou, X., and Zhou, L. (2004). Psychometric properties of the WHO Quality of Life questionnaire (WHOQOl-100. in patients with chronic diseases and their caregivers in China. Bulletin of the World Health Organization, 82(7), 493-502.

Lim, J., and Zebrack, B. (2004). Caring for family members with chronic physical illness: a critical review of caregiver literature. Health and Quality of Life Outcomes, 2, 50.

Li, J., Lambert, C. E, and Lambert, V. A. (2007). Predictors of family caregivers’ burden and quality of life when providing care for a family member with schizophrenia in the People’s Republic of China. Nursing and Health Sciences, 9(3), 192-198.

Meyler, D., Stimpson, J. P, and Peek, M. K. (2007). Health concordance within couples: a systematic review. Social Science and

Medicine, 64(11), 2297-2310.

Pinquart, M., and Sorensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: an updated meta-analysis. The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 61(1), 33-45.

Rehman, U. S., Gollan, J., and Mortimer, A. R. (2008). The marital context of depression: research, limitations, and new directions. Clinical Psychology Review, 28(2),179-198.

Rapaport, M. H., Clary, C., Fayyad, R., and Endicott, J. (2005). Quality-of-life impairment in depressive and anxiety disorders. American Journal of Psychiatry, 162(6), 1171-1178.
Sales, S. (2003). Family burden and quality of life. Quality of Life Research, 12(S1), 33-41.

Saunders, J. C. (2003). Families living with severe mental illness: a literature review. Issues in Mental Health Nursing, 24(2), 175-198.

Scazufca, M., Menezes, P. R., and Almeida, O. P. (2002). Caregiver burden in an elderly population with depression in Sao Paulo, Brazil. Social Psychiatry and Psychiatric Epidemiology, 37(9), 416-422.

Siegel, M. J., Bradley, E. H., Gallo, W. T., and Kasl, S. V. (2004). The effect of spousal mental and physical health on husbands' and wives' depressive symptoms, among older adults: longitudinal evidence from the health and retirement survey. Journal of Aging and Health, 16(3), 398.

Townsend, A. l., Miller, B., and Guo, S. (2001). Depressive symptomatology in middle-aged and older married couples: a dyadic analysis. The Journals of Gerontology Series B: Social Sciences, 56(6), S352–S364.

van Wijngaarden, B., Koeter, M., Knapp, M., Tansella, M., Thornicroft, G., Vazquez-Barquero, J. L, et al. (2009). Caring for people with depression or with schizophrenia: are the consequences different? Psychiatry Research, 169(1), 62-69.

van Wijngaarden, B., Schene, A. H., Koeter, M. W. (2004). Family caregiving in depression: impact on caregivers' daily life, distress, and help seeking. Journal of Affective Disorders, 81(3), 211-222.

Vaddadi, K. S, Gilleard, C., and Fryer, H. (2002). Abuse of carers by relatives with severe mental illness. International Journal of Social Psychiatry, 48(2), 149-155.

Zimet, G. D, Powell, S. S, Farley, G. K, Werkman, S., and Berkoff, K. A. (1990). Psychometric characteristics of the multidimensional scale of perceived social support. Journal of Personality Assessment, 55(3-4), 610-617.

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 2
July 2011– June 2012

Social Work Intervention for Disability Management of Persons with Schizophrenia in India with reference to Rural Areas

L. Ponnuchamy
Assistant Professor of Psychiatric Social Work, School of Social Work
DMI-St.John the Baptist University, Malawi, Central Africa.

Citation:
Ponnuchamy L (2012). Social Work Intervention for Disability Management of Persons with Schizophrenia in India with reference to Rural Areas ***International Journal of Psychosocial Rehabilitation. Vol 16(2) 36-49***

Author for correspondence:
Dr. L. Ponnuchamy M.A.(SW), M.Phil.(PSW), Ph.D(PSW) (NIMHANS),
Assistant Professor of Psychiatric Social Work,
School of Social Work,
DMI-St.John the Baptist University,
Mangochi,
Malawi,
Central Africa.
Email: ponnupsw@gmail.com

Abstract

Schizophrenia is one of the major mental disorders affecting one to two percentage of the general population. It usually affects young people both men and women equally, predominantly between the ages of 15 to 45 years. In-spite of vigorous treatment with continuous medication, about 30% of chronic psychotic persons suffer from certain disabilities in term of asocialization, apathy, alogia and amotivation.

The aim of the present study is to ascertain impact of structured Social Work Intervention for the disability management of persons with schizophrenia in rural areas. The study is followed a Before-After Experimental Research Design Without Control Group. The sample for this study consisted of thirty persons with schizophrenia and thirty significant family members. A proportionate sample covering heterogeneous socio demographic background was drawn for the present study. The results reveal that extent of disability was highest in the domain of participation in society, followed by understanding and communicating, self care, getting along with people, life activities before Social Work Intervention. Also, it reveals that extent of disability of the persons with schizophrenia was reduced significantly in all the domains after Social Work Intervention. It is indicated that the social work intervention has contributed to reduce the level of disability and improves the functioning of the patients in rural areas.

Key words: Schizophrenia, Disability, Social Work Intervention

Introduction

Schizophrenia is one of the major mental disorders severely affecting both men and women predominantly between the ages of 15 to 45 years. Schizophrenia may develop so gradually that no one realizes as something wrong with person for a long period of time. Sometimes it may also develop suddenly with dramatic changes in behaviour occurring over a period of few weeks or even a few days. Emil Kraeplin, who first term this illness as 'Dementia Praecox' described it as progressive and deteriorating course of illness. Accordingly schizophrenia destroys the inner unity of the mind and weakens volition and drive that constitute our essential (Kraeplin, 1971). The persons with schizophrenia are incapacitated to engage and sustain social bonds, and even the society reacts negatively to the social and personal deviance caused by the illness. Because its manifestations are so personal and social, it elicits, fear, misunderstanding and condemnation in society instead of sympathy and concern.

Severe disability is the result of both positive and negative symptoms of schizophrenia. This inturn affects the individual's ability to understand and act according to social cues would diminish markedly. Patients experience unemployment, social isolation, homelessness and dependency on family members. Their relationship with family members and peer groups changes partly because of their unexplained behaviours and the stigma associated with the illness. Similarly, cognitive deficits like decreased attention, concentration and lack of motivation lead to deterioration in their work capacity and are responsible for unemployment among these patients. This further leads to social maladjustment (Appelo, et al., 1992).

Disability is associated with all diseases and its minimization is an important concern of all health practitioners. Mental disorders account for about a quarter of the world's disability. The mental disorders which contribute most to the disability include schizophrenia, major depression, alcohol abuse, bipolar affective disorder and anxiety disorders. Schizophrenia causes a high degree of disability. In a recent 14-country study of disability associated with physical and mental conditions showed that active psychosis was ranked the third most disabling condition (WHO, 2001).

According to WHO (2001) about 30% of chronic psychotic persons suffer from certain disabilities in term of asocialization, apathy, alogia and amotivation in-spite of vigorous treatment with continuous medication. This has given rise to the need for specific modes of treatment in the community, which are more comprehensive in nature encompassing variety of therapeutic approaches, to enable the mentally ill patient function optimally and live satisfactorily in the community. This comprehensive therapeutic treatment is known as Psychosocial Rehabilitation.

Psychiatric Social Work as a professionalized activity that focuses on reducing the psychosocial problems of clients. The Psychiatric Social Work practitioners have postulated that the psychosocial functioning or dysfunctioning was mostly determined by the interaction between the individual needs, aspirations and functional capacities on one side, and environmental (situations) expectations, opportunities and resources on the other side. Linn et al., (1979) emphasized on the modification of client system and the environmental system for better psychosocial functioning.

Review of Literature:

Hogarty and Goldberg (1973) have conducted an evaluation study of Major Role Therapy (MRT) with 374 schizophrenic patients for 2 years. The MRT consisted of Social Case work and Vocational Rehabilitation Counselling. Initially the patients were stabilized on Chlorpromazine. After 2 months the patients were assigned to drug and placebo emerging at four groups - placebo alone, placebo and MRT, drug alone, drug and MRT. The result showed that MRT was found to be lowered the relapse rate significantly after 6 months.

Linn, et al., (1979) have studied the efficacy of social treatment with schizophrenic patients. The intervention focused on enhancing patient's social interaction skills, providing a place to socialize and engaging in productive activities and creating stimulating environment for patients. The analysis of data obtained from randomized groups of patients revealed that social treatment was effective in maintaining patient's social functioning.

Stein and Test (1980) have conducted a study on the efficacy of an environmental intervention namely 'Training in

Community Living' (TCL) with chronically mentally disabled patients to gain living skills to secure material resources, developing support systems for patients and involving environmental systems in the rehabilitation. The subjects were randomly assigned to TCL group and control group. They were assessed before and at every fourth month thereafter for twenty eight months on standardized scales to measure symptom severity, community adjustment and self esteem. The results based on series of t-tests and Analysis of Co-variance indicated that after 14 months the TCL group was better than control group on measure like independent living, satisfaction with the life situation, symptom severity and degree of interpersonal contacts.

Bentley (1990) studied the effects of a short term model of intervention on schizophrenic out patients and their relatives. The Intervention package consisted of in-home ten sessions educational and skill training programme adopted from existing model. The author reported significant improvement in the social functioning, relative's attitude and family stress in sample of 4 cases. The improvement in social measure was found to be significantly associated with improvement in clinic status.

Viswanath and Padmavathi (1992) have conducted a study on family intervention in schizophrenia through Group Work. The sessions were agenda based and conducted in an interactionary style. A Psychiatric Social Worker acted as the facilitator for the sessions. Assessments were made a week after the completion of the programme. There was a change in the attitudes towards the patient. Significant knowledge gains were noticed, particularly in the management of specific problems, while there were not significant changes in the burden scores, the members felt they could face the burden better. The interviews also revealed that members were making attempts to involve other relatives in the care of the patient. In conclusion, conducting a family group in the management of schizophrenic and related problems appears feasible.

In summary, the review of literature indicates the concept of disability is much relevant to the field of mental health as most of the mental illnesses contribute to the psychological, social disturbances to the patient and family members. Psychoeducation as well as Skills Training are conceptualized to be the essential element of psychiatric social work intervention. Outcome researches in schizophrenia have shown long standing disabilities among the patients. The social interventions particularly provided by the Psychiatric Social Workers found to have meaningful benefits with persons with schizophrenia in the west. In the Indian context particularly in rural settings, studies on the effectiveness of Psychiatric Social Work intervention with persons having disability due to schizophrenia are inadequate.

Materials and Methods:

Many Psychiatric Social Work interventions have yet to receive adequate testing and scientific evaluation. Recognizing suitability of particular interventions for particular practice situations must be supported by adequate scientific evidence, which will further contribute to Psychiatric Social Work practice. Further, recognizing that social work research especially in the context of service delivery is a prerogative for social workers. The existing intervention studies (Linn, et al., 1979; Stein and Test, 1980; Hogarty and Goldberg, 1973; Bentlay, 1990; Viswanath and Padmavathi, 1992) in the areas of psychiatric social work practice in Mental Health field are urban based and involves long duration of intervention. Rural areas do not have sufficient inputs from the mental health professionals. In India, the National Mental Health Programme envisages implementation of Mental Health services through District Mental Health Programme, in which a team of Psychiatrist, Psychiatric Social Worker, Psychologist and Psychiatric Nurse deliver the services. In this context, it is needed that how far the management of disability among schizophrenic patients in the rural areas is effective if it is done through Monthly Rural Mental Health Camps. There is no intervention study through Monthly Rural Mental Health Camp in the rural areas in the field of mental health. There is a lacunae in this area. Hence, an attempt is made to focus in this direction.

The aim of study is to ascertain impact of structured social work intervention for the disability management of persons with schizophrenia in rural areas through monthly rural mental health camps. The present study is undertaken to understand the level of disability both before and after the persons are exposed to the psychiatric social work intervention package. The course of study is aimed to develop and implement the psychiatric social work intervention package with the significant family members and the patients in the conjoint sessions. It has been decided to test the efficacy of the intervention at the end of two months, fourth months and six month intervals after the intervention. In view of this nature of research work, a "Before-After Experimental Research Design Without Control Group" is considered for the present study. In this design a single test group is selected before the introduction of the intervention. The intervention package is then introduced and its effectiveness is measured again. The efficacy of the intervention was demonstrated by the changes that occur after the intervention was administered as against the baseline assessments.

All the patients and the significant family members who are availing the services of Monthly Community Mental Health Camp conducted by the Richmond Fellowship Society Sidlaghatta Rural Branch, Sidlaghatta, in rural Karnataka, India consisted the universe of the study. About fifty three cases were diagnosed to have schizophrenia (all type) by the psychiatrist in the Monthly Rural Mental Health Camp during the period from January 2004 to till July 2005. Out of fifty three patients, eight patients were not included in this study due to exclusion criteria. Off these patients, the researcher has drawn thirty samples using Simple Random Sampling technique. The size of the sample for this study consisted of 30 persons with schizophrenia and their significant family members. A proportionate sample covering heterogeneous socio demographic background was drawn.

The inclusion criteria are person having a diagnosis of Schizophrenia (any type) as per tenth version of International Classification of Diseases – 10 (ICD-10) of WHO (1992) diagnostic criteria, and age group between 18 to 45 years. The exclusion criteria are persons with any associated psychiatric problems like substance abuse, mental retardation, affective disorders or any other disorders, and patient who is actively symptomatic.

Tools used for data collection:

1. Socio Demographic Data Sheet:
The proforma is intended to collect information on age, gender, education, religion, marital status, occupational status, income, duration of mental illness and the diagnosis of patients. The profile of the family members consists of relationship with the patient, age, gender, education, types of family, occupational status and income.

2. Disability Assessment Schedule – II, (DAS - II) WHO (2000):
The World Health Organization Disability Assessment Schedule (WHODAS – II) is a new measure of functioning and disability that is conceptually compatible with WHO's recent revision (WHO, 1997) to the International Classification of Functioning and Disability (ICIDH-2). The WHODAS – II distinguishes itself from other measures of health status in that it is based on an international classification system, is cross-culturally applicable to all disorders.

WHODAS-II (2000) assesses disability at the individual level instead of disorder-specific level. Domains of functioning assessed by the WHODAS-II include Understanding and Communicating, Getting Around, Self Care, Getting along with others, Life activities, and Participation in society.
The 89 item version of WHODAS-II was field tested in 21 sites and 19 countries based on psychometric analyses and further field-testing in early 1999. The measure was shortened to have 36 items and a 12-item screening questionnaire was also developed. The WHODAS-II has undergone for its reliability and validity tests in 16 centers across 13 countries. Health services research studies (to test sensitivity to change and predictive validity) were conducted in centers throughout the world in the year 2000 and relevant modifications in scoring of the scale were suggested. Analysis of data from different patient groups indicates that the degree of disability experienced by those with mental or substance use disorders was similar to or greater than that experience by those with physical disorders.

Several versions of the WHODAS-II are available. These include interviewer-administered version, self-administered version, and proxy version. Varying lengths are also offered. The present study is adopted 36 items, interviewer administered version of the WHODAS-II (2000). This version provides the most complete assessment of functioning. Scores for six domains of functioning, as well as an overall functioning score, can be calculated.
Process of social work intervention:

Thirty patients and significant family members involved in the study were divided into 3 groups. Each group was exposed to two group sessions. The intervention package consisted of two components (psychoeducation and skills enrichment) for a group of patients and families. The period of intervention was 2 months i.e., two monthly sessions. Each session lasts for 90 minutes were used.

Data collection and Analysis:

The data was collected from patients and family members at the beginning of the intervention, immediately after intervention, second month after intervention and fourth month after intervention. The sample was divided into three groups according to the convenient of geographical areas with the help of staff of Richmond Fellowship Sidlaghatta Rural Branch at Sidlaghatta, Kolar District. Each group consisted of 20 members. Quantitative analysis was carried out using Statistical Package for Social Sciences (SPSS Version 11). The objectives of the quantitative analysis were to understand the distribution of the sample on the socio demographic and other variables, to assess the efficacy of the intervention package. To meet these requirements, descriptive statistical techniques such as frequency, percentage, mean, standard deviation were used on the individual, family and illness variables. Paired t-test was used to test the difference between baseline scores and immediately after intervention assessment, between baseline scores and second month after assessment, between baseline scores and fourth month after intervention assessment. In addition Repeated Measure Analysis of Variance was used to assess the extent of changes in the variables over the period of intervention and during second month after intervention and fourth month after intervention on

Disability Assessment Schedule.

Informed consent:

Enough freedom was given to the participants to either participate or not participate in the intervention programme. Informed consent was acquired from all the participants after explaining the purpose of the study and procedures involved in this study. Information collected was used only for research purpose and confidentiality was ensured.

Results:

I. Socio-demographic Characteristics of Rural Persons with Schizophrenia:

Social Demographic data of the patients displays that majority (73.4%) of the patients were between 21-40 years of age group. Overall, 62.1% of the patients were male and 86.7% of them were Hindus. Also shows that the majority (53.4%) of the patients were married and 46.7% of them were illiterate. A majority (60.0%) of the patients were not working and had no personal income. Overall, 46.7% of the samples had mental illness for 2 to 4 years. A majority (80.0%) of the patients had the diagnosis of Paranoid Schizophrenia.

II. Socio-demographic Characteristics of Family Members of Rural Persons with Schizophrenia:

Social Demographic data of the family shows that majority (36.7%) of the family members were between 51 – 60 years old. Around 53.3% of the family members were female and 46.7 of them were male. Majority (50.0%) of the family members were illiterate. A majority (56.7) of the families were nuclear and 66.7% of the family members were coolies. Majority (38.9%) of the families had a monthly income of Rs.1001 – 2000 per month.

III. Extent of Changes in Disability Domains:

1. Extent of Changes in Disability Domain (Understanding and Communicating) over different time periods among Rural Persons with Schizophrenia: (1=Before intervention, 2=Immediately After intervention, 3=Second month After intervention, 4=Fourth month After intervention)

The results of Repeated Measure ANOVA conducted on Understanding and Communicating to verify the differences in the mean scores across the four time intervals (1 – 2, 1 – 3, 1 – 4, 2 – 3, 2 – 4, 3 – 4 assessments). It shows that there was a significant ($P<0.001$) reduction in the mean score on this domain of Disability during this period. Moreover, the results also indicate that improvement in the Understanding and Communicating was sustaining during the subsequent assessments followed by the Psychiatric Social Work Intervention. The overall change in the mean value of this domain is shown in figure: 1.

1. Extent of Changes in Disability Domain (*Understanding and Communicating*) over different time periods among Rural Persons with Schizophrenia: (1=Before intervention, 2=Immediately After intervention, 3=Second month After intervention, 4=Fourth month After intervention)

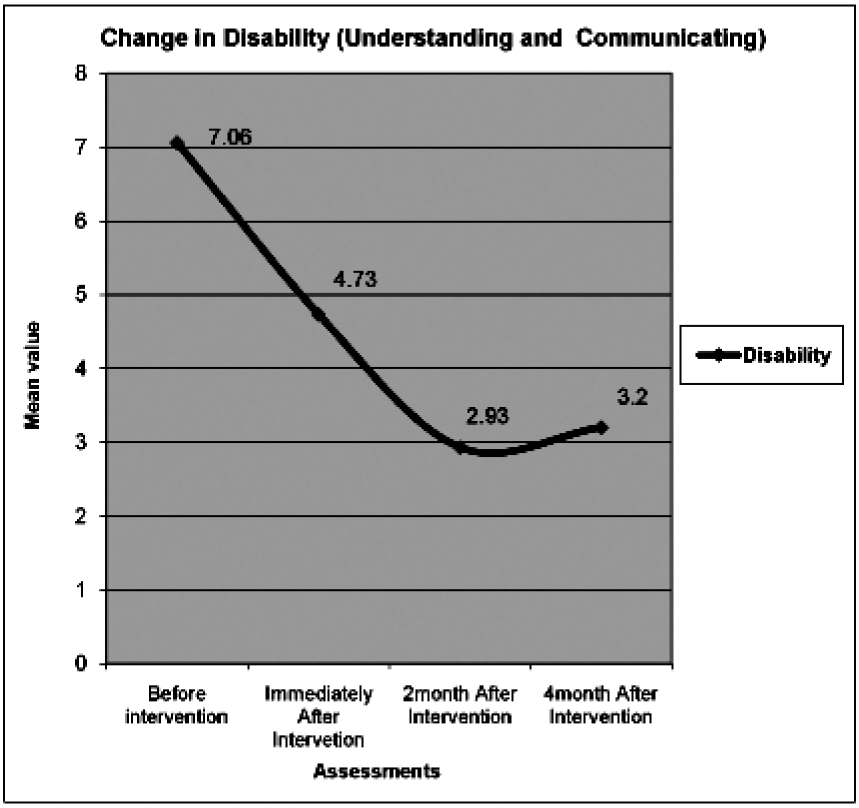


Figure-1

2. Extent of Changes in Disability Domain (Getting Around) over different time periods among Rural Persons with Schizophrenia: (1=Before intervention, 2=Immediately After intervention, 3=Second month After intervention, 4=Fourth month After intervention)

The results of Repeated Measure ANOVA conducted on Getting Around to verify the differences in the mean scores at four time intervals (1 – 2, 1 – 3, 1 – 4, 2 – 3, 2 – 4, 3 – 4 assessments). It shows that there was a significant (P<0.001) reduction in the mean score on this domain of Disability during this period. Moreover, it indicates that improvement in the Getting Around was sustaining during the subsequent assessments followed by Psychiatric Social Work Intervention. The overall change in the mean score of this domain is shown in the figure: 2.

2. Extent of Changes in Disability Domain (*Getting Around*) over different time periods among Rural Persons with Schizophrenia: (1=Before intervention, 2=Immediately After intervention, 3=Second month After intervention, 4=Fourth month After intervention)

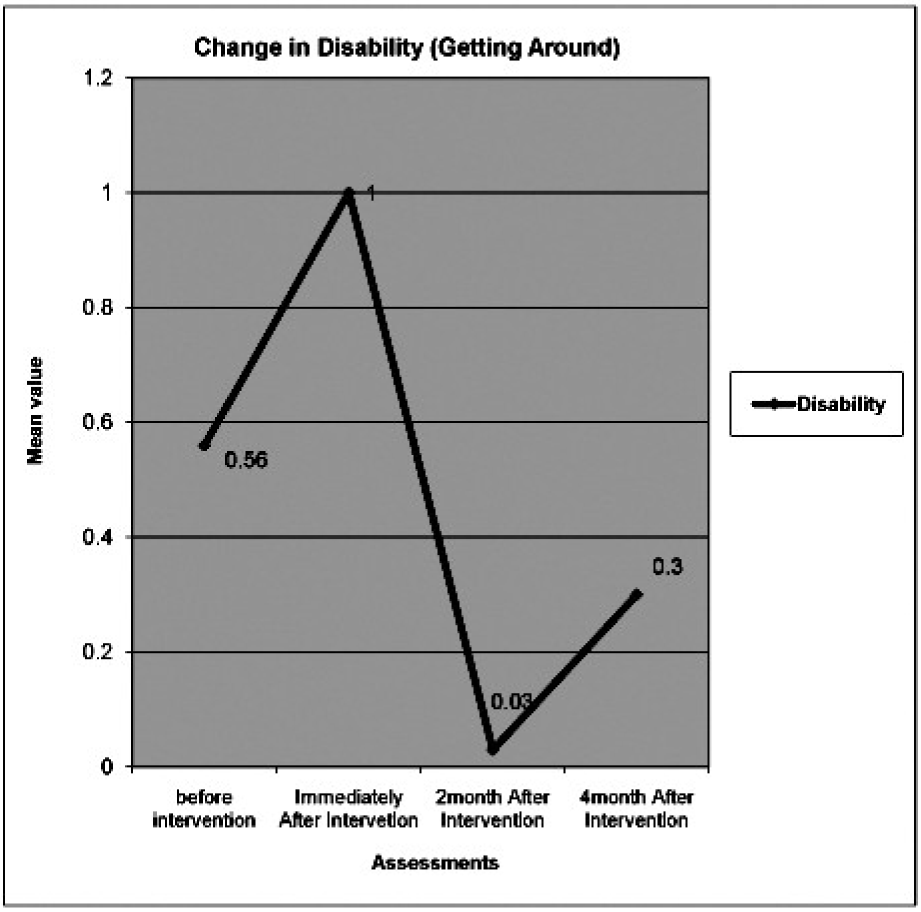


Figure-2

3. Extent of Changes in Disability Domain (Self Care) over different time periods among Rural Persons with Schizophrenia: (1=Before intervention, 2=Immediately After intervention, 3=Second month After intervention, 4=Fourth month After intervention)

The results of Repeated Measure ANOVA conducted on Self Care to verify the differences in the mean scores at four time intervals (1 – 2, 1 – 3, 1 – 4, 2 – 3, 2 – 4, 3 – 4 assessments). The mean score on Self Care of Disability domain has significantly ($P<0.001$) reduced during this period. Moreover it also indicates that the improvement in the self care was sustaining during the subsequent assessments followed by the Psychiatric Social Work Intervention. The overall change in the mean value of this domain is shown in figure: 3.

3. Extent of Changes in Disability Domain (*Self Care*) over different time periods among Rural Persons with Schizophrenia: (1=Before intervention, 2=Immediately After intervention, 3=Second month After intervention, 4=Fourth month After intervention)

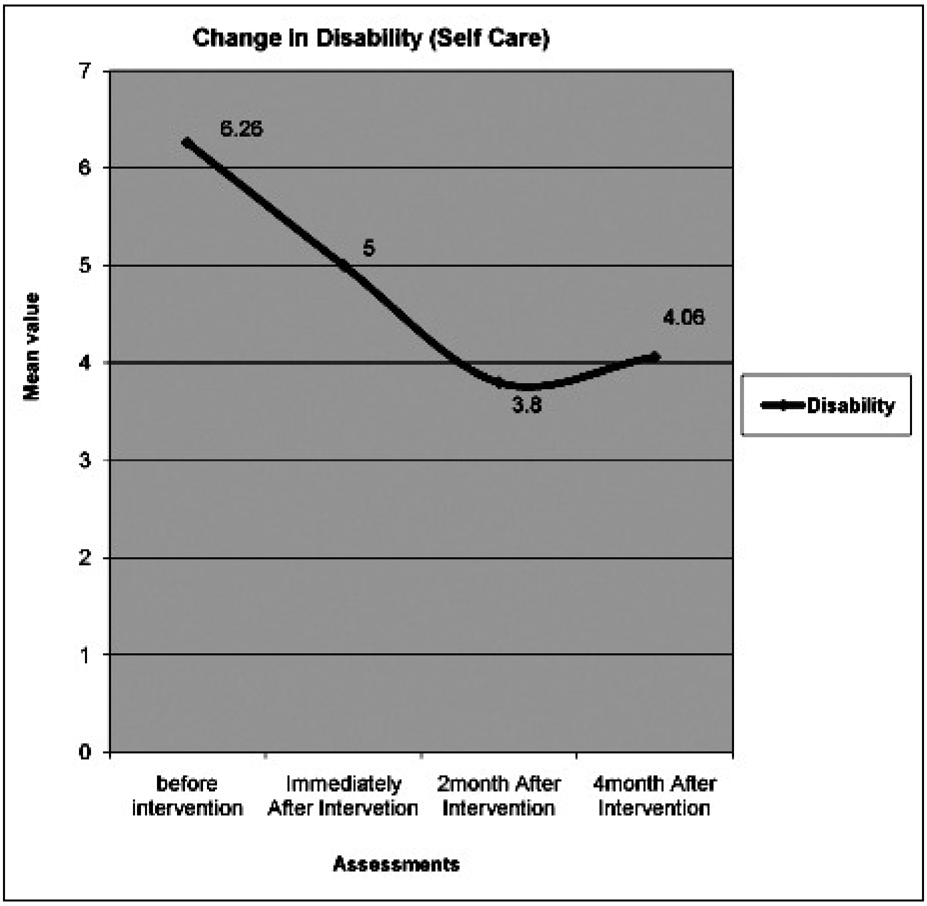


Figure-3

4. Extent of Changes in Disability Domain (Getting along with People) over different time periods among Rural Persons with Schizophrenia: (1=Before intervention, 2=Immediately After intervention, 3=Second month After intervention, 4=Fourth month After intervention)

The results of Repeated Measure ANOVA conducted on Getting along with People to verify the differences in the mean score at four times intervals (1 – 2, 1 – 3, 1 – 4, 2 – 3, 2 – 4, 3 – 4 assessments). It shows that there was a significant ($P<0.001$) reduction in the mean scores on this domain of disability during this period. It also shows that improvement in the Getting along with People was sustaining during the subsequent assessments followed by the Psychiatric Social Work Intervention. The overall change in mean value of this domain is shown in figure: 4

4. Extent of Changes in Disability Domain (*Getting along with People*) over different time periods among Rural Persons with Schizophrenia: (1=Before intervention, 2=Immediately After intervention, 3=Second month After intervention, 4=Fourth month After intervention)

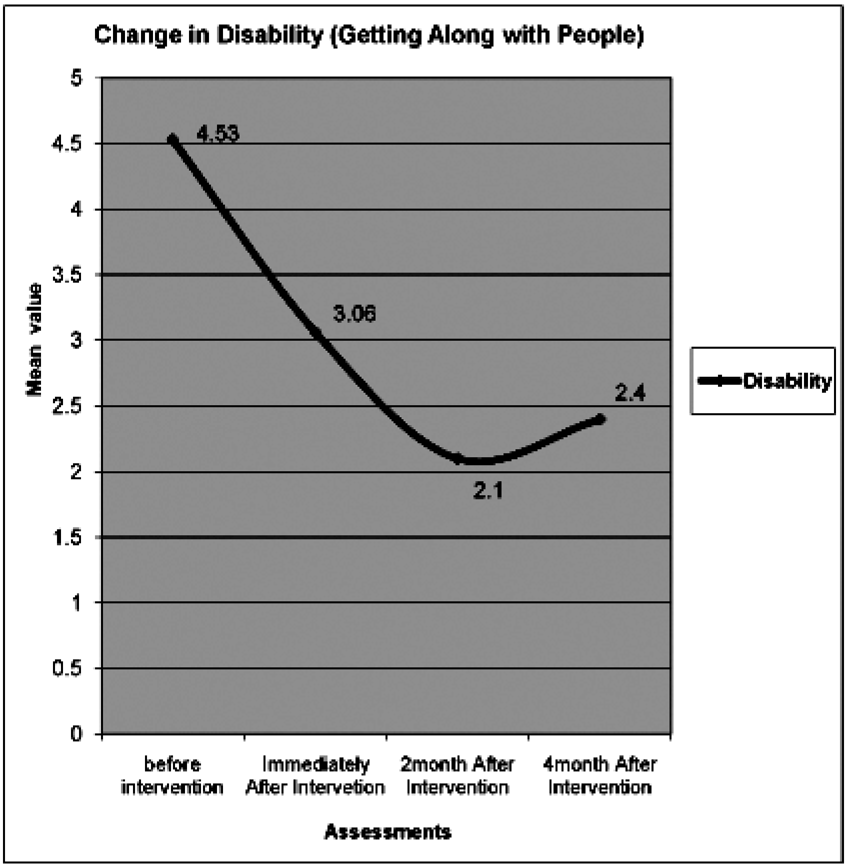


Figure-4

5. Extent of Changes in Disability Domain (*Life Activities*) of over different time periods among Rural Persons with Schizophrenia: (1=Before intervention, 2=Immediately After intervention, 3=Second month After intervention, 4=Fourth month After intervention)

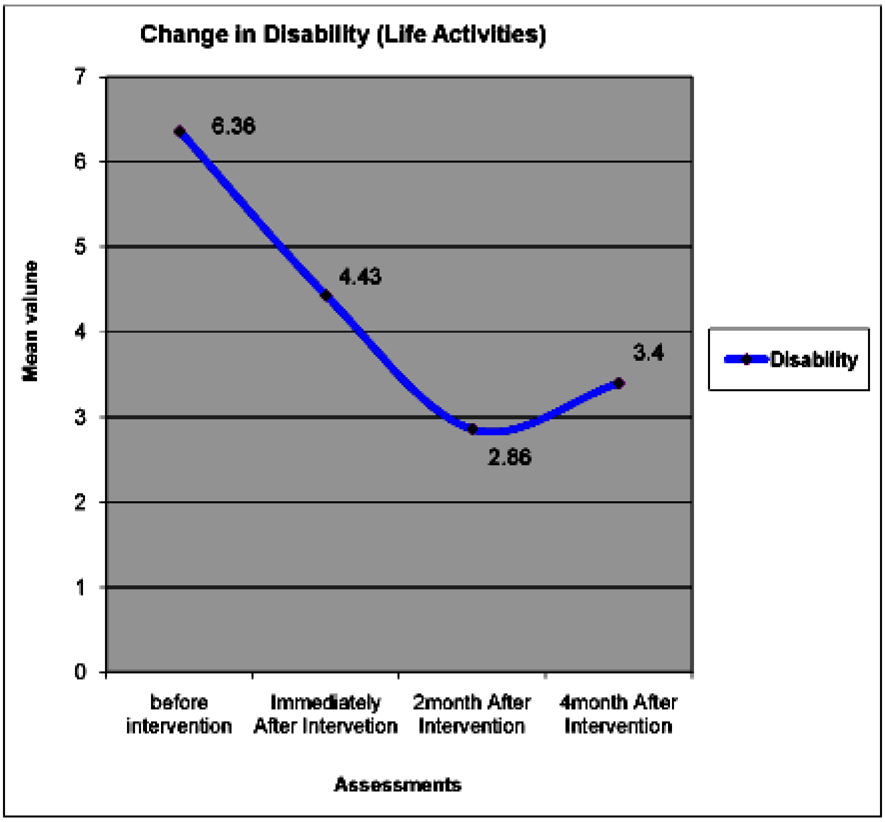


Figure-5

6. Extent of Changes in Disability Domain (Participation in Society) over different time periods among Rural Persons with Schizophrenia: (1=Before intervention, 2=Immediately After intervention, 3=Second month After intervention, 4=Fourth month After intervention)

The results of Repeated Measure ANOVA conducted on Participation in Society to verify the differences in the mean scores at the four time intervals (1 – 2, 1 – 3, 1 – 4, 2 – 3, 2 – 4, 3 – 4 assessments). It shows that there was a significant (P<0.001) reduction in the mean score on this domain of Disability during this period. Moreover it also indicates that improvement in the Participation in Society was sustaining during the subsequent assessments followed by the Psychiatric Social Work Intervention. The overall change in mean value of this domain is shown in figure: 6.

6. Extent of Changes in Disability Domain (*Participation in Society*) over different time periods among Rural Persons with Schizophrenia: (1=Before intervention, 2=Immediately After intervention, 3=Second month After intervention, 4=Fourth month After intervention)

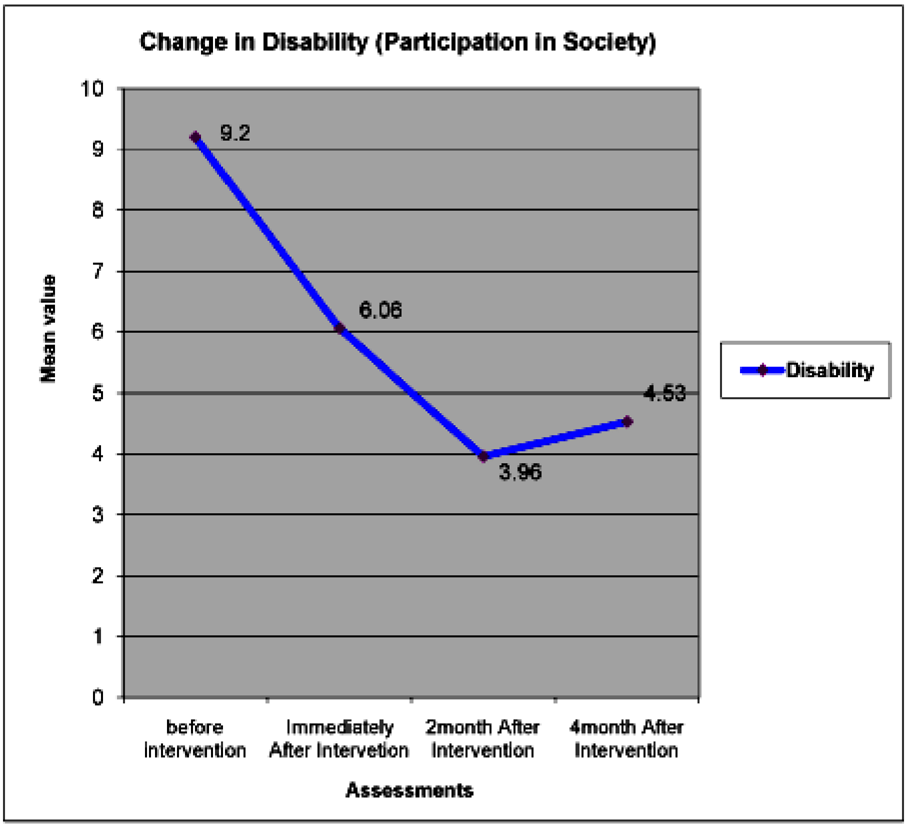


Figure-6

Discussion:

I. Socio-demographic Characteristics of Rural Persons with Schizophrenia:

Majority (72 %) of the samples were in the age range of 18 – 40 years. Among these samples 36% of them were in the age group of 21 – 30 years and highlighting the fact that most individuals affected by the schizophrenia were in the economically productive age group. The gender wise distribution of the sample indicated that sixty two percent of the samples in the study were male patients. Several studies have documented the reason for the under utilization of health services by women in India was lack of access to health care (Ramalingaswami, 1987; Khan et al., 1982). With regard to marriage, 53% of the samples in the study were married while 30% were never married. A majority of the patients were Hindu (86.7%) and Muslim contributed 13.3% of the sample. The unequal representation of the sample is due to national characteristics. Majority (30%) of the subjects in the samples were primary school educated. On the whole the highest educational qualification among the respondents was higher secondary which was done by 6% of sample. Majority of the respondents 46% were illiterate. Educational impairment was well documented in literature on Quality of Life in patients with schizophrenia (Calvocoressi et al, 1998).

The occupational status of the respondents is also an indicator of disability related issues. Around 60% of the sample in the study was unemployed due to schizophrenia and 26.7% of the samples were coolies. Many of the respondents who employed are performing poorly and may be in danger of losing their jobs. As far as the income of the respondents is concerned 60% of the respondents did not have any income of their own, 30% percent of them had a monthly income of below Rs.500 and only 6.7% had a monthly income of Rs. 1001 – 2000. The group was characterized by low educational levels, poor occupational status and low income levels. These findings reflect the low per capita income of unorganized sector in our country. Lower income can also intensify the problems in the family following the diagnosis of Schizophrenia. With regard to duration of illness 46% of the samples had illness for 2-4 years, 16% of them had illness between 6-8 years and 23% of the subjects had illness more than 10 years. Majority (80%) of the respondents had the diagnosis of paranoid Schizophrenia.

II. Socio-demographic Characteristics of Family Members of Rural Persons with Schizophrenia:

In this study, majority (56.7%) of the caregivers belong to nuclear family, reflecting the changing structure of families in the Indian society and changes in the social support system networks that can result to this. Indian families are in a state of transition and the joint family structure is undergoing radical changes resulting in the nuclear households as a means of adaption. This shrinkage of the family size also results in narrowing down the supportive networks that is essential in the coping process with schizophrenia more during the symptomatic stage.

With regard to the age distribution of care givers of the respondents, majority (36.7%) of the family members were between 51 – 60 years, and about 53.3% of the care givers were female and majority (66.7%) of them were working as coolies. Care giving is a complex and challenging phenomenon and women often face the dual challenge of care giving and dealing with their own vulnerability. As Bharat (1995) pointed out, in countries like India, care givers would either be the elderly parents, often physically and financially weaker, or wives or partners who mainly occupy position of dependency. Thus, on the whole the subjects in the study are heterogeneous in nature covering several background variables.

III. Extent of Changes in Disability Domains (Effects on Disability among persons with Schizophrenia in Rural Areas):

One of the aims of Social Work intervention in the field of psychosocial rehabilitation is to improve the level of disability of persons with severe mental illness like Schizophrenia. As far as the effects of Psychiatric Social Work intervention is concerned, the findings of the present study showed that overall, there was a significant reduction in the mean scores of all the domains of Disability like Understanding and Communicating, Self Care, Getting along with People, Life Activities, and Participation in the Society except Getting Around. The improvement in disability was consistent at different level of assessments such as immediately after intervention, second month after intervention and fourth month after intervention. Similar to these findings, Chandrasekhar-Rao (1994), who reported that the Social Work intervention was shown significant improvement in persons with depression consistently over different time periods.

After the Psychiatric Social Work Intervention, there was a significant reduction in this domain of disability namely-Participation in Society. Hogarty, et al., (1979), who reported that during the total period of intervention, the effect of Social Work intervention was significantly more in reducing the level of disability along with psychopharmacology drugs. The improvement in this domain was sustained during the subsequent assessments such as second month after intervention and fourth month after intervention. There was a significant reduction in the mean score of this domain-Getting along with people. The finding of the present study is similar to the findings of Thara and Latha (1998), who have reported that the schizophrenic patients had significant improvement in the area of dealing with people after intervention. The improvement in this domain was sustained even in the second month after intervention and fourth month after intervention. There was no significant change in the domain of Getting Around immediately after the Social Work intervention. But there was a significant change during the subsequent assessments such as second month after intervention and fourth month after intervention.

Overall, after the Social Work Intervention, there was a significant reduction in the mean scores of all the domains of disability like Understanding and Communicating, Self Care, Getting along with People, Life Activities, Participation in the Society, and Getting Around. This proves that the Social Work Intervention could reduce the disability and improve the social functioning of persons with schizophrenia in rural areas. This is consistent with earlier research studies (Hogarty and Goldberg, 1973; Linn et al., 1979; Stein and Test, 1980; Bentley, 1990; Viswanath and Padmavathi, 1992).

Limitations of the Study:

The limitations of the present study are as follows:

1) The sample size for the intervention group was only 30. This size is not big enough for generalization of the findings.
2) The inclusion criteria of the sample ensured that only patients who were not actively symptomatic included in the study. This excludes a number of patients who have serious symptomatology. Whether Social Work intervention is useful for them or not, cannot be gauged from the study.
3) Owing to time constrains, the assessment after intervention was restricted to 2nd month and 4th month assessments only.

Conclusion:

The purpose of this research work was to establish Psychiatric Social Work Intervention model for persons with schizophrenia in the rural areas. In doing this, factors that are associated with the development of the intervention model and the outcome in terms of disability management were specifically studied. It is evident from the findings that Psychiatric Social Work Intervention is effective in helping the persons with schizophrenia in reducing their disability and improving their social functioning. The study established the usefulness of a Group Work Approach in dealing with patients suffering from schizophrenia in rural areas. Conducting similar studies in different settings, would contribute the Social Work knowledge so as to make this profession more meaningful in future.

References:

1. Appelo,M.T., Woonings,FM.J., Van Nieuwenhuizen,C.J., Emmelkamp,F., Slooff,C.J., & Louwerens,J.W. (1992). Specific skills and social competence in Schizophrenia. Acta Psychiatrica Scandanavica, 85,419-422.

2. Bentlay,J.K. (1990). An Evaluation of Family-based Intervention with Schizophrenia using Single-system Research. British Journal of Social Work, 20,101-116.
3. Bharat,S. (1995). Issues in care and Support. The Indian Journal of Social Work, 6, 177-193.
4. Calvocoressi,L., Libman,D., Vegso,S.J., McDougle,C.J., & Price,L.H. (1998). Global functioning of inpatients with Schizophrenia, OCD, Major Depression. Psychiatric Services, 49, 379-81.

5. Chandrasekhar-Rao. (1994). Social Work Measures with Neurotic Depression. Ph.D thesis (Unpublished), submitted to Bangalore University, Bangalore.

6. Hogarty,G.E., & Goldberg,S.C. (1973). Drug and Sociotherapy in the Aftercare of Schizophrenic Patients. Archives of General Psychiatry, 28, 54-64.
7. Hogarty,G.E., Schooler,N.R., Olrich,R. (1979). Fluphenazine and Social Therapy in the Aftercare of Schizophrenic patients. Archives of General Psychiatry, 36, 1283-94.

8. Khan,M.E., Gosh-Dastitar,D.K., & Singh,R. (1982). Nutrition and health practices among rural women: A case study of Uttar Pradesh, India. Paper presented at the International symposium on problems of development of under privileged communities in the Third World, October, 1982, New Delhi.

9. Kraeplin,E. (1971). Dementia Praecox and Paraphrenia, (translated) by R.M.Barclay Huntington, New York, RE Kreiger.

10. Linn,M.W., Caffey,E.M. & Klett,C.J. (1979). Day Treatment and Psychotropic Drugs in the Aftercare of Schizophrenic patients. Archives of General Psychiatry, 36, 1055-1066.

11. Ramalingaswami,P. (1987). Women's access to health care. Economic and Political Weekly, July 4, 1075-1076.

12. Stein,L.I. & Test,M.A. (1980). Alternative to Mental Hospital Treatment. Archives of General Psychiatry, 37, 392-412.

13. Thara,R & Latha,S. (1998). Management of Social Disabilities in Schizophrenia. Indian Journal of Psychiatry, 8(3-4), 35-39.

14. Viswanath,N.K. & Padmavathi,R. (1992). Family intervention in Schizophrenia through group sessions: an experiential study. Indian Journal of Social Psychiatry, 8(3-4), 35-39.

15. World Health Organization. (1992). International Classifications of Diagnostic Guidelines for Behavioural and Mental Disorders, Avenue Appia 20, 1211, Geneva.

16. World Health Organization. (2000). WHO Disability Assessment Schedule – II, Version 3.1a., WHO, Geneva.

17. World Health Organization. (2001). World Health Report, Mental Health: New understanding. New Hope, Geneva.

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 2
July 2011– June 2012

Unpacking drug detoxification in Nepal: in-depth interviews with participants to identify reasons for success and failure.

Dr. Chandra Kant Jha, PhD
Holloway Aged Care Services
East Keilor, Victoria
Australia

Professor David Plummer
James Cook University & Queensland Health

Citation:
Kant CK & Plummer D. (2012) Unpacking drug detoxification in Nepal: in-depth interviews with participants to identify reasons for success and failure. ***International Journal of Psychosocial Rehabilitation. Vol 16(2) 50-61***

Correspondence:
Dr. Chandra Kant Jha, PhD
13 Bronzewing St
Williams Landing, VIC 3027
Email: chandrajha@hotmail.com

Acknowledgement:
Sincere thanks to the participants for sharing their important insights and experiences regarding drug detoxification in Nepal.

Abstract

Objective: This study conducted an in-depth exploration of the factors which helped people to detoxify from drugs and the factors which led to relapse among 20 participants from Kathmandu and Pokhara in Nepal.
Methods: The research took a phenomenological approach using in-depth interviews for data collection and all data were analyzed using a grounded theory framework.
Results: The study found that detoxification and rehabilitation services for drug users were mostly provided by private organizations. Some of these organizations had a comprehensive plan, trained staff and counselors. Most counselors were ex-drug users, and they functioned as mentors and role models who helped some drug users to realize that successful detoxification from drugs is possible. This approach enabled current drug users to adhere to the detoxification program. These service providers recognized that 'frustration' and lack of support are leading causes of a relapse. The best programs included activities to help the drug users to confront these frustrations. Participants who demonstrated a strong ability to manage the frustrations inherent in drug withdrawal were considered to be more able to avoid relapse after discharge.
Conclusions: The evidence-base is lacking concerning successful detoxification and rehabilitation in Nepal. There is also no clear policy on detoxification and rehabilitation services. The Government of Nepal needs to develop guidelines for coordination, supervision, monitoring, evaluation and accreditation of organizations which provide detoxification and rehabilitation services.

Key words: Nepal, drug use, detoxification, rehabilitation, counseling, relapse

Background

The World Health Organization (WHO) estimates that there are between 3.4 and 5.6 million injecting drug users living in South-East Asia (WHO 2008). It is estimated that there are 150,000 drug users in Nepal, of which 5% are female (The Press Institute 2010). Although the region has a predominance of heroin use, the use of pharmaceutical drugs is increasing (usually in a combination of two or more brands, such as buprenorphine, benzodiazepines and antihistamines) (WHO 2008). In the light of increasing HIV and other serious health consequences of injecting drug use, detoxification is becoming a growing priority. High relapse rates raise questions on the contents and efficacy of detoxification programs, which aim to enable drug users to remain drug free in the long term (WHO 2009; WHO 2010).

Traditionally, it has been considered that holding drug users in custody or prison would prevent their access to drugs, and that staying away from drugs for a few months would enable them to live without drugs indefinitely (Fletcher, Lehman et al. 2009; Coviello, Cornish et al. 2010; Lobmaier, Kunoe et al. 2010). However, these approaches have historically fallen well short of expectations, not least because drugs are often accessible in prisons. Moreover, despite staying in custody without drugs, in some cases for years, relapsed after release was common (Jha 2006). Contextual factors, such as, the availability of drugs, peer networks with links to drugs, and not having other means of income generation, contributed to high rates of relapse (Washton 1988; Jha 2006; Wang and Wang 2007; Jha and Madison 2009).

In contrast to the classic “prohibitionist approach” outlined above, a second strategy known as harm reduction emerged as an attractive alternative. Here the focus shifts to a more pragmatic approach, especially safer drug use in the interim until permanent detoxification can be achieved (Ritter and Cameron 2006; Ball 2007; Zador, Lintzeris et al. 2008). A key priority of harm reduction was to minimize HIV and Hepatitis C transmission between drug users. However, this approach was not palatable to many policy makers and bureaucrats, especially where it entailed the distribution of sterile needle and syringe to drug users and their subsequent disposal (Ball 2007; Zador, Lintzeris et al. 2008; Des Jarlais, McKnight et al. 2009). On the contrary, harm reduction was considered to be a ‘recipe’ for encouraging drug use. Although this program showed ground breaking results in containing HIV transmission in other countries, it remained controversial and undermined large-scale implementation of harm reduction in many countries (Ritter and Cameron 2006; Ball 2007; Zador, Lintzeris et al. 2008; Des Jarlais, McKnight et al. 2009), including Nepal (Jha 2006). Although detoxification and rehabilitation was considered to be a core component of harm reduction, these aspects received far less attention than did needle and syringe distribution and disposal. Never-the-less, harm reduction was started in Nepal in 1993 by an NGO in limited parts of the Kathmandu Valley, but from the beginning, the approach was constrained by lack of funding and weak political and bureaucratic support and ultimately it was not sustainable (Expert Forum on Demand Reduction in South and South West Asia 1995; Seminar on harm reduction 2000; Peak, Rana et al. 2001; Jha 2006; Jha and Madison 2009).

A third strategy for reducing drug use was known as “demand reduction”. This approach emphasized “awareness and education” programs (DADRP 1996). The Ministry of Home Affairs in Nepal has a narcotic control section, which stresses law enforcement, and runs the Drug Abuse Demand Reduction Project (DADRP). DADRP focuses on demand reduction by creating awareness of the risks of drug use among young people (Jha 2006). Although the program probably helped many youths to become aware of drugs, and to avoid the risks associated with drugs (Einstein 2007; Degi 2009), the project does not provide any assistance to current drug users.

NGOs provide the majority of detoxification and rehabilitation services to drug users in Nepal. The duration of detoxification varies from three to twelve months. Most of these NGOs are privately run by ex-drug users, who have devised strategies of detoxification from their personal experiences (Singh 1997; Jha 2006). While there is no doubt that personal experience is extremely valuable, these programs lack a rigorous evidence-based focus and vision. These NGOs do not have trained clinical staff, such as nurses and doctors to provide effective treatment and care to their patients, although a few NGOs consult general physicians for symptomatic treatment if someone experiences intense withdrawal symptoms. In other cases, the ex-drug users provide the same medications that they used for their own detoxification. Some NGOs use a "cold turkey" approach with purely psychological treatment (Jha 2006). The drop-outs from those centers are high largely during the withdrawal phase.

A few major hospitals in Nepal have psychiatric units which provide drug treatment without specific counseling or rehabilitation services. Although the content and effectiveness of rehabilitation process is not documented, a few NGOs provide rehabilitation services. Common rehabilitation activities include 'Twelve Steps' 'Narcotics Anonymous', yoga, meditation, sport, education, counseling and vocational training (Jha 2006).

The Government of Nepal provided methadone substitution therapy to some drug users in Kathmandu Valley in 1994, through a mental hospital. Although this program was initially effective in keeping some drug users enrolled in the treatment, drop-outs started to increase (UNGASS 2010). However, this program was severely restrained due to lack of funding, logistical resources and insufficient trained psychiatrists and nurses, which led to its closure. Recently, the government of Nepal initiated a pilot project with buprenorphine and methadone substitution therapy to contain HIV transmission in injecting drug users (IDUs) through two Kathmandu-based hospitals and one Pokhara-based regional hospital. However, the number of the enrolled drug users accessing these hospitals has been documented to be small (UNGASS 2010). The other popular pharmacological combinations used in psychiatric units in Nepalese hospitals are naltrexone and clonidine (Tamrakar and Koirala 2007). Some private clinics provide these treatments to clinic attendees, however, their compliance is not assured. Apparently, hospitals and clinic-based treatments do not incorporate psychological support and rehabilitation services, leading to relapse or discontinuation of the treatment (Singh 1997; Jha 2006; Jha and Madison 2009).

The above outline clearly demonstrates that there is a lack of scientific and evidence-based drug detoxification and rehabilitation services in Nepal. Although a small number of private organizations and hospitals run detoxification services, they do not have solid foundations of evidence, quality and audit. These services lack holistic care and they also lack the technical and clinical capacity to address the issues of detoxifying drug users effectively. Methadone substitution received inconsistent funding and logistical support, and the program subsequently closed. The Government and donors seem to have paid insufficient attention to formulating effective policies and implementing systematic evidence-based strategies, including monitoring and evaluating service providers.

Purpose of the study

Given the complexities around recovery from illicit drug use, this study aims to explore and unpack the major issues associated to drug detoxification and rehabilitation services in Nepal, by exploring the in-depth experiences of drug-users who have attempted drug withdrawal and rehabilitation. The findings will be instrumental for reforming policies and strategies to scale up drug detoxification and rehabilitation services. As the relapse rates are currently very high, the findings will be crucial to plan relapse prevention strategies as well.

Methodology:

In order to explore the complex issues around drug detoxification and rehabilitation, the lived 'experiences' of drug user, who sought detoxification and rehabilitation services will constitute a rich source of data for this research. Employing a suitable theoretical approach to study the 'experiences' of the participants, has been crucial. Therefore, this study used phenomenology based on Moustakas (Moustakas 1994) as the theoretical framework to explore the meanings embedded in participants' 'experiences', in relation to their efforts to detoxify and rehabilitate from drugs. This version of phenomenology, sometimes known as transcendental phenomenology aims to capture the very central meanings attributed to an object or phenomenon by an individual. These meanings are often embedded in the core of peoples' experiences (Stroker 1993; Moustakas 1994). Transcendental phenomenology aims to capture the wholeness of human experiences, which have been constructed with direct and indirect interaction with the nearest material and abstract world, which entirely reflects on the surroundings, broader social and cultural contexts (Stroker 1993;

Moustakas 1994). This methodology reflects the need of the research to examine drug related experiences in association with social factors, social context and through the underlying meanings which inform participants experiences and which they use to interpret, understand and regain control over their world.

Learning to use drugs and efforts to quit drugs are entirely the social experiences (Jha 2006). These happen when the individual comes into interaction with other individuals or the circumstances created by people in which drug use or recovery from drug use is possible (Jha 2006; Jha and Madison 2009). While reflecting on participants' drug use and detoxification experiences, it is crucial to examine their backgrounds, life patterns, life-goals, familial and social contexts, status of drug detoxification and rehabilitation services, government's health and human related plan, policies, status of support systems and so on. In short, to take an holistic approach which aims to capture meaningful picture, which is as complete as possible.

This study uses grounded theory as a sophisticated tool for data analysis, which leverages the coding of data to generate themes and concepts (Glaser and Strauss 1967). Transcendental phenomenology and grounded theory have similar analytical approaches, as both use coding to reveal major concepts and to develop themes (Glaser and Strauss 1967; Moustakas 1994). In addition, the latter stresses the recruitment of participants with contrasting characteristics, which offers diversity in data, suggesting how the themes can be related to complex social situations (Glaser and Strauss 1967). As the analytical approach of grounded theory employs comparisons and contrasts as well as pattern finding, it is believed that the final results will be particularly rich in meaning and, under the right circumstances, potentially transferrable (Glaser and Strauss 1967; Strauss and Corbin 1998).

Objective: The main objective of this study is to explore the factors, which helped the participants to detoxify from drugs and to stay drug-free, and the factors which led to relapse into drug use in Nepal.

Samples and geographical areas: The study included 20 heroin users (15 males and 5 females) from the Kathmandu Valley and Pokhara. Recruitment was achieved through a combination of purposive and snow ball sampling techniques (Llewellyn, Sullivan et al. 1999; Schofield and Jamieson 1999). The participants were recruited through a number of local detoxification centers and non-government organizations (NGOs) which work with drug users. Participants were between 19 to 45 years of age. An information sheet, which detailed the study, was provided to NGOs, so that the prospective participants could read, and make an informed decision whether or not to voluntarily participate in the study. The study was anonymous, and a range of measures were taken to safeguard the privacy and confidentiality of participants.

Data collection and analysis: In-depth interviews were conducted with participants using methods described by Minichiello et al (Minichiello, Aroni et al. 1995). Each interview was between one and two hours in length. Emphasis was put on knowing what factors were helpful when stopping drug use; how participants felt while detoxifying; what factors contributed to relapse; and what factors helped them remain drug free. All interviews were conducted in Nepali and then transcribed into English. The meanings in data were captured and summarized using codes. Codes with similar meanings were clustered and then major categories were identified (Glaser and Strauss 1967; Strauss and Corbin 1990). These categories reflected emerging concepts that demonstrated relevance to the research (such as 'ambivalence' around drug detoxification in Nepal).

Ethical approval: This study was approved by the ethics committee of the University of New England, Australia.

Limitations of the study: Although some findings are comparable to studies undertaken elsewhere, generalization from this study should only be done with caution. This study attempts to catch as complete picture as possible through sampling of diverse cases, but sampling was not random. The study was more concerned with examining cases in depth than in quantity. What emerged were illustrative cases which can be used as a roadmap for further studies and as a basis for planning in Nepal. Beyond Nepal, there are lessons that can be learned from this study, which people might draw upon.

Another limitation of this study is that it does not attempt to forecast how long former drug users will stay drug-free. A number of factors, including social and economic circumstances seem to contribute to relapse as indicated in this study. The participants were not followed up after the collection of data.

Results

The participants had both positive and negative experiences regarding the role of drug detoxification centers. Although some participants described the 'intrinsic factors' and overall management of drug detoxification centers in positive ways, they were not confident that they would be able to stay drug-free. Some participants were highly critical, arguing that some of these centers were counterproductive in their attempts to quit drugs. Both the positive and negative experiences of the participants associated with drug detoxification centers are discussed below.

Constructive experiences with drug detoxification and rehabilitation centers

Some participants felt that the role of the detoxification centre was instrumental in helping them to quit drugs and to stay drug free. A number of the participants' concerns relating to detoxification were explored. For example, some participants emphasized the cost of seeking detoxification; the need for support from family members; the importance of providing for very basic needs such as food and shelter; the need to protect their morale; and the need to exhibit caring attitudes. Although these concerns emerged as dominant, participants who were disconnected from family, or who did not have family support, placed even higher priority on those concerns while deciding whether to undergo detoxification. As Seema states:

People from a detoxification centre have helped me to detoxify from drugs. They have provided free treatment. They are providing free food, shelter, love and affection. These are major supports. For a junkie there is no fixed place where they can eat and stay. [Seema]

Seema, who has been left by her husband, felt she had no support from her family for her detoxification. Having free detoxification, including food, shelter, support and affection from staff members of a detoxification centre, was crucial for her attempts to give up drugs.

By and large, participants experienced coping with 'withdrawal symptoms' as a major challenge. For example, Bhawana explains her difficulties while not taking drugs and the ways she overcame them:

When I came to a drug rehabilitation centre I became sick due to not taking drugs there. I had many feelings compelling to take drugs. That time I felt that I can't live without taking drugs. At the same time, I went to the coordinator of that centre and I shared my feelings that I can't stay here without taking drugs. She counseled me so nicely that the desires to take drugs were automatically changed. If she had threatened or shouted at me, that could not have helped me to detoxify at that stage. I found their approaches of counseling, assuring and giving examples really useful. I liked that in the beginning. [Bhawana, p9]

Bhawana's narrative highlights crucial issues, which are potentially useful for the rehabilitation centers. At the start of detoxification, drug users are not fully prepared to cope without taking drugs. They are often irrational and agitated when they present. Handling or helping drug users at that stage needs professional skills. However, the research found that there are some rehabilitation centers which do not have skilled staff to help drug users to overcome their desire to take drugs. Mishandling such cases will lead either to conflict or to participants dropping out of the program.

After detoxification, Shailu entered into the rehabilitation phase. In rehabilitation, there were a series of group sessions. These sessions aimed at resolving concerns on the part of detoxifying drug users, including Shailu, which would impede their recovery, in particular how they would cope in life without drugs. In such meetings, they were encouraged to share their worries and opinions and these were discussed interactively. Staff members, those who have already recovered from drugs, and counselors, shared their opinions as well. Shailu states that these interactions helped him to overcome his problems.

There are sharing sessions in the rehab in which fellow brothers, seniors, counselors and staff participate. They are good examples for us. They provide hope, courage and feedback to us. I attend their lectures. [Shailu]

Shailu's experiences reveal something of how rehabilitation centers work; what their activities are, and how these activities are helpful for drug users to overcome their need for drugs. The data demonstrates how, presumably by providing access to personal experience and support, the activities inside rehabilitation centers strengthen the 'self-determination' of drug users to stay drug-free.

The risk while going through the rigors of withdrawal is non-compliance and relapse. Although drug users reported feeling stronger during the supported treatment, staff kept monitoring them for signs that they may relapse. One of the indicators for this assessment was how well drug users handled "delayed gratification". There was evidence that staff deployed "delayed gratification" with their clients, both as part of the treatment and in order to assess how participants were able to deal with frustrations. As Pralaya's narratives reveals:

Sometimes we like to go home. In that case, they keep assessing us whether we can be patient and not take drugs. Once I asked for permission to go to my home, but they said not today, but tomorrow. I was a bit disappointed with that. We are supposed to learn to be patient. Although that's boring, tolerance has been developed. If we face or experience something undesirable, such things also help us to be patient. [Pralaya]

The focus of rehabilitation centers seems to be aimed at helping drug users to become 'tolerant and patient' and that relapsing, impatience and intolerance are major concerns. However, changing this whole 'mindset' of drug users is very challenging and takes strategic effort.

According to some participants, rehabilitation centers run 'integrated' programs. When a drug user detoxifies from drugs, a routine is made for him or her which determines what he or she will need to do at the rehabilitation centre. Those who improve well are asked to conduct sessions for other drug users at the rehabilitation centre. Besides that, they engage in other activities there, including meditation. As Amar says:

There are some detoxifying drug users in the rehabilitation centre. I take classes for them and participate in meditation. We share our problems. I am improving day by day. I feel relaxed there [Amar]

The role of rehabilitation centers, as discussed above, shows that they are shaping drug users knowledge, attitudes and behaviors constructively. Such positive changes appear to be instrumental in detoxifying people from drugs and to prevent relapse. There is a major transition underway in drug users' lives: at one stage they are living with drugs, at the next they are living without them. While using drugs, they lived a more 'irresponsible life'; after quitting, they learn to live a 'responsible life'. The role of rehabilitation centers, is crucial for some drug users to detoxify from drugs, and to prepare them to take control of their new lives.

Dissatisfying experiences with detoxification and rehabilitation centres:

Despite such a constructive contribution on the part of rehabilitation centers, some participants have clearly expressed their disappointment toward the quality of at least some detoxification programs. It was found that some rehabilitation centers lack a daily plan and activities, as well as supervision and monitoring systems. In the absence of these structural elements, participants had a dilemma to know what they could do there. In the absence of appropriate programs, they felt that staying in the rehabilitation centre was counterproductive. As Hairan states:

At a rehabilitation centre we learned about drugs which we didn't know even existed before. One of the detoxifying drug users shared about a new drug that is 'mandres'. He told us all about that drug, such as the power and energy it gives, how it works, where it is found, feelings and enjoyment…We learned many bad things there. [Hairan]

In the above narrative, poor management did indeed lead Hairan to use new drugs. Such an experience discouraged Hairan and his colleagues from attending any detoxification centre. This also reflects on the government's weakness in monitoring these organizations and ensuring the quality of their work. Organizations which work in the drug field or have drug detoxification programs are registered with the Ministry of Home Affairs if they meet certain criteria. If such weaknesses are not addressed, rehabilitation centers may even become implicated in aggravating drug use, rather than helping users to give them up.

Cost and value for money were also a source of dissatisfaction, as illustrated by Baba:

There are many rehabilitation centers these days. They do not provide quality detoxification and rehabilitation programs. All are motivated to make money. Wherever you go charges vary from Rs 6500, Rs 8000 to Rs 10000. Despite charging that amount of money they don't provide even good food. I have attended 10-12 treatment centers. These days I don't like to go to any of these rehab centers to detoxify. [Baba]

Baba gave insights into the core aspects of rehabilitation centers. The activities involved in helping people to detoxify from drugs should be competent, efficient and meet certain standards, including the provision of food and other facilities. This highlights the importance of having standardized guidelines and of ensuring the compliance of detoxification centers with those guidelines to ensure the quality of their services. However, such a comprehensive guideline and monitoring system does not appear to be provided by the government. If drug users feel that their services are not helping them to detoxify from drugs effectively, then detoxification will be drawn into disrepute; money belonging to those who often can least afford it will be wasted, and centers will merely become a way of making money and exploiting the vulnerable.

Lack of financial and moral support to homeless drug users:

Raju, an injecting drug user, has good support from his parents. Despite the high fees charged by rehabilitation centers, he attended various. In contrast, many drug users do not have such familial support. Raj, another injecting drug user has not been in contact with his family for several years. Although he is mentally prepared to detoxify, he faces a lack of money to do so.

I have heard about the various organizations, which provide drug detoxification and rehabilitation services but I haven't heard any of them providing free treatment and services. We don't have money so that we can't go for the treatment. Even remembering those organizations name won't be worthwhile. [Raj]

In Raj's narrative, he expects that he will be given treatment free of charge, or that some external support will provide help for his detoxification. Although some of these rehabilitation centers receive financial assistance from donor organizations to support poorer drug users to detoxify from drugs, this fact is not known to many drug users. **As Ram relates:**

I heard some of these organizations are given financial aid by the donor organization. How do they spend this funding? If a drug user goes for the treatment, they charge money. Then, what's the use of the aid? Donors are helping such organizations not the addicts. [Saroj]

According to Saroj, drug users, as a target group or beneficiaries do not know about what services are available for them and how these services are provided. Both the donor organizations and rehabilitation centers have not promoted their programs widely to drug users. If the organizations are funded by donor agencies to provide services, such as drug detoxification, it is important to disseminate this message to the users. Organizations which lack transparency will be the subject of criticism and their credibility will be in doubt.

Lack of motivation to detoxify from drugs

In contrast to Saroj, who feels that he cannot detoxify from drugs due to a lack of money, Lamjoi's narrative highlights that 'interest' in giving up drugs is another important factor, especially for drug users who come from wealthy family backgrounds. For example, Lamjoi's brothers and parents are willing to provide him all means of support for the cost for detoxification, food and living. However, he is not ready to take advantage of this.

My younger brothers tell me to quit drugs. They will manage all my food and living expenses. My dad has a paddy farm in the village and he receives a retirement pension. All three younger brothers work and earn money so there is no problem for me. [Lamjoi]

Lamjoi's ability to afford drugs seems to be a facilitating factor for him to continue using drugs. If Lamjoi detoxifies, his familial support will be crucial to engage him in activities that will be helpful for his rehabilitation. However, his desire to continue drugs keeps his family's expectation and their support aside. He earns money by dealing drugs, which he spends on his own drug use.

Discussion:

This study outlines some of the realities of drug detoxification and rehabilitation in Nepal by exploring the real life experiences of drug users regarding detoxification and rehabilitation. The crucial findings of this study are that many organizations which provide detoxification and rehabilitation do not have a conceptually sound frame work and do not work to consistent standards. The activities undertaken by these organizations occur in an 'ad hoc' manner. The study underscores the importance of: counseling and psychological support; overcoming withdrawal symptoms by enhancing personal efficacy; acceptance of drug users; developing coping skills to handle frustrations; role modeling and mentoring; and preparing the drug users to take responsibilities. Managing these issues well was considered to help drug users' efforts to detoxify and to remain drug free.

When users experienced 'withdrawal' symptoms, this led some to drop out of detoxification. The centers which recognized that 'withdrawal symptoms' could be a precursor to relapse, developed approaches in advance that were designed to address the needs of drug users both medically and psychologically. This is consistent with findings in other studies where it was found that symptomatic treatments, counseling and psychological supports have been crucial to overcome withdrawal symptoms in heroin users (O'Connor, Marchand et al. 2008; Chuang 2009; Lee and Cameron 2009; Singh and Sharma 2009).

Participants needed to remain free of heroin for at least the few weeks of detoxification. During this time, their self-esteem was compromised. Generally, they experienced mounting frustration, not least because of their withdrawal symptoms and their desire to relieve themselves by using drugs again. Another study highlighted that the drug users who self-reflect on their past lives and deeds, especially in relation to crimes committed to purchase drugs, felt frustrated and found it hard to cope with such frustrations, and that this can lead to relapse (Jha 2006; Einstein 2007; Jha and Madison 2009). In the current study, the staff members at some detoxification centers seemed to be skilled at helping users to overcome such frustrations. They undertook various activities to challenge their ability to cope with the frustrations. It appears that the participants gradually increased their psychological strength to cope with the frustrations associated with detoxification.

Some participants made several attempts to detoxify from drugs, but relapsed. This lowered their confidence in their ability to quit drugs. Some rehabilitation centers recognized the impact of such perceptions on drug users, and employed ex-drug users as mentors and "role models". These ex-users were able to share their positive experiences of how they could stay drug free. Their experiences motivated some users to remain in detoxification programs, and to follow the day-to-day plans of the centers.

In contrast to above, some organizations did not have a conceptual framework and day-to-day routines designed to address the various needs of the drug users. In the absence of a day-to-day plan, participants had little to distract them from their withdrawal symptoms and their desire to use drugs again to relieve them. In these cases, participants found little support from the detoxification centers to cope. Moreover, because they were poorly supervised, they had ample opportunity to access and continue taking drugs. This finding highlights the urgent need for accreditation of the detoxification and rehabilitation centers, and their compliance with the minimum standards, which is lacking in Nepal.

While relapse is well known among drug users, the lack of standards almost certainly results in more relapses than there should be. Not having clear plans and strategies for detoxification and rehabilitation, indicates that little importance is attached to detoxification and rehabilitation centers and the people who need them. Enrolling in such centers is a financial burden to the users and their families and having programs that are indifferent to their outcome is unacceptable. Such relapses decrease the motivation of the users to seek further detoxification and undermine the credibility of drug treatment more generally.

While the efficacy of these centers remains an ongoing question, a large number of drug users do not have sufficient money to attend the centers. A significant proportion of drug users in Nepal are homeless (Jha 2006; Jha and Madison 2009). Others, who live in a joint family, also tend to live on the street or with drug using colleagues due to intense familial stigma. As far as successful detoxification and rehabilitation is the ultimate goal, the issues of homeless and poorer drug users impose serious challenges. Their drug use is sustained by their dual roles: as drug user and as drug seller. They use the income earned from dealing in drugs to buy drugs and maintain their habit, as well as for their survival needs (Jha 2006; Jha and Madison 2009). Some drug users engage in pick-pocketing and theft (Jha 2006; Jha and Madison 2009). The direct and indirect costs of attending detoxification and rehabilitation centers rule these services out-of-reach for homeless and poorer drug users. For these people integrated and long-term support is needed from government and donor agencies. It will also be crucial to have their health, social, financial, housing and legal needs attended to before undertaking detoxification and rehabilitation. By not addressing these concerns, gaps are left in the continuum of detoxification and rehabilitation, which will lead to relapse eventually. This situation underscores the need to have a long-term vision and support from government and donor organizations. Such a project will provide an opportunity to the street-based and homeless drug users to detoxify from drugs and undertake rehabilitation activities effectively and on a scale that is meaningful.

Although the donor organizations have funded some of the organizations, which work in the drug field, such funding is largely directed at creating awareness and decreasing the risk of HIV transmission. Most detoxification centers are privately operated and have a commercial motive. For many, the cost is simply not feasible and the profit motive is clearly compromising public health.

Conclusions and recommendations:

This study highlights the lack of a formal official conceptual framework concerning drug detoxification and rehabilitation in Nepal. Instead, there has been an ad-hoc approach using various models and inconsistent or absent standards. There is also a clear gap in providing a continuum of services to drug users between their first consultation with a drug detoxification center and follow-up support after their discharge. Complexities around drug addiction have long term implications on socio-cultural, economic, and health grounds, not to mention the well-being of drug users themselves. There is a lack of coordination between the government, family, community and related stakeholders on the issues of drug detoxification and rehabilitation. The following recommendations are deemed to be instrumental:

Partnerships between hospital-based mental health units and community-based NGOs: The study highlights that the private sector alone does not have adequate resources, expertise or capacity to provide holistic detoxification and rehabilitation services. On the other hand, hospital based mental health units who provide detoxification lack rehabilitation services. Therefore, it is crucial to foster collaboration and partnership between hospitals and community-based rehabilitation centers to utilize their services for the continuum of detoxification and rehabilitation services. For example, in the first consultation with a drug user who seeks detoxification, the NGO staff should assess his or her genuine motivation for quitting drugs, and refer to the mental health unit for the detoxification, which may last 2 to 4 weeks. If the mental health unit does not have adequate beds, alternative arrangements should be made to provide pharmacological treatment under the direct supervision of trained clinical staff. After detoxification, the client should be discharged to a well-equipped NGO for 2 to 6 months for rehabilitation, which includes adequate nutrition, trained staff, well structured activities (such as recreation, sporting, meditation, yoga), counseling and psychotherapy, self-help groups, vocational training, family therapy, education and awareness and regular health reviews. NGO staff should assess the determination of patients and the potential for relapse. As unemployment contributes to relapse, the rehabilitation center should also focus on developing vocational skills which may be helpful to get a job after discharge. After completion of rehabilitation, the family-based counseling will be useful to help individuals to receive familial support. After discharge, the rehabilitation center should design a follow up plan in consultation with the ex-drug users and their families, where possible.

- **Operational guidelines, supervision, monitoring and evaluation:** The Government of Nepal's drug prevention program and the Ministry of Health should provide advocacy and leadership by bringing the relevant drug rehabilitation centers together. Both ministries should conduct regular meetings with the rehabilitation centers, and develop a common reporting mechanism on a periodic basis. The Government of Nepal should have a clear policy, goal and strategies to encourage and support drug detoxification, promote rehabilitation and provide support to drug users to avoid relapse. The government should encourage the rehabilitation organizations to develop their goals and strategies which will complement the government's goals. This will help the rehabilitation centers to comply with the recommended guidelines. Such a consolidated approach will be worthwhile to evaluate the effectiveness of the goals and strategies and to measure changes in the lives of drug users. The government of Nepal should also have a formal process of accreditation of those organizations, which will contribute to ensuring the quality of services provided by these organizations.

- **Capacity building:** While many such organizations lack clear strategy and approaches, it will be highly appreciated that the government of Nepal, as a central coordinating body, organize experts who will gather evidence from other detoxification and rehabilitation centers, and use these results for evidence-based practice and to train staff in these organizations. Capacity building will be crucial to optimize the services of the local detoxification and rehabilitation centers. The Government of Nepal also needs to allocate funding, as well as coordinate with donor organizations to support detoxification and rehabilitation initiatives.

References:

Ball, A. L. (2007). "HIV, injecting drug use and harm reduction: a public health response." Addiction 102(5): 684-690.

Chuang, P. (2009). "[A case report on methadone withdrawal syndrome]." Hu Li Za Zhi 56(6): 95-100.

Coviello, D. M., J. W. Cornish, et al. (2010). "A randomized trial of oral naltrexone for treating opioid-dependent offenders." Am J Addict 19(5): 422-432.

DADRP (1996). National Drug Demand Reduction Strategy 1996-1999. Kathmandu, Nepal, United Nations International Drug Control Programme under the Drug Abuse Demand Reduction Project (NEP/92/775): 1-37.

Degi, C. L. (2009). "A review of drug prevention system development in Romania and its impact on youth drug consumption trends, 1995-2005." Drug Alcohol Rev 28(4): 419-425.

Des Jarlais, D. C., C. McKnight, et al. (2009). "Doing harm reduction better: syringe exchange in the United States." Addiction 104(9): 1441-1446.

Einstein, S. (2007). "Traditional and other drug use(r) intervention: necessary critical parameters." Subst Use Misuse 42(2-3): 447-463.

Expert Forum on Demand Reduction in South and South West Asia (1995). Nepal: The drug abuse scene. New Delhi, Expert Forum on Demand Reduction in South and South West Asia: 1-20.

Fletcher, B., W. Lehman, et al. (2009). "Measuring collaboration and integration activities in criminal justice and substance abuse treatment agencies." Drug Alcohol Depend 103 Suppl 1: S54-S64.

Glaser, B. and A. Strauss (1967). The discovery of grounded theory: Strategies for qualitative research. Chicago, Aldine.

Jha, C. (2006). Reconstructing the self: A Nepalese context of living with stigma, HIV and marginality; Published PhD thesis. School of Health. Armidale, University of New England. PhD: 282.

Jha, C. and J. Madison (2009). "Disparity in health care: HIV, stigma, and marginalization in Nepal." J Int AIDS Soc 12(1): 16.

Lee, N. and J. Cameron (2009). "Differences in self and independent ratings on an organisational dual diagnosis capacity measure." Drug Alcohol Rev 28(6): 682-684.

Llewellyn, G., G. Sullivan, et al. (1999). Sampling in qualitative research. Handbook for research methods in health sciences. V. Minichiello, G. Sullivan, K. Greenwood and R. Axford. Sydney, Pearson Education Australia: 658.

Lobmaier, P. P., N. Kunoe, et al. (2010). "Naltrexone implants compared to methadone: outcomes six months after prison release." Eur Addict Res 16(3): 139-145.

Minichiello, V., R. Aroni, et al. (1995). In-Depth Interviewing. Sydney, Pearson Education australia Pty Limited.

Moustakas, C. (1994). Phenomenological Research Methods. USA, SAGE Publications, Inc.

O'Connor, K., A. Marchand, et al. (2008). "Cognitive-behavioural, pharmacological and psychosocial predictors of outcome during tapered discontinuation of benzodiazepine." Clin Psychol Psychother 15(1): 1-14.

Peak, M., S. Rana, et al. (2001). HIVand Injecting Drug use in Selected Sites of the Terai, Nepal. Kathmandu, Family Health International: 56.

Ritter, A. and J. Cameron (2006). "A review of the efficacy and effectiveness of harm reduction strategies for alcohol, tobacco and illicit drugs." Drug Alcohol Rev 25(6): 611-624.

Schofield, M. and M. Jamieson (1999). Sampling in quantitative research. Handbook for research methods in health sciences. V. Minichiello, G. Sullivan, K. Greenwood and R. Axford. Sydney, Pearson Education Australia: 658.

Seminar on harm reduction (2000). Harm reduction program in Nepal. Seminar on harm reduction, Jersey, UK.

Singh, M. (1997). "A harm reduction programme for injecting drug users in Nepal." AIDS STD Health Promot Exch(2): 3-6.

Singh, S. M. and B. Sharma (2009). "Unintentional rapid opioid detoxification: case report." Psychiatr Danub 21(1): 65-67.

Strauss, A. and J. Corbin (1990). Basics of qualitative research: Grounded theory procedures and techniques. Newbury Park, CA, Sage Publications.

Strauss, A. and J. Corbin (1998). Basics of qualitative research: Grounded theory: Techniques and procedures for developing grounded theory. Thousand Oaks, CA, Sage.

Stroker, E. (1993). Husserl's transcendental phenomenology. Stanford, California, Stanford University Press.

Tamrakar, S. M. and N. R. Koirala (2007). "Latest advances in de-addiction strategies." Kathmandu Univ Med J (KUMJ) 5(1): 124-128.

The Press Institute (2010). "Drug Addiction and HIV Rates on the Rise in Nepal ". from http://www.globalpressinstitute.org.

UNGASS (2010). "UNGASS country progress report Nepal." from www.unaids.org.

Wang, Z. Z. and Q. Wang (2007). "Investigation of direct causes of drug relapse and abstainers' demands in a compulsive detoxification center in Wuhan City of China." Biomed Environ Sci 20(5): 404-409.

Washton, A. M. (1988). "Preventing relapse to cocaine." J Clin Psychiatry 49 Suppl: 34-38.

WHO (2008). Operational guidelines for the management of opioid dependence in the South-East Asia Region. New Delhi.

WHO (2009). Guidelines for the Psychosocially Assisted Pharmacological Treatment of Opioid Dependence. Geneva.

WHO (2010). "Treatment of opioid dependence." from http://www.who.int/substance_abuse/activities/treatment_opioid_dependence/en/.

Zador, D., N. Lintzeris, et al. (2008). "The fine line between harm reduction and harm production--development of a clinical policy on femoral (groin) injecting." Eur Addict Res 14(4): 213-218.

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 2
July 2011– June 2012

Positive effects of Spirituality on Quality of life for People with Severe Mental Illness

Dr. Young, K.W., PhD, RSW
Social work Department
Baptist University of Hong Kong

Citation:
Young KW (2012).Positive effects of Spirituality on Quality of life for People with Severe Mental Illness. ***International Journal of Psychosocial Rehabilitation. Vol 16(2) 62-77***

Correspondence
Dr. Young, K.W.
Social work Department
Baptist University of Hong Kong
1/F, Blk 1 Low-rise Building, Renfrew Road,
Kowloon Tong, Kowloon, Hong Kong
E-mail: danielyoungkw@yahoo.com.hk

Abstract

Recently, various bio-psycho-social factors have been identified in relation to quality of life for people with mental illness, but the role of spiritual factor on it has been relatively neglected. This study aims at exploring the positive effect of spirituality on quality of life for people with severe mental illness. 103 Chinese people with severe mental illness who are Christian and have received service from two community-based psychiatric rehabilitation projects in Hong Kong are included in this study. Respondent's quality of life is measured by Chinese World Health Organization Quality of Life Instrument, while respondents' spirituality is assessed by Chinese Daily Spiritual Experience Scale. Daily spiritual experience is found moderately and positively related to individual's overall quality of life (r=.433, p=.000) and all quality of life sub-domains. Also daily spiritual experience can predict individual's overall quality of life and explain 18.7% variance of it. As spirituality has positive effects on quality of life for people with severe mental illness, mental health professionals should further explore effective spiritual interventions in enhancing quality of life for our service users.

Keywords:. Spirituality, Quality of Life, Mental Illness

Introduction

In mental health service, interest in quality of life is stimulated by de-institutionalization movement. In the past few decades, people with severe mental illness are consistently found to have a lower quality of life than the general population without mental illness in n Western and Chinese societies (e.g. Baker, Jordey, & Intaglia, 1992; Chan & Yu, 2004; Evans, 2007; Langeland, Wahl, Kristoffersen, Nortvedt, & Hanestad, 2007; Murphy & Murphy, 2006; Ritsner & Gibel, 2007). Also, the quality of life of people with severe mental illness is found lower than people with common mental disorders (Evans, 2007). Moreover, their lower level of quality of life is found to remain relatively stable throughout the course of mental illness (Ritsner & Gibel, 2007).

Recently, researchers have tried to identify those factors leading to better quality of life for people with severe mental illness. However, many research studies have focused on the negative impact of psychiatric symptoms on individual's quality of life (Eack, NewHill, Anderson, Rotondi, 2007). These research studies consistently report that quality of life are negatively affected by current psychiatric symptoms, especially symptoms of depression and anxiety, experienced by people with severe mental illness (Chan, Ungvari, Shek, & Leung, 2003; Hansson, 2006; Langeland et al., 2007; Norholm & Bech, 2006; Middlelboe, 1997; Norman, Malla, McLean, Voruganti, Cortese, McIntosh, Cheng, Rickwoord, 2000; Sullivan, Wells, & Leake, 1992; UK700 Group, 1999).

Other researchers have tried to identify psycho-social factors influencing quality of life for people with mental illness. Quality of life is found related to: social functioning (Norman et al, 2000; Sullivan, 1992; Timko, Nguyen, Williford, & Moss, 1993); negative life events (Chan et al, 2003); emotional distress (Ritsner & Gibel, 2007); coping style (Caron, Lecomte, Stip, & Renaud, 2005); perceived freedom (Young, 2004); perception of mastery (Rosenfield, 1992; Askerson, 2000; Hsiung. Pan, Liu, Chen, Peng & Chung, 2010); self-esteem (Murphy, & Murphy, 2006); self-efficacy (Ritsner & Gibel, 2007); stigma and discrimination (Chan & YU, 2004). Moreover, objective life conditions in living environment, family relationships, social relationships, vocational status, safety, leisure and financial, etc are related to quality of life (Evans, 2007; Lehman et al., 1982). In addition, better family interaction (Sullican et al, 1992); having a competitive job (Priebe, Warner, Hubschmid, & Eckle, 1998; Ritsner & Gibel, 2007); social support (Carton et al., 2005; Eack, 2007; Young, 2006); social integration (Middelboe, 1997); and fewer unmet needs (UK700 group, 1999; Eack et al., 2007) are all related to quality of life.

While above studies focus on exploring the bio-psycho-social factors influencing quality of life, few studies explore the role of spirituality in enhancing quality of life for people with severe mental illness.

Spirituality

For many years, spirituality and religion have been considered by some mental health professionals to be strong contributors to mental illness, and thus any positive role that spirituality and religion might play in the treatment of severe mental illness receive little attention by researchers (Koenig, Larson, & Weaver, 1998). Systematic reviews of research literature have consistently reported that spiritual and religious involvement contribute to desirable mental outcomes, such as: reducing symptoms for people with schizophrenia, depression and anxiety disorder; and lowering the rate of suicide and substance abuse (Koenig, McCullough, & Larson, 2001; Plante & Sharma, 2001; Swinton & Kettles, 2001). About two thirds of people with severe mental illness see spirituality as important to them (Bellamy, Jarrett, Mowbray, MacFartane, Mowbray, & Holter, 2007) and have positive impacts on their illness (Coursey & Lindgern, 1995). The majority of people with severe mental illness reported that they used spiritual and religious coping methods to cope with daily difficulties (Tepper, Rogers, Coleman & Malony, 2001); and these coping methods have been shown to have positive effects for them (Plante & Sherma, 2001; Tepper et a., 2001).

Research findings also have shown that spirituality and religion can enhance individuals' quality of life by positively contributing to greater life satisfaction, happiness, positive affect, morale, and hope (Koenig et al., 2001; Levin, 2001; Plante & Sharma, 2001; Swinton & Kettles, 2001; Thoresen, Harris, & Oman, 2001). In particular, life satisfaction are positively related to religious belief (Koenig et al., 2001) and church attendance (Thoresen et al., 2001). However, most of these research findings come primarily from studies of healthy, community-dwelling persons, persons who are elderly, persons with medical illness, or various ethnic groups (Koenig et al., 1998; Plante & Sharma, 2001). Little research has been done on the effects of spirituality on quality of life for people with severe mental illness (Corrigan, Mcrkle, Schell, & Kidder, 2003; Koenig et al., 1998).

Recently, two large-scale surveys have been done in this area. In a survey of 1,824 people with mental illness living in the community and involved in Consumer Operated Service Project in the United States, Corrigan and colleagues (2003) showed that self-reported spirituality and religiousness were related to individual's subjective well-being. Similarly, in another survey of 1,835 people with mental illness involved in clubhouse and consumer drop-in centers in the United States, Bellamy and colleagues (2007) reported that spirituality was related to overall quality of life.

Although these two studies contribute to our understanding of the role of spirituality in the lives of persons with mental illness, they have methodological constraints that limit generalization of research results. For example, in the study done by Bellamy et al., spirituality was measured by a single question: "Is spirituality important to you?" which assesses importance versus other aspects of spiritual involvement. In the study done by Corrigan et al., the focus was on subjective well-being rather than quality of life, which is a different variable both conceptually and operationally (Orley, Saxena, & Herrman, 1998). It is, therefore, important to provide clear conceptualizations and measurement of spirituality and further clarify what type of spiritual involvement is associated with what kind of mental health variables under what conditions and for whom (Thoresen et al., 2001).

This study attempts to explore the positive effects of spirituality on quality of life for people with severe mental illness.

Definition Issues

Defining Spirituality

It is now commonly accepted among researchers that spirituality is conceptually different from religion and that spirituality is regarded as a broader concept than religion. For example, Canda defined spirituality as the "person's search for a sense of meaning and morally fulfilling relationships between oneself, other people, the encompassing universe, and the ontological ground for existence" (Canda, 1990, p.13), which is distinguished from religion: "Religion involves the pertaining of spirituality beliefs and practices into social institutions, with community support and traditions maintained over time" (Canda, 1997, p.173). However, within mental health professionals, a variety of definition of spirituality has been emerged, and there is no commonly accepted definition of spirituality (Burke, 2006). A recent literature review on spirituality has found that the lack of agreement among researchers and scholars about the definition and concept of spirituality may reflect the cross cultural, cross religious and plurality in health care disciplines (McCarroll, O'Connor, & Meakes, 2005), as well as a diverse conceptual construct on spirituality (Parament & Zinnbauer, 2005). In this study, the conceptual framework of Parament & Zinnbauer (2005) on spirituality is adopted here and spirituality defined as people's search for the Transcendent (God, the Divine).

Defining Quality of Life

Similar to spirituality, there has been a lack of consensus and universal definitions among researchers regarding the concept of "quality of life" (Skevington, Lofty, & O'Connell, 2004). In this study, the World Health Organization's (WHO) concept of quality of life is used as it is based on a large scale international and transcultural study and has been shown applicable to Chinese culture and societies (Skevington et al., 2004). WHO defines quality of life as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept affected in a complex way by the persons' physical health, psychological state, level of independence, social relationships and their relationships to salient features of their environment" (Skevington et al., 2004, p. 299).

Research Method

Research Design and Data Collection

The study sample was drawn from a population of mental health service users who had contacted with two community-based psychiatric rehabilitation projects in Hong Kong; and have Christen spirituality. The first project provided spiritual group and fellowship for people with mental illness and Christian belief. The first project consisted of about 220 members, although each spiritual group consists of about 15 members. Each group organized various educational talk, pray, sharing, mutual support, volunteer services, recreational activities for their group members. The other project was an integrated rehabilitation centre providing vocational training and halfway house for people with severe mental illness. This second project involved about 220 mental heath users. The agencies of these two projects had allowed the researcher to conduct this research study, and were willing to provide assistance in the research process. To be eligible to participate in the current study, service users had to be assessed by project mental health professionals as being mentally stable and having Christian belief. Service users meeting these criteria were then contacted individually and invited to participate in the study by project mental health professionals who explained the aims of the study and the purpose of data collection. This process resulted in a studied sample of 103 respondents who indicated interest in the study and gave their written consent to participate in this research. 74 subjects come from the first project and is named spiritual group, while 29 subjects come from the second project and is named church group in this research project.

Participants completed self-administered questionnaires designed to assess spirituality and quality of life (described below). Also, participants provided their basic demographic information, including: sex, age, marital status, education level, employment status, financial status, religious affiliation and church / fellowship attendance in a separate sheet designed by the researcher. Information on participants' medical background, including mental health diagnosis, number of psychiatric hospitalizations, and period of mental illness, was collected mainly by participants' self-report. If necessary, project mental health professionals would provide this information for participants on their request and consensus. Data collection began in March, 2009 and was completed in August, 2009.

Measuring Instruments

Measurement of Spirituality

Chinese Daily Spiritual Experience Scale (DSES). The spirituality of respondents was measured by the Daily Spiritual Experience Scale (Underwood & Teresi, 2002). DSES is used to measure "a person's perception of the transcendent in daily life and his or her interaction with or involvement of the transcendent in life" (Underwood & Teresi, p.23). It consists of 16 items. The first 15 items are scored using a modified Likert scale, with 6 represents many times a day and 1 represents never or almost never. The 16th item has four responses with a modified Likert scale, with 4 represents as close as possible and 1 represents not close at all. Scores are summed over items such that higher scores indicate higher level of spirituality. The possible range of the DSE is 16 to 94. The reliability and validity of DSES have been tested to be satisfactory (Underwood & Teresi, 2002). The reliability and validity of the Chinese version of DSES has been tested to be satisfactory, too (Ng, Fong, Tsui, Au-Yeung, Law, 2009). In this study, the reliability of this scale is also found to be high, and the Cronbach's alpha (a) of the DSES is 0.93.

Chinese WHO Quality of Life Instrument (WHOQOL-BREF). As a measure of quality of life, the WHOQOL-BREF has been reported as demonstrating satisfactory estimates of reliability and validity, having cross-cultural sensitivity (Skevington et al., 2004), and suitable for use with people with mental illness (Orley et al., 1998). In the current study, the Chinese version of the WHOQOL-BREF was used to measure the quality of life of respondents, which also has been reported as demonstrating adequate validity and reliability (Leung, Tay, Chu, & Ng, 2003). This 28-item Chinese version of the WHOQOL-BREF assesses four domains (physical health, psychological, social relationships, and environmental). Two items of the 28 items can be analyzed separately: one item asks about respondents' overall perception of their quality of life and one item asks about overall perception of health. The response set for each item ranges from 1 to 5, with 1 representing "very dissatisfactory" and 5 representing "very satisfactory." The overall quality of life and overall perception of health score of WHOQOL range from, 1 to 5 with 5 indicates better overall quality of life. The score of WHOQOL domains are calculated by multiplying the means of all items score included in each domain by a factor of 4 and accordingly, the possible scores for each domain range from 4 to 20, with higher scores indicate higher levels of quality of life. In the current study, reliability estimates based on Cronbach's alpha is high for the total WHOQOL-BREF scale ($\alpha = .93$). Also, reliability estimates for Physical Health Domain subscale ($\alpha = .74$); Psychological Domain subscale ($\alpha = .87$); Social Domain subscale ($\alpha = .70$), and Environmental Domain subscale ($\alpha = .80$) are all satisfactory.

Research Results

Characteristics of Research Sample

The whole study sample consisted of 103. The basic demographic characteristics are summarized in Table 1.

	Spiritual Group	Church	Total

			Group			
	N	%	N	%	N	%
Total number of participants	74	**100**	29	**100**	103	**100**
Sex						
Male	28	**37.8**	11	**39.3**	39	**38.2**
Female	46	**62.2**	17	**60.7**	63	**61.8**
Age *(Mean yrs)*	42.01		45.23		42.86	
(S.D., Range)	(8.88,	**24-61)**	(10.88,	**23-61)**	(9.49,	**23-61)**
Marital Status						
Single, divorced, separated or widowed	53	**71.6**	24	**82.8**	77	**74.8**
Married	21	**28.4**	5	**17.2**	26	**25.2**
Educational level						
None	1	**1.4**	1	**3.4**	2	**1.9**
Primary	3	**4.1**	5	**17.2**	8	**7.8**
Secondary	55	**74.3**	19	**65.5**	74	**71.8**
Tertiary	15	**20.3**	4	**13.8**	19	**18.4**
Work status						
Unemployed	36	**48.6**	6	**20.7**	42	**40.8**
Attending vocational training	3	**4.1**	21	**72.4**	24	**23.3**
Having a part-time or full time job	35	**47.3**	2	**6.9**	37	**35.9**

Financial status						
Relying on governmental financial assistance	37	**50.0**	27	**93.1**	64	**64.2**
Diagnosis						
Schizophrenia	47	**63.5**	18	**69.2**	65	**65.0**
Mood Disorder	24	**32.4**	7	**26.9**	31	**31.0**
Others psychosis	3	**4.1**	1	**3.8**	4	**4.0**
Duration of mental illness *(Mean yrs)*	**15.86**	**-**	**23.64**	**-**	**17.70**	**-**
(S.D., Range)	(6.96,	2-29)	(11.05,	4-42)	(17.70,	3-42)
Number of Hospitalization (Mean)	**3.03**	**-**	**4.38**	**-**	**3.36**	**-**
(S.D., Range)	(3.03,	0-15)	(3.59,	0-12)	(3.21,	0-15)

Table 1. Basic Demographic and clinical characteristics of the sample

The study sample was predominant female, single, schizophrenia, and with a mean age of 43 years. Over two thirds had reached secondary school level. Only one third had full-time or part-time competitive job and most of them had to rely on governmental financial assistance to support their lives.

The two studied groups did not show significant difference in their age, sex, education, marital status and diagnosis, but had significant difference work status (Pearson Chi-Square=55.65, p=000) source of income (Pearson Chi-Square=16.45, p=000), and duration of illness (ANOVA F=15.522, p=.000). The spiritual group had a higher proportion of having part-time or full-time job, and relied on salary to support their life. Also this group had relative shorter period of mental illness. The church group had longer duration of mental illness, having higher proportion of receiving vocational training and most of them relied on governmental financial assistance to support their life.

Quality of Life

The data of quality of life of the studied groups are shown in Table 2. The spiritual group and church group did not differ in overall quality of life and all quality of life sub-domains.

In general, the whole sample regarded their overall quality of life as average, with a mean score of 3.46 (SD = 0.83, ranging from 1.00 to 5.00), and about half (52.5%, n = 53) were satisfied or very satisfied with their overall quality of life. Similarly, they regarded their overall heath as average, with a mean score of 3.02 (SD = 1.06, ranging from 1.00 to 5.00), and less than half (42.7%, n = 44) were satisfied or very satisfied with their overall health. Also, this sample regarded all quality of life domains as average, and the mean score of these quality of life domains ranged from 12.91 to 13.13. Relatively, respondents were most satisfied with their physical domain; and were least satisfied with their social domain.

Spirituality

All studied subjects were Christian. The studied group and church group differed in their attendance in religious activity (Pearson Chi Square=21.43, p=.000), and the spiritual group attended religious activity more frequently. The majority of the spiritual group (77.0%) attended religious activity at least once weekly. About one third (31.0%) of the church group attended religious activity at least once weekly, while another one third (37.9%) attended religious activity at least once monthly.

The studied group and church group did not differ in their daily spiritual experience (DSE) (Table 2). In general, the study sample regarded their spirituality as above average, and respondents reported a mean total DSE score of 60.89 (SD = 13.77, ranging from 29 to 94).

Spirituality in relation to Quality of Life

Pearson correlation analyses were conducted using SPSS for Windows to test the relationships between spirituality and quality of life for the whole studied sample, i.e. 103 respondents. Results are shown in Table 3. Individual's total DSES score was found moderately and positively related to individual's overall quality of life score (Pearson Correlation=.433, p=.000). In addition, individual's total DSES score was moderately and positively related to physical domain (Pearson Correlation=.398, p=.000), psychological domain (Pearson Correlation=.459, p=.000), social domain (Pearson Correlation=.364, p=.000), and environment domain (Pearson Correlation=.256, p=.000).

Table 2 Quality of Life and Spirituality of the study sample

		Spiritual Group	Church Group	Total Sample	*N*	ANOVA *F* value	sig. (2-tailed)
Overall QoL	*Mean*	**3.41**	**3.55**	**3.46**	101	.544	.463
	S.D.	.85	.78	.83			
	Range	1.00-5.00	2.00-5.00	1.00-5.00			
Overall Health	*Mean*	**3.07**	**2.90**	**3.02**	103	.543	.463
	S.D.	1.00	1.21	1.06			
	Range	1.00-5.00	1.00-5.00	1.00-5.00			
QoL Physical Domain	*Mean*	**13.18**	**12.96**	**13.13**	103	.160	.690
	S.D.	2.34	2.50	2.37			
	Range	6.86-18.29	8.00-20.00	6.86-20.00			
QoL Psychological Domain	*Mean*	**12.96**	**12.99**	**12.97**	103	.002	.964
	S.D.	2.81	2.95	2.84			
	Range	5.50-18.50	7.00-20.00	5.50-20.00			
QoL Social Domain	*Mean*	**12.72**	**13.38**	**12.91**	103	.911	.342
	S.D.	3.04	3.47	3.15			
	Range	4.00-20.00	8.00-20.00	4.00-20.00)			
QoL	*M*	**12.93**	**13.49**	**13.09**	1	1.072	.303

Environmental Domain	*ean*				03			
	S.D.	2.37	2.72	2.47				
	Range	6.50-17.50	6.50-20.00	6.50-20.00				
Spirituality DSES	*Mean*	**60.80**	**61.14**	**60.89**	03	1	.013	.911
	S.D.	13.40	14.93	13.77				
	Range	29.00-94.00	37.00-94.00	29.00-94.00				

* *p*< 0.5, ***p*< .01

Further analyses were conducted to explore the possible correlation between demographic or medical variables with individual's quality of life. Results are shown in Table 3. Religious activity attendance is found unrelated to overall quality of life. Also, all, except one, demographic and medical variables such as age, sex, marital status, educational status, medical diagnosis, number of hospitalization, and duration of mental illness were found unrelated to overall quality of life. Work status was found related to overall quality of life; and those who had part-time or full time competitive job had better overall quality of life than those who were unemployed and retired.

Hierarchical regression analysis is performed with data of 103 respondents by using SPSS for Windows. Overall quality of life is entered into the regression equation as the dependent variable. Variables, which are related to overall quality of life, are selected for regression analysis. At the first level of regression analysis, daily

spirituality experience is entered into the equation. Then at the second level of regression analysis, various quality of life domains, including: physical, psychological, social, and environmental quality of life, are then entered into the equation. The regression analysis is then done step by step for the above variables. The results are shown in Table 4. Daily spiritual experience alone can explain 18.7% of variance in overall quality of life, while physical, psychological, social, and environmental quality of life altogether can explain 27.0 % of variance in overall quality of life.

Table 3. Correlation among Quality of Life, Spirituality and other variables

Item	Test	Overall QoL			DSE		
		N	Value (r / F)	sig. (2-tailed)	N	Value (r / F)	sig. (2-tailed)
QoL (Physical Health Domain)	Pearson Correlation	101	**.587**	**(.000)****	101	**.398**	**(.000)****
QoL (Psychological Domain)	Pearson Correlation	101	**.584**	**(.000)****	103	**.459**	**(.000)****
QoL (Social Relations Domain)	Pearson Correlation	101	**.574**	**(.000)****	103	**.364**	**(.000)****
QoL (Environmental Domain)	Pearson Correlation	101	**.534**	**(.000)****	103	**.256**	**(.009)****
Daily Spiritual Experience (DSES)	Pearson Correlation	101	**.433**	**(.000)****	103	1.00	--
Religious Activity Attendance (RAA)	Pearson Correlation	101	.039	(.699)	103	**.210**	**(.034)***
Setting	ANOVA	101	.544	(.463)	103	.013	(.911)
Age	Pearson Correlation	101	-.005	(.961)	103	-.013	(.902)
Sex	ANOVA	101	.018	(.893)	103	.664	(.417)

Education	ANOVA	101	.407	(.748)	103	.224	(.880)
Marital Status	ANOVA	101	.100	(.753)	103	.040	(.852)
Work status	ANOVA	101	**3.943**	**(.011)***	103	.015	(.998)
Financial status	ANOVA	101	3.714	(.057)	103	1.550	(.216)
Diagnosis	ANOVA	101	.357	(.701)	103	2.340	(.102)
No. of Hospitalization	Pearson Correlation	101	.096	(.353)	103	.037	(.715)
Period of mental illness (yrs)	Pearson Correlation	101	.089	(.401)	103	-.034	(.746)

() indicates significance (2-tailed) ; * *p*< 0.5, ***p*< .01

Table 4 Hierarchical regression analysis (Overall QoL as dependent variable)

Dependent variable	Model	Predictors	Standardized Coefficients (Beta)	F	df	Sig.	R^2	Std. Error of the Estimate
Overall QoL	1	(Constant)		22.829	99	.000	**.187**	.7528
		DSES	.433					
Overall QoL	2	(Constant)		16.018	95	.000	**.457**	.6280
		DSES	.188					
		Physical QoL	.200					

Psychological QoL	.084
Social QoL	.216
Environmental QoL	.161

Discussion

The current findings suggest that spirituality is beneficial to people with severe mental illness. Specifically, daily spiritual experience is found positively related to and predicting overall quality of life for people with severe mental illness. These findings are consistent with other research studies that show positive effects of spirituality on quality of life for persons with mental illness (Bellamy et al., 2007; Corrigan et al., 2003).

Attachment theory, originally introduced by Bowlby, has been adopted and modified by Kirkpatrick to explain the ways of spirituality in enhancing individual's general well being (Kirkpatrick, 1995). According to the attachment theory, the Transcendent or God can become an important attachment figure for people. People will turn to the God for comfort and security during stressful circumstances as if a child asks for the protection from his parents during stressful circumstances. People who experience a secure connection with God would experience greater strength, confidence, and comfort. Researcher evidences tend to support this attachment theory by showing that general community residents who report a close connection to God experience a number of health-related benefits, including less depression, less loneliness, greater relational maturity, greater psychosocial competence, and better psychosocial adjustment when facing with life stress (Hill & Pargament, 2008). This research finding supports this attachment theory by showing that individual's closeness to the Transcendent, as reflected by the DSES, is positively correlated with overall quality of life and various quality of life domains for people with severe mental illness.

In addition, the attachment theory suggests that the effects of individual's closeness to God is greater than that of individual's attendance of religious activity (Hill & Pargament, 2008). This research finding support this result by showing that individual's closeness to the Transcendent, as reflected by the DSES is moderately positively related to and predicts overall quality of life. On the other hand, religious activity attendance is found not related to quality of life.

On the other hand, most demographic and medical variables measured in this study, including: age, sex, marital status, educational status, medical diagnosis, number of hospitalization, duration of mental illness are found unrelated to overall quality of life. These findings are also consistent with other previous research reports, which have found that these demographic and medical variables are unrelated, or at most weakly related, to overall quality of life (Ritsner & Gibel, 2007; Young, 2004).

Although there has been movement to bring spirituality into general clinical practice and intervention, the role of spirituality in the lives of people with severe mental illness have been relatively neglected by mental health professionals (Huguelet, Nohr, & Borras, 2006). As spirituality has shown to be beneficial for people with severe mental illness, mental health professionals should adopt holistic treatment strategies that integrate spiritual factor into assessment and intervention, as advocated by many other writers (e.g. Corrigan et al., 2003; Fallot, 1998; Koenig et al., 2001; Plante & Sharma, 2001; Swinton & Kettles, 2001). Such treatment approaches, including the bio-psycho-social- spiritual model and the Body-Mind-Spirit model, have been advocated by many mental health professionals for assessment and interventions (e.g. Chan et al., 2002; Prest & Robinson, 2006). In addition, spiritually-oriented therapeutic interventions for people with severe mental illness have also been documented (e.g. Koenig, 2005). For example, Koenig (2005) has reviewed several models and research studies on spiritually-based group therapy for people with severe mental illness and found that these groups yielded positive results. Moreover, a number of religious and spiritual activities are thought to encourage more frequent daily spiritual experience (Underwood & Teresi, 2002), and these activities can then promote individual's closeness with the Transcendent and quality of life. In future, mental health professionals need to further explore various effective spiritual interventions in enhancing quality of life for our service users.

Several limitations of this study should be acknowledged. The study sample is non-randomized and has small size, which may limit the generalization of the research result. In fact, this sample is predominated with Christian affiliation, requiring caution in interpreting results. Also this is a cross-sectional study which has limitations in establishing the prospective causal effects of spirituality on quality of life. In future, a prospective longitudinal study with a larger sample size is needed in this area.

References:

Ackerson, B. (2000). Factors influencing life satisfaction in psychiatric rehabilitation. *Psychiatric Rehabilitation Journal*, 23(3), 253-261.

Baker, F., Jordey, D., & Intaglia, J. (1992) Social Support and quality of life of community support clients. *Community Mental Health Journal,* 28:397-411.

Bellamy, C. D., Jarrett, N. C., Mowbray, O., MacFartane, P., Mowbray, C. T., & Holter, M. C. (2007). Relevance of spirituality for people with mental illness attending consumer-centered service. *Psychiatric Rehabilitation Journal, 30*(4), 287-294.

Burke, K. (2006). Religion, Spirituality and Health. In Gehlert, S. & Browne, T.A. (Eds.), *Handbook of Health Social Work* (pp.282-394). John Wiley & Son Inc.

Canda, E.R. (1990). Afterword: Spirituality Reexamined. *Spirituality and Social Work Communicator,* 1(1), 13-14.

Canda, E.R. (1997). Spirituality. In Richard, L.E (Ed.), *Encyclopedia of social work 19th edition supplement* (pp.299-309). Washington DC: National Association of Social Workers.

Caron, J., Lecomte, Y., Stip, E., & Renaud, S., (2005). Predictors of Quality of life in schizophrenia Community Mental Health Journal, 41(4), 339-417.

Chan, C .L. W., Ho, P. S. Y., & Chow, E. (2002). A Body-Mind-Spirit Model in health: An Eastern approach. In A. C. Jackson, & S. C. Segal (Eds.), *Social work health and mental health: Practice, research and programs* (pp. 261-282). New York: The Haworth Press Inc.

Chan, S.& Yu, I.W. (2004). Quality of life of clients with schizophrenia. Journal of Advanced Nursing, 45(1), 72-83.

Chan, W.L., Ungvari, G..S., Shek, T.L., Leung, J.P. (2003). Hospital and community based care for patient with chronic schizophrenic in Hong Kong. *Social Psychiatry and Psychiatric Epidemiology* 38:196-203.

Corrigan, P., Mcrkle, B., Schell, B., & Kidder, K. (2003). Religion and Spirituality in the Lives of People with Serious Mental Illness. *Community Mental Health Journal*, 39(6), 487-499.

Coursey, R.D. & Lindgern, K.N. (1995). Spirituality and Serious Mental Illness: A Two-part study. *Psychosocial Rehabilitation Journal*, 18(3), 93-111.

Eack, S.M., Newhill, C.E., Anderson, C.M., Rotondi, A.J. (2007). Quality of life for persons living with schizophrenia: More than just symptoms. *Psychiatric Service Journal,* 30, 219-222.

Evans, S. (2007). Quality of life in mental health services. In Ritner, M.S. & Awad, G.A. (Eds.), *Quality of life impairment in Schizophrenia, Mood and Anxiety Disorder* (pp. 173-226). Netherlands: Springer.

Fallot, R.D. (1998). The Place of Spirituality and Religion in Mental health Services. In Fallot, R.D. (Ed.), *Spirituality and Religion in recovery from mental illness* (pp. 3-12). San Francisco: Jossey Bass Publisher.

Fallot, R.D. (2007). Spirituality and religion in recovery: some current issues. *Psychiatric Rehabilitation Journal*, 30(4), 261-270.

Hansson, L. (2006). Determinants of quality of life in people with severe mental illness. *Acta Psychiatrica Scandinavica,* 113 (Suppl. 429), 46-50.

Hill, P.C., & Paragament, K.I. (2008) Advances in the conceptualization and measurement of religion nad spirituality. *Psychology of Religion and Spiriautlity,* S(1), 3-17.

Hong Kong Speical Administrative Region (2008) *Hong Kong The Facts : Religion and Customs* HK: Infomation Sevice deparment, HKSAR.

Hsiung, P.C., Pan, A.W., Liu, S.K., Chen, S.C., Peng S.Y., and Chung, L. (2010). Mastery and stigma in predictng subjective quality of life of patients with schizophrenia in Taiwan. *Journal of Nervous and Disease*, 198(7), 494-500.

Huguelet, P., Mohr, S., Borras, L., et al. (2006). The Spirituality and religion practices among out-patients with schizophrenia and their clinicians. *Psychiatric Services,* 57(3), 336-372.

Kirkpatrick, L.A. (1995). Attachment theory and religious experience, In Hood R.W. Jr. (Ed.), *Handbook of religious experience* (pp.446-475). Birmingham, AL: Religious Education Press.

Koenig, H.G. (2005). *Faith and Mental Health.* Templeton Foundation Press.

Koenig, H.G., Larson, D.B., Weaver, A.J. (1998). Research on Religions and Serious Mental Illness. In Fallot, R.D. (Ed.), *Spirituality and Religion in Recovery from Mental Illness* (pp.81-95). San Francisco: Jossey Bass Publisher.

Koenig, H.G., McCullough, M.E., & Larson, D.B. (2001). *Handbook of Religion and Health.* Oxford University Press.

Langeland, E., Wahl, A., Kristoffersen, K., Nortvedt, M.W., & Hanestad, B.R. (2007). Quality of life among Norwegians with chronic mental health problems living in the community versus the general population. *Community Mental Health Journal*, 43(4), 321-339.

Lehman, A.F., Ward, N. & Linn, L. (1982). Chronic mental patients: the quality of life issue. *American Journal of Psychiatry*, 10:1271-1276.

Leung, K. K., Tay, S. M., Chu, M. L., & Ng, S. W. (2003). *Chinese WHO Quality of Life Instrument: Development and validation of the interview version of the Hong Kong Chinese WHOQOL-BREF.* Hong Kong: Health Service Research Committee.

McCarroll, P., O'Connor, J.T., & Meakes, E. (2005). Assessing Plurality in Spirituality Definitions. In Meier, A., O’Connor, T.J. & VanKatwyk, P. (Eds.), *Spirituality and Health Multidisciplinary Explorations* (pp. 43-60). Wilfrid Laruier University Press.

Middelboe, T. (1997). Prospective study of clinical and social outcome of stay in small group homes for people with mental illness. *The British Journal of Psychiatry*, 171, 251-255.

Murphy, H., Murphy E.K. (2006) Comparing quality of life using the World Health Organization Quality of Life measure (WHOQOL-100) in a clinical and non-clinical sample: exploring the role of self-esteem, self-efficacy and social functioning. *Journal of Mental Health*, 15(3), 289-300.

Ng, S.M., Fong, T.C., Tsui, E.Y., Au-Yeung, S.F. & Law, S.K. (2009). Validation of the Chinese Version of Underwood's Daily Spiritual Experience Scale-Transcending Cultural Boundaries? *International Journal of Behavioral Medicine,* 16(2), 91-97.

Norholm, V., & Bech, P. (2006). Quality of life in schizophrenic patients: Association with depressive symptoms. *Nordic Journal of Psychiatry*, 60(1), 32-37.

Norman, R.M.G., Malla, A.K., McLean, T., Voruganti, L.P.N., Cortese, L., McIntosh, E., Cheng, S., Rickwoord, A. (2000). The relationship of symptoms and level of functioning in schiizophrenia to general wellbeing and quality of life scale. Acta Psychiatr Scand, 102, 303-309.

Orley, J., Saxena, S., & Herrman, H. (1998). Quality of life and mental illness. *British Journal of Psychiatry*, *172*, 291-293.

Parament, K.I., Zinnbauer, B.J. (2005). Religiousness and Spirituality. In Paloutzian, R.F. (Ed.), *Handbook of Psychology of Religion and Spirituality* (pp.21-42). New York: The Guilford Press.

Plante, T.G., & Sharma, N.K. (2001). Religious Faith and Mental Health Outcomes. In Plante, T.G., & Sherman, A.C. (Eds.), *Faith and Health Psychological Perspective* (pp.240-261). New York: The Guilford Press.

Prest, L.A. and Rosinson, W.D. (2006). Systemic Assessment and Treatment of Depression and Anxiety in Families: The BPSS Model in Practice. *Journal of Systemic Therapies*, vol. 25 (3), 4-24.

Priebe, S., Warner, R., Hubschmid, T., & Eckle, I. (1998). Employment, attitudes toward work, and quality of life among people with schizophrenia in three countries. *Schizophrenia Bulletin*, 24, 469-477.

Ritsner, M.S. & Gibel, A. (2007). Quality of life impairment syndrome in schizophrenia. In Ritner, M.S. & Awad, G.A. (Eds.), *Quality of life impairment in Schizophrenia, Mood and Anxiety Disorder* (pp. 173-226). Netherlands: Springer.

Rosenfiled, S. (1992). Factors contributing to the subjective quality of life of the chronically mentally ill. *Journal of Health and Social Behaviour*, 33, 299-315.

Skevington S. M., Lotfy, M., & O'Connell, K. A. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial - A report from the WHOQOL group. *Quality of Life Research, 13*, 299-310.

Sullivan, G., Wells, K.B., & Leake, B. (1992). Clinical factors associated with better quality of life in a seriously mentally ill population. Hospital and Community Psychiatry, 43(8), 794-798.

Swinton, J., & Kettles, A. (2001). Spirituality and Mental Health Care Exploring the Literature. In Swinton, J. (Ed.), *Spirituality and Mental Health Care—Rediscovering a Forgotten Dimension* (pp.64-134). London and Philadelphia: Jessica Kingslay Publisher.

Tepper, L., Rogers, S.A., Coleman, E.M., Malony, H.N. (2001). The prevalence of religious coping among persons with persistent mental illness. *Psychiatric Services*, 52, 660-665.

Thoresen, C.E., Harris, A.H.S., & Oman, D. (2001). Spirituality, religion and health: Evidence, issues and concerns. In Plante, T.G.., & Sherman, A.C. (Eds.), *Faith and health: Psychological perspectives* (pp.15-52). New York: Guilford Press.

Timko, C., Nguyen, A.O., Williford, W.O., & Moos, R.H. (1993). Quality of care and outcomes of chronically mentally ill patients in hospitals and nursing homes. *Hospital and Community Psychiatry,* 44, 241-246.

UK 700 Group (1999). Predictors of quality of life in people with severe mental illness. *British Journal of Psychiatry*, 175, 426-342.

Underwood, J.G. & Teresi, J.A. (2002). The daily spiritual experience scale: development, theoretical description, reliability, exploratory factor analysis, and preliminary construct validity using health-related data. *Annals of Behavioral Medicine*, 24(1):22-33.

Young, K.W. (2004). Factors Predicting Overall Life Satisfaction for People with Long-Term Mental Illness Factors. *International Journal of Psychosocial Rehabilitation,* 9(1), 23-35.

Young, K.W. (2006). Social Support and Life Satisfaction. *International Journal of Psychosocial Rehabilitation*, 10 (2), 155-164.

The International Journal of Psychosocial Rehabilitation

Home Care Services – the basic instrument of support for the mentally ill in Poland.

Pawel Bronowski, Ph.D. (1)

Maryla Sawicka, Ph.D. (1)

Katarzyna Charzynska M.A. (2)

1. Academy of Special Education, Warsaw, Poland
2. Institute of Psychiatry and Neurology, Warsaw, Poland

Citation:
Bronowski P, Sawicka M, & Charzynska K (2012).Home Care Services – the basic instrument of support for the mentally ill in Poland. ***International Journal of Psychosocial Rehabilitation. Vol 16(2) 88-105***

Correspondence
Institute of Psychiatry and Neurology
Sobieskiego 9
02-957 Warsaw, Poland
e-mail: sierk@ipin.edu.pl
tel. 22 45 82 521
fax. 22 858 91 72

Abstract

The purpose of this study is to evaluate the functioning of home care services - the basic instrument of support for the mentally ill in Poland. Data was collected using a Sociodemographic Questionnaire, Map and Neighborhood Questionnaire and Social Support Inventory. 103 ill people, mainly diagnosed with schizophrenia, from three districts of Warsaw were included in the study. The findings show that people included in the Home Care Services Program have weak and not very efficient social networks whose central places are occupied by professional therapists providing most important support functions. Natural sources of support, such as neighbors or friends are rarely included in their social networks.

Key words: home care services, mental disorders, social support network, schizophrenia

Introduction

The World Health Organization, despite several decades of efforts, could not develop an optimal model of psychiatric care that is adjusted to local environment due to the organizational and ideological pluralism in different countries. In a bid to overcome this phenomenon, in 2005 the European Commission published The Green Paper, a document outlining new common standards for health policy in the field of psychiatric care. Poland also joined this environmental movement introducing Mental Health Act in 2008. The primary goal of this reform is to disseminate the environmental treatment by shifting the burden of responsibility for the welfare of the patient and his family from the level of large psychiatric hospitals to that of mobile, multidisciplinary community units (Meder et al., 2008). The number of psychiatric day care centers has been steadily increasing. In 1980, there were 53 day units, and by 2007 this figure has risen to 241. Similar increase was noted in the number of environmental treatment units – from 12 in

1990 to 35 over the following decade (Balicki, et al., 2000).

Nowadays more attention is being paid to ensure that the therapeutic treatment provided for the chronically mentally ill takes into account the entire situational context in which they live (Hoffman, Iserman, 2000). This requires a holistic approach encompassing different aspects: pharmacotherapy, family problems solving, unemployment and poverty prevention, offsetting poor social support networks and restoring hope for satisfying life. Majority of these problems arise after leaving an asylum which is a hospital. After their initial struggle to adopt to old life schemes, patients realize that they can no longer deal with new challenges (Kaszyński, 2005). The immediate support needed in this situation is psycho-social intervention whose primary objective is to improve social functioning of the patients. This aim is achieved by supporting the patients in complying with therapeutic recommendations, by monitoring their mental status in order to reduce number of hospitalizations, by helping them to develop ways of coping with persistent symptoms and by helping family in bearing the burden of mental illness (Roick, Fritz, 2007). Integrated therapeutic activities, rehabilitation and support programs for social functioning are now concentrated on the local level and form a standard in working with people suffering from mental illness. The environmental model, as compared to the asylum care which is based on the model of large psychiatric hospitals, has definite advantages: availability of numerous therapeutic programs, equality in distributing aid and greater efficiency in providing support. The environmental model reinforces the patients in the place where they live as well as sustains and develops their natural social networks by preventing marginalization (Załuska, Paszko, 2005; Załuska, Suchecka, 2005).

In Poland, the social support systems include provision of daily support facilities such as self-help environmental homes for people suffering from serious difficulties in social functioning, occupational therapy workshops as well as prepare people to take up employment. These services are complemented with sheltered housing and home care services. While the creation of sheltered housing was not an entirely new concept in Poland, as it has been already established in the 70s, home care services are rather new development. Their main objectives are as follows:

- to build or restore skills needed for independent functioning.
- to support patients in their everyday activities.
- to intervene and assist them in crisis situations.
- to assist them in addressing important life issues.

The key to effective functioning of the program is its multidisciplinary team of professionals. Staff providing home care services should have specific qualifications in the field of certain professions, such as psychology, education, social work, occupational therapy or psychiatric nursing. Additionally, they should have long experience in working with the mentally ill and in conducting psychosocial interventions.

Home care services have been being carried out since 1997 and current study is the first attempt to evaluate the functioning of home care services for patients with schizophrenia.

Materials and Methods

Subjects

Home care services users fulfilling two criteria were included:

- 3 or more months of home care services use.
- Diagnosis of F20 to F29 (ICD – 10).

Measures

The following set of instruments was used:

- Socio-demographic Questionnaire (designed by the authors).
- Map and Neighborhood Questionnaire (Bizoń, 2001). The tool enables measurement of the size of social support networks as well as their composition.
- The Social Support Inventory (Bizoń, 2001). The tool enables the assessment of the type of support provided as well as defines the size and scope of the base offered.

All tests were carried out at study participants homes during the period from October 2008 to May 2009.

Results

A total of 103 people participated in the study. 59 (56.2%) were females and 46 (43.8%) were males. The average age was 52. About 7.6 % of the subjects had higher education and 44.8% secondary education.

Twelve of them (11.4%) were married, and others (88%) were single.

Over 87% of the respondents had disabilities or permanent benefits. Almost the entire group (97.1%) had been diagnosed with paranoid schizophrenia and the rest with delusional or paranoid syndrome. The average duration of the illness was 22 years, with average age of onset being 29 years. Almost all participants (97.1%) were regular users of psychiatric care. 99 people (94.3%) reported regular intake of medicines as prescribed by the psychiatrist.

This percentage should be considered high, as the standards consider 80% as a good level of compliance (Seo, 2005; Mitchel, Selmes, 2007).

Individual social support networks

Individual systems of support usually included up to 6 people (table 1).

Table 1. Overall size of individual social support systems.

Size	N	%
1 to 4 people	43	41,0
5 to 10 people	53	50,5
11 to 15 people	4	3,8
16 to 20 people	4	3,8
Over 21 people	1	1,0
Total	105	100,0

A significant group of people (41%) who had four or less persons in their systems are of special interest to this study.

Table 2. The average number of persons providing support in each category of the support systems.

Category	Mean	SD
Therapists	1,90	1,292
Closest family	1,34	1,108

Flat mates	0,77	1,154
Other relatives	0,60	1,173
Other friends	0,51	1,020
Other significant people	0,40	0,909
Neighbours	0,37	0,624
Colleagues	0,18	0,585

As presented in table 2, therapists were most frequently present in the support system (1.90), followed by closest family (1.34).
Data on the extents of shortages in various categories of people constituting different systems of support shows that the largest shortage was in the category of "colleagues"; that is 89.5% of the respondents did not have any colleagues in their social surrounding. Other most commonly missing persons were "other significant people" (72.5%) and "friends" (72.4%) (table 3).

Table 3. Composition of individual support systems

Category	Absent		Present in the system	
	N	%	N	%
Colleagues	94	89,5	11	10,5
Other significant people	79	75,2	26	24,8
Friends	76	72,4	29	27,6
Neighbors	72	68,6	33	31,4
Distant family	72	68,2	33	31,4
Flat mates	62	59,0	43	41,0
Closest family	21	20,0	84	80,0
Therapists	0	0,0	105	100,0

Scope of support systems

The scope of support system included eight functions: comfort, rescue, care, favoritism, unconditional support, advice, sparing, trust. As many as 96.2% of the respondents had access to all eight functions; no one complained of experiencing "selective" or "narrow" support (table 4).

Table 4. Scope of support

Scope	N	%
Selective (1- 2 functions)	0	0,0

Narrow (3– 4 functions)	0	0,0
Average (5 – 6 functions)	4	3,8
Wide (7 – 8 functions)	101	96,2
Total	105	100,0

Table 5 presents the data on the average number of people that provide support in various functions. It can be seen that "comfort" was provided by most numerous group of people, followed by "emergency assistance" and "care".

Table 5. The average number of people providing support within different functions.

Support function	Mean	SD
Comfort	2,43	2,561
Emergency assistance	2,20	1,852
Care	2,08	1,426
Favoritism	2,08	1,296
Unconditional support	1,95	1,992
Advising	1,86	1,014
Sparing	1,75	1,167
Trust	1,74	1,563

Table 6 presents the data on the average number of services provided by different categories of people constituting individual systems of support. It can be seen that the category providing the largest number of functions was that of the "therapists" (an average of 5.9 functions), followed by "closest family" (an average of 2.4 functions).

Table 6 The average number of support functions provided by different supporters

Supporter	Mean	SD
Therapists	5,9143	2,05274
Closest family	2,4667	2,65687
Flat mates	1,7048	2,67439
Other friends	0,5619	1,48663
Other relatives	0,5524	1,65687

Other significant people	0,4381	1,26281
Neighbors	0,3619	1,13615
Colleagues	0,1048	0,63434

Table 7: Composition of the support system by the support functions.

Supporters	Support functions															
	Advising		Sparing		Favoritism		Care		Emergency help		Comforting		trust		Unconditional support	
		N	%	N	%	N	%	N	%	N	%	N	%	N	%	N %
Therapists	8	6 4,8	6 4	5 1,4	5 5	6 1,9	6 7	5 4,3	5 0	6 7,1	5 5	6 1,9	6 0	6 7,1	5 3	4 41 ,0
Closest family	3	2 1,9	2 4	2 2,0	2 0	2 9,0	1 5	2 3,8	2 5	2 3,8	2 2	2 1,0	2 5	2 3,8	2 9	3 37 ,1
Flatmates	9	1 8,1	1 4	1 3,3	1 6	1 5,2	1 4	1 3,3	1 6	1 5,2	1 0	1 ,5	9 3	1 2,4	1 1	2 20 ,0
Other friends		6 ,7	5	5 ,8	4	1 ,0	1	3 ,9	2	7 ,7	6	7 ,7	6	3 6,2	9	1 1, 0
Other relatives		4 ,8	3	5 ,8	4	7 ,7	6	5 ,8	4	7 ,7	6	6 ,7	5	6 ,7	5	8 7, 6
Other significant people		4 ,8	3	4 ,8	3	4 ,8	3	7 ,7	6	6 ,7	5	3 ,9	2	2 ,9	1	6 5, 7
Colleagues		2 ,9	1	1 ,0	1	1 ,0	1	1 ,0	1	1 ,0	1	1 ,0	1	1 ,0	1	1 1, 0
Neighbors		1 ,0	1	1 ,0	1	3 ,9	2	2 ,9	1	4 ,8	3	6 ,7	5	5 ,8	4	4 3, 8

Table 8. Number of people providing specific support functions

Supporters	Support functions															
	Advising		Sparing		Favoritism		Care		Emergency help		Comforting		Trust		Unconditional support	
	average	sd	average	sd	average	sd	average	sd	average	sd	average	sd	average	sd	average	sd
Therapists	1,09	0,67	0,84	0,76	1,24	0,75	1,13	0,90	1,03	0,77	1,25	0,83	0,87	0,71	0,55	0,69
Closest family	0,31	0,56	0,32	0,56	0,31	0,61	0,38	0,64	0,43	0,70	0,39	0,67	0,35	0,58	0,67	0,79
Flat mates	0,24	0,56	0,40	0,75	0,25	0,57	0,29	0,68	0,28	0,63	0,19	0,50	0,18	0,45	0,32	0,61
Other friends	0,08	0,39	0,06	0,28	0,03	0,30	0,19	0,13	0,14	0,51	0,13	0,46	0,11	0,46	0,00	0,09
Other relatives	0,05	0,23	0,09	0,40	0,09	0,38	0,04	0,21	0,11	0,42	0,09	0,35	0,07	0,09	0,10	0,39
Other significant people	0,03	0,19	0,02	0,21	0,03	019	0,06	0,25	0,07	0,30	0,08	0,37	0,09	0,40	0,09	0,35
Colleagues	0,01	1,13	0,0	0,0	0,01	0,19	0,00	0,09	0,00	0,00	0,00	0,09	0,00	0,98	0,09	0,35
Neighbors	0,00	0,09	0,03	0,19	0,02	0,16	0,01	0,13	0,03	0,19	0,05	0,23	0,04	0,21	0,11	0,48

Analysis of the data in Tables 7 and 8 indicates that the fundamental groups of society which provided support functions were "therapists" and "closest family members." Other categories played relatively insignificant role with the exception of “flat mates.”. The dominance of "therapists" in certain functions of support is clearly visible. Only in case of "unconditional support", the number of people from "closest family" was slightly higher than the average number of "therapists".

Discussion

In the current study the number of individuals constituting social support systems was 6 on average and thus can be considered as scarce. In Pattison study the support systems were defined for 8 to 12 people, but in the case of very severe disease, the number was reduced to 6 people (Pattison, Pattison 1981). In the study group, if therapists engaged in home care services are excluded, the number of individuals in the support system decreases to as few as 4.9 persons. In Polish studies on social networks of the participants of rehabilitation centers, the average number of people forming support system was significantly higher (10 people) (Bronowski, Załuska, 2008; Bronowski, et al., 2009b, 2009).

It is also worth mentioning that as many as 41% of the respondents had 1 to 4 people in their social networks. In the earlier studies of support systems for patients with day rehabilitation facilities, as few persons in the system were found for only 10% of the respondents (Bronowski, et al., 2008a). In those very few systems of social support, the most numerous group was constituted by "therapists". In individual systems, it was an average of 1.9 people. Second most largest group were "closest family members" with an average of 1.3 people. Other categories were very sparse and did not add much to the individual systems of support.

Although eight core functions of support ("comfort," "emergency aid", "care," "favoritism," "unconditional support", "advice", "sparing", "trust") were fulfilled by limited number of support systems members, they turned out to be surprisingly efficient. 96% of the sample had access to the all eight functions. This result is slightly different from those obtained through similar studies of the populations of mentally ill people using the facility of daily support. The implementation of the "trust" involved many more people in the daily support (Bronowski et al., 2008b). In the case of participants of this study group covered by the program of home care services, implementation of this function, in terms of 'trust' and 'close emotional contact', has been much more difficult.

The analysis of different functions of support provision showed interesting findings. Among all the functions of support, except for one, the "therapists" provided the greatest support. The only function in which the respondents included more people from the category of "closest family", rather than the "therapists", was the function of "unconditional support". Despite the dominant position of "therapists" in the system, the respondents were aware that in terms of definitive commitment, "institutional support" might not be forthcoming in adequate measure and hence they might rely more on people from close family circle. It can be concluded that the participants avail themselves of very few systems of support of home care services, which is confirmed by the results of other studies on the chronically mentally ill (Bronowski, et al., 2008b).

The experience of other countries, such as the Netherlands and England, underscores the importance of congenial and tolerant environment in the implementation of therapeutic treatments, which are essential for the mentally ill (Amaddeo, 2007; LGA, 2006; Boardman, 2007). Research on Poland reveals that its local communities are not adequately prepared to adopt the mentally ill (Wciórka, 2008). This finding was confirmed in the current study where the social support networks were built primarily on the basis of the professionals.

The results obtained are important for the ongoing psychiatric system reform in Poland. They not only provide data on the participants of the support system, but also could be of use while preparing social environment for similar projects implementation.

Analysis of the collected data allows for the following conclusions:

1. The study group's characteristics (chronically mentally ill people, single, living only on disability benefits and diagnosed with paranoid schizophrenia) shows that home care services, designed specifically for the most disadvantaged patients, are being provided to target users.

2. Majority of the people surveyed were under regular psychiatric care and taking medications prescribed by the psychiatrists. It can be assumed that this is related to the support in the treatment process provided by the therapists.

3. Therapists constitute the largest category of people working with the home care services users. They are of the highest relevance to the support systems, and their presence makes the process of obtaining various functions of support easy. The second largest category, in terms of number and relevance to the systems, was the "closest family members." Other categories of people (neighbors, friends, colleagues, other relatives) were not numerous in the support systems. The program of home care services significantly strengthens the social networks of individual subjects, thus demonstrating its usefulness.

References:

Amaddeo F., Becker T., Fiorritti A., Burti L. & Tansella M. (2007). Mental Health Policy and Practice across Europe. The future direction of mental health care: reforms in community care: the balance between hospital and community-based mental health care, World Health Organization, 236-239.

Balicki A., Leder S. & Piotrowski A. (2000). Focus on psychiatry in Poland. *The British Journal of Psychiatry, 177,* 375-381

Bizoń Z., Kokoszka A., Roszczyńska J., Bryła L. & Wojnar M. (2001). Ocena otoczenia i oparcia społecznego według Zdzisława Bizonia. Opis metody i jej zastosowanie. In: Kokoszka A, Wojnar M (Ed.) Profesor Zdzisław Bizoń i jego idee, Kraków.

Boardman J. & Parsonage M. (2007). Delivering the Government's Mental Health Policies. Services, staffing and costs: Community-based teams, The Sainsbury Centre for Mental Health, 26-36.

Bronowski P. & Załuska M. (2008). Social support of chronically mentally ill patients. *Archives of Psychiatry and Psychotherapy, 2,* 13-19.

Bronowski P. & Sawicka M. (2008a). Jakość życia u osób przewlekle chorujących psychicznie objętych środowiskowym programem wsparcia społecznego. *Człowiek, Niepełnosprawność, Społeczeństwo, 1 (17),* 53-69.

Bronowski P., Sawicka M. & Kluczyńska S. (2008b). Sieci społeczne osób chorujących psychicznie objętych środowiskowym programem wsparcia i rehabilitacji. *Postępy Psychiatrii i Neurologii, 4,* 291 – 298.

Bronowski P., Sawicka M. & Kluczyńska S.(2009a). Charakterystyka populacji objętej środowiskowym systemem rehabilitacji i wsparcia społecznego. *Psychiatria Polska, 4,* 421-434.

Bronowski P., Sawicka M. & Kluczyńska S. (2009b). Funkcjonowanie społeczne osób przewlekle chorych psychicznie uczestniczących w środowiskowych programach wsparcia społecznego. *Postępy Psychiatrii i Neurologii, 1,* 43-50.

Hoffmann K., Iserman M. & Kaiser W. (2000). Quality of life in the course of deinstitutionalization – part IV of the Berlin Deinstitutionalisation Study. *Psychitrische Praxis*, 27(4), 183-188.

Kaszyński H. (2005). Przeciwdziałanie wykluczeniu społeczno-zawodowemu chorujących psychicznie w Polsce. In: Cechnicki A. & Kaszyński H. (Eds.), *Praca, zdrowie psychiczne, gospodarka społeczna.* (pp. 91-100). Kraków: Stowarzyszenie na Rzecz Rozwoju Psychiatrii i Opieki Środowiskowej.

Local Goverment Association, The NHS Confederation, Sainsbury Centre for Mental Health, Association of Directors of Social Services (2006). Policy Paper, The Future of Mental Health: a Vision for 2015, The Sainsbury Centre for Mental Health, 6-7.

Meder J., Jarema M. & Araszkiewicz A. (2008). Psychiatryczna opieka środowiskowa w Polsce. Raport IPiN, PTP.

Mitchel AJ. & Selmes T. (2007). Why don't patients attend their appointments? Maintaining engagement psychiatric services. *Advances in Psychiatric Treatment, 13,* 423-434.

Pattison M. & Pattison M. (1981). Analysis of schizophrenia Psychosocial Network. *Schizophrenia Bulletin, 7(1),* 135-143.

Roick C., Fritz A. & Matchinger H. (2007). Health habits of patients with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology,* 42 (4), 268 -276.

Seo MA. & Min SK. (2005). Development of a structural model explaining medication compliance of persons with schizophrenia. *Yonsei Medical Journal, 46 (3),* 331-340.

Wciórka B. & Wciórka J. (2008). Osoby chore psychicznie w społeczeństwie. Komunikat z badań, Centrum Badania Opinii Społecznej.

Załuska M., Paszko J., Suchecka D. & Traczewska Z. (2005). The influence of the new social help facilities on the reduction of hospitalizations of chronically mentally ill patients. *Archives of Psychiatry and Psychotherapy* , 7 (3), 25–35.

Zaluska M., Suchecka D., Traczewska Z. & Paszko J. (2005). Implementation of social services for the chronically mentally ill in a Polish mental health district: consequences for service use and costs . *The Journal of Mental Health Policy and Economics* , 8 (1), 37-44.

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 2
July 2011– June 2012

Peer-led vs. Clinician-led Recovery-Oriented Groups: What Predicts Attendance by Veterans?

Kathryn A. Bottonari, PhD
Charlie Norwood Veterans Administration Medical Center & Medical College of Georgia

Mark R. Schultz, PhD
Center for Health Quality and Economic Research, Edith Nourse Rogers Memorial Hospital

Sandra G. Resnick, PhD
VISN 1 MIRECC & Yale University School of Medicine

Lisa Mueller, PhD
VISN 1 MIRREC & Edith Nourse Rogers Memorial Hospital

Jack Clark, PhD
Center for Health Quality and Economic Research, Edith Nourse Rogers Memorial Hospital &
Boston University School of Public Health

Dolly C. Sadow, PhD, ABPP
MedOptions

Susan V. Eisen, PhD
Center for Health Quality and Economic Research, Edith Nourse Rogers Memorial Hospital &
Boston University School of Public Health

Citation:

Bottonari K, Schultz M, Resnick S, Mueller L, Clark J, Shadow, DC, Eisen SV (2012).Peer-led vs. Clinician-led Recovery-Oriented Groups: What Predicts Attendance by Veterans? ***International Journal of Psychosocial Rehabilitation. Vol 16(2) 96-113***

Correspondence:
Susan V. Eisen, PhD
Professor
Health Research Scientist
Center for Health Quality Outcomes and Economic Research (CHQOER)
Edith Nourse Rogers Memorial Veterans Hospital
200 Springs Road (152), Bedford, MA 01730.
Email: Susan.Eisen@va.gov

Author Note
This research was supported by VA grant IIR # D4464R from the Veterans Administration Rehabilitation Research & Development (RR&D) Service. The work was conducted at the Bedford and West Haven Veterans Administration Medical Centers. The views expressed in this article are those of the authors and do not necessarily represent the views of the Department of Veterans Affairs. This manuscript is the result of work supported with resources and the use of facilities at the Bedford VA and support to the first author through a VA Health Services Research Postdoctoral Fellowship.

Abstract

The Veterans Health Administration (VHA) is transforming its mental health services to incorporate a stronger focus on psychosocial rehabilitation and recovery. Peer-led groups may offer unique benefit in addition to conventional clinician-led services. There is limited empirical evidence comparing attendance at peer-led services compared to clinician-led services among veterans. Data were examined from the treatment arms (peer-led vs. clinician-led) of a 2-site, randomized study of recovery-oriented groups for veterans diagnosed with mental illness. Baseline self-report and interview data were examined as predictors of attendance over the course of the 12-week study, using negative binomial regressions. Results demonstrated modest attendance rates (3.8 + 4.3 groups out of 12 weeks), with no statistically significant difference in attendance or predictors of attendance between clinician-led vs. peer-led groups. Age, education, AUDIT score, and site predicted attendance at the recovery-focused groups in a combined model. Future investigations are needed to examine factors to improve attendance.

Key Words: peer support, recovery model, veterans, attendance

Introduction

In an effort to improve mental health services for veterans, the Veterans Health Administration (VHA) is working to incorporate a stronger focus on psychosocial rehabilitation and recovery throughout its treatment centers (Uniformed Mental Health Services Handbook, 2008). A recent review of VHA psychosocial rehabilitation services highlights the increase in recovery-oriented services, including local recovery coordinators, peer support services, peer support technicians, family services, Veterans Mental Health Council, Psychosocial Rehabilitation and Recovery Centers, Mental Health Intensive Case Management, Therapeutic and Supported Employment Services, and Skills training (Goldberg & Resnick, 2010). Mental health ‘recovery’ focuses on reclaiming one’s life and minimizing the effect of illness on quality of life (Davidson & Roe, 2007). Davidson and colleagues (2009) define recovery-oriented services as being person-centered, strengths-based, and collaborative. Ideally, the mental health consumer, friends, family, and treatment providers work together towards recovery.

Peer support is one important component of recovery-oriented services, particularly in the VHA (Barber, Rosenheck, Armstrong, & Resnick, 2008; Hebert, Rosenheck, Drebing, Young, & Armstrong, 2008). Empirical research has found positive effects for a range of peer support programs including improvements in practical knowledge, empowerment, in symptoms and social functioning; development of new coping skills; and enhancement of quality of life, with decreases in symptoms and feelings of isolation, and reduced psychiatric hospitalization rates (e.g., Barbic, Krupa, & Armstrong, 2009; Burti et al. 2005; Campbell, 2004; Cook et al., 2009; Davidson et al., 1999; Fukui et al., 2010; Paulson, Herinckx, Demmler, Clarke, Cutter, & Birecree, 1999; Sells, Davidson, Jewell, Falzer, & Rowe, 2006; Solomon & Draine, 2001; Sledge, Lawless, Sells, Wieland, O'Connell, & Davidson, 2011; Yanos, Primavera, Knight, 2001). Other recovery-oriented services have also been found to be effective, including supported employment programs, supportive housing, assertive community treatment and mental health case management (Drake & Bond, 2008; O'Connell, Kasprow, & Rosenheck, 2010; Rapp & Goscha, 2004).

However, the effectiveness of these recovery-oriented programs may depend on the level of participant attendance. Empirical examination of this question has been hampered by noted difficulty in adequately measuring variables of adherence and attendance within recovery-oriented, peer-led interventions (Falzer, 2011). However, several recent studies of peer support/peer-led interventions have noted greater improvement with increased attendance. Cook and colleagues (2009) reported that participants who attended six or more recovery-oriented group sessions showed greater improvement than those attending fewer sessions. Similarly, Starnino and colleagues (2010) reported positive effects of their WRAP intervention with at least 75% participation in the program. Swarbrick and colleagues (2009) found a relationship between years of attendance and empowerment, though they could not determine the predictor of this relationship. As such, research is needed to understand predictors of attendance and whether these factors vary as a function of the type of intervention being offered.

Review of the literature reveals investigations of both conventional, clinical-led intervention and peer-led (particularly with a focus on substance use groups); however, there is a limitation in that most studies focus on one particular type of intervention (i.e., peer-led or clinician-led but not both). Empirical investigations of self-help group attendance have previously identified that older age, being single, having better coping skills, strong social functioning, more formal education, living in an urban area, and more significant mental health and substance use problems all predicted longer time in self-help treatment (Jonikas, Kiosk, Grey, Hamilton, McNulty, & Cook, 2010; Luke, Roberts, & Rappaport, 1993; Yanos, Primavera, Knight, 2001). Furthermore, investigations of a specific form of peer support, substance-use focused self-help groups (i.e., NA/AA), have identified increased attendance among those who were older, unemployed, African-American background, more highly educated, not religious, less socially isolated, previous substance use treatment, higher self-efficacy regarding sobriety, more arrests, earlier age of onset of substance use disorder, history of physical or sexual abuse, living in supportive housing, and more acute substance abuse/mental health problems (Brown, O'Grady, Farrell, Flechner, & Nurco, 2001; DiNitto, Webb, Rubin, Morrison-Orton, & Wambach, 2001; Laudet, Magura, Cleland, Vogel, & Knight, 2003; Kelly, & Moos, 2003; Schneider, Burnette, & Timko, 2008; Weiss et al., 2000). Investigations of attendance at more conventional clinician-led mental health services have found provided conflicting evidence with several investigations indicating that no-show to one's appointments and/or lower attendance was predicted by younger age, less formal education, lack of sick leave, personality disorder diagnosis, particularly low or high functioning, no previous mental health treatment, substance abuse, fearful attachment style, interpersonal hassles (Fenger, Mortensen, Poulsen, & Lau, 2011; Ilardi & Kaslow, 2009) whereas others have identified higher attendance as predicted by social isolation, personality disorder, higher formal education, and more acute mental health disorder (Centorrino et al, 2001). Of direct relevance to veteran populations, Resnick and Rosenheck (2008) reported improvements in level of personal empowerment and confidence as well as overall functioning among veterans who participated in Vet-to-Vet as compared to veterans who had not participated in the program. Their 2010 investigation reported that almost 88% of their sample drawn from an observational study had participated in Vet-to-Vet prior to the study period and approximately 50% attended at least one session during the study period. Predictors of attendance included attending Vet-to-Vet prior to study enrollment, ongoing participation in the concurrent day program following completion of the study, lower recovery orientation, lower activities of daily living and older age (Resnick & Rosenheck, 2010).

The present study expanded on these findings by a) examining attendance in both peer- and clinician-led recovery-oriented groups in the context of a randomized study, b) examining differences in attendance between peer-led (Vet-to-Vet) and clinician-led groups, and c) identifying predictors of attendance in both peer-led and clinician-led groups.

Methods

Overview

This investigation is part of a randomized study of a recovery-oriented group intervention led by either peer facilitators (Vet-to-Vet; Resnick, Armstrong, Sperrazza, Harkness, & Rosenheck, 2004), or by clinicians. The intervention supplemented participants' individualized treatment plans, which they continued during the 3-month study period. Participants completed a baseline assessment (including a structured diagnostic interview) at enrollment and a follow-up assessment at the end of the intervention (3-months).

Participants

Eligibility criteria included being English-speaking, adult (at least 18 years old), having a mental health diagnosis, and having received mental health services through the VHA in the last 12 months. We enrolled a convenience sample of veterans receiving mental health services from one of two participating sites. This analysis includes 198 veterans who consented to the study and were randomized to either the peer-led or clinician-led recovery groups.

Measures

Demographic Characteristics: Age, gender, race, employment, disability status and housing arrangements were obtained by structured interview at enrollment in the study.

Psychological variables. We measured pre-intervention levels of hope (Snyder Hope Scale; Hope; Snyder et al., 1991), personal empowerment (Rogers Empowerment Scale; EMP; Rogers, Chamberlin, Ellison, & Crean, 1997, social support (MOS Social Support Survey; MOS; Sherbourne & Stewart, 1991), recovery (Recovery Assessment Scale; RAS; Corrigan, Giffort, Rashid, Leary, & Okeke, 1999), and patient activation (Patient Activation Measure; PAM; Hibbard, Stockard, Mahoney, & Tusler, 2004). All of these measures have demonstrated reliability and validity and most have been used in previous investigations examining recovery-oriented groups (e.g., Cook et al., 2009).

Mental Health and Substance Abuse Status. The pre-intervention (baseline) assessment included the following self-report measures of mental health symptoms and problems as well as substance use: Behavior and Symptom Identification Scale (BASIS-24, Eisen, Normand, Belanger, Spiro, & Esch, 2004), Veterans Short Form of the SF-12 (VR-12) from which we derived the Physical (PCS) and Mental (MCS) Component Scores (Kazis et al., 2004), Alcohol Use Disorders Identification Test, (AUDIT, Saunders, Aasland, Babor, De La Fuente, & Grant, 2006); Drug Abuse Screening Test; (DAST, Cocco & Carey, 1998). Each of these measures has demonstrated reliability and validity and has been used extensively with veterans for both research and clinical purposes. In addition to these self-report measures we assessed lifetime psychiatric diagnoses using the mood, anxiety, psychotic, and substance use disorder modules from the Structured Clinical Interview for DSM-IV Diagnosis (SCID-I, First, Spitzer, Gibbon, & Williams, 1997), from which we created four dichotomous variables indicating presence or absence of diagnoses in each of these categories.

Treatment Utilization. Participants self-reported their VA and non-VA care in the 3 months prior to study enrollment, including inpatient and outpatient mental health treatment, transportation difficulties regarding getting to treatment, and prior utilization of peer support.

Attendance. The dependent variable was the total number of study-related groups attended during the 3-month study period, ranging from 0-12.

Procedure

Sample Recruitment. Veterans were informed about the study via fliers posted in clinic waiting areas and presentations at community meetings within mental health programs at each site. Veterans who expressed interest were given detailed information about the study by study personnel. All those who agreed to participate signed a written informed consent form approved by their VAMC's Institutional Review Board (IRB). After signing consent, the research interviewer informed the veteran which study arm s/he was randomized to, and told them when and where the group met. Randomization was done separately by site to equalize randomization at each site. Veterans were not paid for group attendance, but they were paid for up to $60 total for study assessments. Attendance rosters were collected from the group leaders after every meeting. Veterans were not considered 'drop-outs' unless they formally requested to be withdrawn from the study, which occurred in only two cases. Rather, since attendance was the dependent (outcome) variable in this study, no attendance was considered a valid outcome.

Sites. The study was conducted at two large VAMCs in the Northeast. Veterans were recruited from several programs at Site 1, including a structured residential program, a day treatment program, an outpatient mental health clinic, a long-term inpatient unit, several community residential care (CRC) homes, and a state-run residence for veterans. Recruitment at Site 2 was conducted at a VA Community Care Center, which provides a range of psychosocial, medical and educational services. These two sites were selected for the study because they each have extensive, well-established recovery-oriented mental health services.

Recovery Groups. The peer-led and clinician-led groups shared many features. All groups (i.e., Peer and Clinician at Site 1 and 2) met at least weekly for 45 minutes, were recovery-oriented, with a focus on psychosocial rehabilitation and community integration. The peer-led groups used the Vet-to-Vet model. They were led by two peer facilitators who received training regarding implementation of the Vet-to-Vet model. In addition, they had weekly supervision and ongoing evaluation by both a professional and a peer supervisor. Peer facilitators were other veterans in treatment for a mental illness. As peer providers, they are encouraged to share their personal experiences during group meetings. Peer facilitators were paid as independent contractors; thus they were not VA employees. The peer-led (Vet-to-Vet) groups followed an established curriculum using recovery-focused written materials, such as the Recovery Workbook (Spaniol, Koehler, & Hutchinson, 1994), or Pathways to Recovery (Ridgway, McDiarmid, Davidson, Bayes & Ratzlaff, 2002). Each meeting focused on a different workbook chapter introduced by the facilitators and following a read and discuss format in which facilitators and participants discuss the topic and share their experiences. Examples of workbook chapters included managing life's stresses, building personal support, setting personal goals, and recognizing strengths. Clinician-led groups were led by a master's level mental health clinician. Some of the clinician-led group leaders chose to use the same recovery-focused written materials as were used by the peer facilitators, although this was not required. However, all clinician-led groups followed a recovery-oriented model focused on enhancing interpersonal and functional skills. Although both Vet-to-Vet and clinician led groups were structured around recovery issues, they are not "manualized" therapies in which the precise contents of each session are documented in a manual; consequently, the content of each group could vary from week to week.

Two major differences between the Vet-to-Vet and clinician-led groups were expectations regarding sharing/disclosure of personal information, and clinical training. Peer leaders of the Vet-to-Vet groups were expected to share their own experiences with group participants, whereas clinician leaders were not. Clinician group leaders have professional clinical training, whereas peer leaders have a much briefer training program, which is however, followed up with continued training and ongoing supervision. Of course, peer leaders also have personal experience as both a veteran and a person with a serious mental illness.

Site 1 had 4 clinician-led groups and 4 Vet-to-Vet groups which ran over a 2-year period, but ended when the last study participants completed their 3-month follow-up assessments because research grant funds used to pay the peer facilitators were depleted. Site 2 had 1 rolling, clinician-led group and 5 rolling Vet-to-Vet groups over the course of the study.

Data Analysis

Data analyses were performed using SAS (SAS Institute Inc, 2008) and SPSS (SPSS Inc, 2009). Self-report measures were scored using each measure's published algorithms. First, we computed descriptive statistics to examine attendance patterns for the sample as a whole and divided by study arm (clinician- vs. peer-led). Second, we used negative binomial regression to assess association between type of group (peer- vs. clinician-led) and attendance. Negative binomial regression is appropriate for this analysis because attendance is a count variable and because of the relatively large number of cases who did not attend any groups (Hilbe, 2007). To identify predictors of attendance, and whether predictors might differ for peer- vs. clinician-led groups, we regressed attendance on each patient characteristic alone and in interaction with type of group (peer- vs. clinician-led). However, since none of the interactions with type of group were significant, we computed bivariate correlations to examine the relationship between participant characteristics and attendance (i.e., pearson correlations or point biserial correlations when one of the variables is binary). Variables that were significant at $p<.05$ were entered into a negative binomial mixed-model regression to examine unique predictors of attendance.

Results

Sample Characteristics

As expected in a population of veterans, the majority of the sample were males (92%). Average age was 52 + 10 years; 53% had some post-high school education. Approximately one-quarter (28%) of the participants were non-Caucasian and 10% were Hispanic/Latino. Mood disorders, substance use disorders and post-traumatic stress disorder (PTSD) or other anxiety disorders were all highly prevalent, occurring in more than 50% of study participants. There were no statistically significant differences between study arms (peer- vs. clinician-led) in demographic characteristics, diagnosis category, or any of the T1 self-report measures with the exception of self-reported drug use (Peer-led group reported significantly higher use than the Clinician-led group; F(1,197)=5.64, p=0.0185). Table 1 presents the sample characteristics.

Table 1. *Participant Characteristics*

	%	M(SD)	Range
Demographics			
Gender			
Male	92%		
Age (years)		52 ± 10	
Ethnicity			
Hispanic/Latino	10%		
Race[c]			
American Indian	3%		
Asian	0.5%		
African American/Black	28.8%		
Pac Islander	0%		
Caucasian/white	71.7%		
Education			
High School diploma or less	47%		
More than High School diploma	53%		
Relationship status			
Married/partner	7%		
Separated	1		

Divorced Widowed Never married	1% 40% 5% 37%		
Lives alone	15%		
Has no source of social support	8%		
Has independent housing	20%		
Has paid job	14%		
Receives disability	60%		
Psychological Characteristics			
Empowerment[a]		80.5(7.56)	28-112
Hope[a]		23.43(3.76)	12-48
Patient activation[a]		36.85(9.43)	0-52
Recovery[a]		163.6 (20.9)	42-210
Social Support[a]		58.8(18.3)	19-95
Mental Health/Substance Use Status and Diagnoses			
Physical health (PCS, VR-12)[a]		43.14(13.19)	unbounded

Mental health (MCS, VR-12)[a]		42.92(13.88)	unbounded
Behavior and symptoms (BASIS-24)[b]		1.23(.666)	0-4
Alcohol Use (AUDIT)[b]		7.65(8.29)	0-40
Drug Use (DAST-10)[b]		2.82(3.62)	0-10
SCID-I Diagnosis			
Mood Disorder	64%		
PTSD/Other Anxiety Disorder	51%		
Psychotic Disorder	28%		
Substance Use Disorder	64%		
Treatment Use in 3 Months Before Study Entry			
Outpatient medical care	81%		
Emergency medical care	29%		
Inpatient medical care	17%		
Outpatient mental health care	88%		
Emergency mental health care	34%		
Inpatient mental health care	43%		
Outpatient substance abuse treatment	28%		

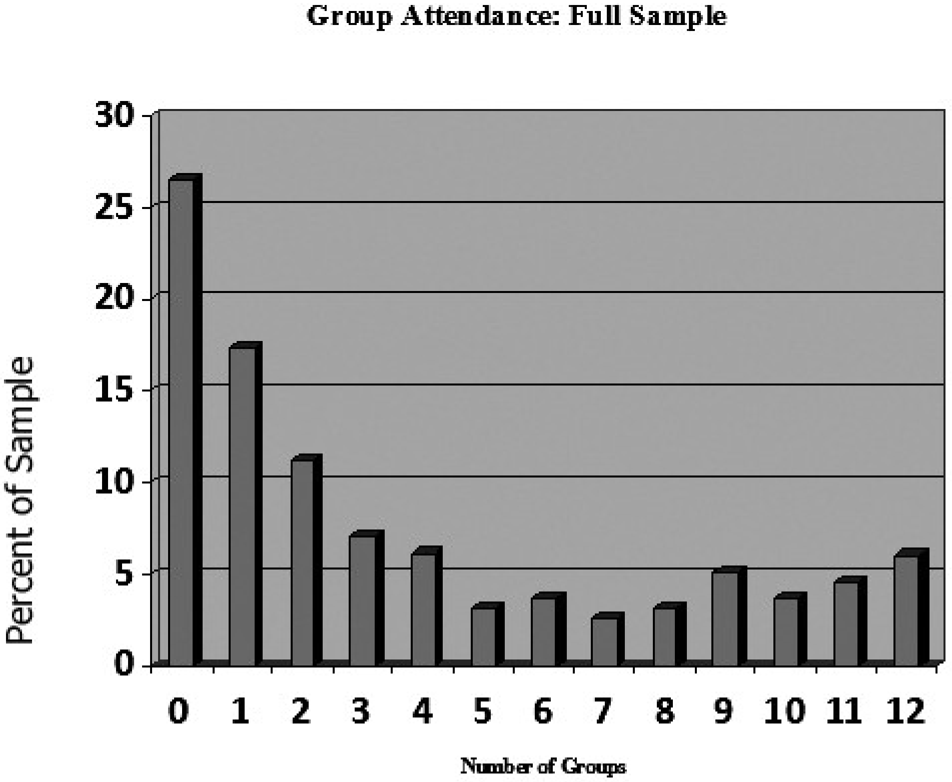
Substance abuse detoxification	15%		
Inpatient substance abuse treatment	25%		
Stayed overnight for treatment	48%		
Problem getting to treatment (i.e., transportation problems)			
Big Problem	8%		
Small Problem	15%		
Ever used mental health peer support services?	7%		
Ever used addiction peer support services?	49%		
Ever used other peer support services?	10%		

Note. [a]Higher scores are better; [b]Lower scores are better; [c]Multiple responses accepted

Attendance at Recovery-Oriented Groups

Across the full sample participants attended an average of 3.8 + 4.3 groups over the 12 week study period. Approximately one-quarter (26.5%) of the sample did not attend any study-related groups. There was no significant difference in attendance by type of group with veterans assigned to peer-led groups attending 3.8 + 4.6 groups and veterans assigned to clinician-led groups attending 3.8 + 3.9 groups. Since there were no group differences, attendance is presented for both groups combined (Figure 1).

Figure 1 Group Attendance: Full sample



Predictors of Attendance.

The following baseline variables were significantly positively correlated with attendance ($p<.05$): older age, higher education, better mental health (MCS), more Hope and Psychotic Disorder diagnosis. The following variables were significantly negatively correlated with attendance: emergency and inpatient mental health care, outpatient, detoxification, and inpatient substance abuse treatment, AUDIT and DAST scores, any inpatient treatment in the past 3 months, and transportation difficulties getting to treatment (Table 2). Site was also a significant predictor of attendance.

The following significant predictors were entered into a negative binomial regression model: age, education, overnight treatment, difficulty getting to treatment, AUDIT, DAST, Hope, MCS, SCID psychotic disorder diagnosis and site. Because of high correlations between the AUDIT, DAST and substance abuse treatment variables, as well as between inpatient and emergency treatment we excluded the substance abuse and inpatient/emergency treatment variables from the regression model to minimize the impact of multicollinearity.

In the final model only age, education, AUDIT score, and site remained as significant predictors of attendance (see Table 2). Older age and more education predicted better attendance. Higher levels of alcohol use assessed by the AUDIT predicted lower attendance. In addition, attendance was higher at Site 1 than Site 2.

Table 2. Association between Variables and Group Attendance

	Correlation with attendance	F-value from final model

Demographics

Gender	0.01	
Age	0.23^{*}	9.24^{**}
Ethnicity	0.03	
Race	0.12	
Education	0.21^{*}	8.64^{**}
Relationship Status	0.06	
Lives Alone	-0.10	
Has no source of social support	0.03	
Has independent housing	-0.03	
Has Paid Job	0.03	
Receives Disability Income	-0.13	
Psychological Characteristics		
EMP[a]	0.02	
HOPE[a]	0.19*	2.27
PAM[a]	0.03	
RAS[a]	0.02	
MOS[a]	0.12	
Mental Health/Substance Use Status and Diagnoses		
PCS[a]	-0.03	
MCS[a]	0.19*	0.17
BASIS-24[b]	-0.12	
AUDIT[b]	-0.26*	4.04

DAST [b]	-0.28*	2.47
SCID-I Diagnosis Mood Disorder PTSD/Other Anxiety Disorder Psychotic Disorder Substance Use Disorder	-0.13 -0.10 0.15* -0.11	1.67
Treatment Use in 3 Months Before Study Entry		
Outpatient medical care	0.09	
Emergency medical care	-0.05	
Inpatient medical care	-0.07	
Outpatient mental health care	-0.07	
Emergency mental health care	-0.20*	
Inpatient mental health care	-0.27*	
Outpatient substance abuse treatment	-0.16*	
Substance abuse detoxification	-0.21*	
Inpatient substance abuse treatment	-0.20*	
Stayed overnight for treatment	-0.27*	0.20
Transportation problem getting to treatment	0.17*	0.83
Ever used mental health peer support services?	0.00	
Ever used addiction peer support services?	-0.10	
Ever used other peer support	0.07	

services?		
Study Characteristic		
Site	-0.39 *	19.19*

Note. *p<0.05, **p<0.01, HOPE=Snyder Hope Scale; EMP=Rogers Empowerment Scale; RAS=Recovery Assessment Scale; PAM=Patient Activation Measure; BASIS-24= 24-item Behavior and Symptom Identification Scale; PCS=Physical Component Score of VR-36; MCS=Mental Component Score of VR-36; AUDIT=Alcohol Use Disorders Identification Test; DAST=Drug Abuse Screening Test

Discussion

This study examined attendance and predictors of attendance in peer-led and clinician-led groups within the VHA. Although attendance levels were modest for both types of groups they were higher than that reported by Resnick and Rosenheck (2010), in which only 51.5% went to a group during their study period (though 87% had attended at least one Vet-to-Vet meeting before study entry). Our investigation of potential predictors of attendance identified only age, education, AUDIT score, and site as statistically significant. Older age, lower AUDIT scores, and higher level of education was associated with increased attendance, which is consistent with findings from Resnick and Rosenheck's (2008) quasi-experimental study and (2010) investigation of Vet-to-Vet attendance, as well as several other studies (DiNitto et al., 2001; Laudet et al., 2003; Luke et al., 1993; Ogrodniczuk, Piper, & Joyce, 2006; Yanos et al., 2001).

Though unexpected, site was a significant predictor of attendance, with veterans at Site 1 attending an average of 5.3 groups in comparison to 2.2 groups at Site 2. There were several site differences (e.g., in sample characteristics, facilitators and clinical programs) that could account for this effect. Examination of demographic and clinical characteristics between participants at the two sites showed differences in race (higher percentage African-American at Site 2 than Site 1), Hispanic ethnicity (higher percentage of Hispanic veterans at Site 2), gender (more females at Site 2), recent substance use (more substance use at Site 2), and service use in the previous 3 months (higher level of service usage at Site 2). This last finding is of interest as Site 2 reported higher level of service usage but attended fewer groups. This may be consistent with the findings of Zemore and Kaskutas (2008), who noted in their investigation of day-hospital and residential programs, that attendance varied at curricular vs. extra-curricular (non-prescribed groups) as a function of type/intensity of current treatment. As AUDIT score varied between site and also predicted attendance, it may be that self-reported alcohol use partially accounts for the site difference in attendance. However, there may be other program characteristics and unmeasured site characteristics which also partially account for the site differences.

The fact that only four variables remained as significant predictors, raises questions as to what other factors might predict attendance. Participant satisfaction with the groups, cultural sensitivity of offerings, utilization of other treatment modalities, number of concurrent groups being attended, and engagement in other structured activities (e.g., work) could also be examined as possible predictors of attendance. Furthermore, there is some evidence from the addiction literature that research should be addressing level of participation, rather than attendance, as a predictor of outcome (Weiss et al., 2005).

Strengths and Limitations

There are a number of strengths to this investigation. First, the previous literature has been vague about participation rates in recovery-oriented services and our study design allowed us to systematically track and report attendance. Second, although there is a growing body of literature on peer support services, this is the first randomized study examining peer-led versus clinician-led recovery-oriented groups for veterans with a mental illness. Third, our study measured several patient-level factors, including demographics, psychological factors, mental health status, and treatment utilization variables, allowing us to investigate a wide range of possible predictors of attendance.

This study also has limitations. First, there is an inherent paradox between the idea of a randomized clinical trial in which participants agree to attend whatever intervention is part of the randomized trial, and the ideals of personal empowerment and self-determination that are integral components of recovery-oriented mental health services. Clinicians tend to assume that more treatment (i.e., higher attendance) is better than less treatment, whereas empowered consumers may prefer and benefit from less intervention. A second limitation is that the study was conducted at only two sites in one region of the country and the sample was largely composed of middle-aged veterans who were longstanding recipients of VA mental health care. Replication of these results with younger veterans and in a national sample would greatly enhance their generalizability. Third, given the relatively short time frame of the study and the generally low attendance levels, it was not feasible to examine attendance patterns beyond the total number of groups attended during the study period. It is possible that there are different predictors of attendance among those who attend a few groups and do not return versus those individuals who attend few groups at first, but more later on. Finally, assessment of specific clinic and group leader characteristics might also be useful in understanding factors that affect attendance.

Future directions and clinical implications

The randomized study, of which this investigation is a component, is attempting to learn more about the content and outcome of recovery-oriented mental health groups. Given the findings from this analysis, future work should focus in on mechanisms to increase motivation for treatment and also identification of appropriate treatment modalities. Though group leaders may often search for patient characteristics to explain non-attendance, one potentially obvious, but possibly overlooked, explanation may be that poor attendance is associated with the group not meeting patients' needs (e.g., McKisack & Waller, 1996). Alternatively, given that higher levels of education were predictive of increased attendance, it may be that a brief educational orientation to recovery-focused services may aid consumers in making an educated decision regarding the value of adding recovery-focused groups to their treatment plan. Pretherapy orientation has been shown to improve attendance at traditional psychotherapy groups (e.g., France & Dugo, 1985; Sheeran, Aubrey, & Kellett, 2007). Finally, given that veterans have a choice between clinician-led and peer-led groups at their treatment facilities, future research might want to offer them an option to attend either and examine patterns of attendance when both modalities are available. Beyond examination of attendance or adherence to recommended treatment interventions, recovery-focused, patient-centered care should continue to explore the kinds and quantities of services desired or preferred by consumers, as well as the links between services and clinical outcomes.

References:

Barber, J. A., Rosenheck, R. A., Armstrong, M., & Resnick, S. G. (2008). Monitoring the dissemination of peer support in the VA Healthcare System. Community Mental Health Journal, 44, 433–444.

Barbic, S., Krupa, T., & Armstrong, I. (2009). A randomized controlled trial of the effectiveness of a modified recovery workbook program: Preliminary findings. Psychiatric Services, 60(4), 491-497.

Brown, B. S., O'Grady, K. E., Farrell, E.V., Flechner, I.S., & Nurco, D.N. (2001). Factors Associated with Frequency of 12-Step Attendance by Drug Abuse Clients. American Journal of Drug and Alcohol Abuse, 27(1), 147–160

Burti, L., Amaddeo, F., Ambrosi, M., Bonetto, C., Cristofalo, D., Ruggeri, M., & Tansella, M. (2005). Does additional care provided by a consumer self-help group improve psychiatric outcome? A study in an Italian community-based psychiatric service. Community Mental Health Journal, 41(6), 705-720. DOI 10.1007/s10597-005-6428-1

Campbell, J. (2004). Consumer-operated services program (COSP) multisite research initiative overview and preliminary findings. Retrieved July 15, 2009 from http://www.power2u.org/downloads/COSPVAREPORT.pdf.

Centorrino, F., Hernán, M. A., Drago-Ferrante, G., Rendall, M., Apicella, A., Längar, G., & Baldessarini, R. J. (2001). Factors associated with noncompliance with psychiatric outpatient visits. Psychiatric Services, 52(3), 378-380. doi:10.1176/appi.ps.52.3.378

Cocco, K. M., & Carey, K. (1998). Psychometric properties of the Drug Abuse Screening Test in outpatients. Psychological Assessment,19, 408-414.

Cook, J. A., Copeland, M.E., Hamilton, M.M., Jonikas, J.A., Razzano, L.A., Floyd, C.B., … & Grey, D.D. (2009). Initial outcomes of a mental illness self-management program based on Wellness Recovery Action Planning. Psychiatric Services, 60(2), 246–249.

Corrigan, P. W., Giffort, D., Rashid, F., Leary, M., & Okeke, I. (1999). Recovery as a psychological construct. Community Mental Health Journal, 35, 231-239. DOI: 10.1023/A:1018741302682

Davidson, L., Chinman, M. J., Kloos, B., Weingarten, R., Stayner, D., & Tebes, J. K. (1999). Peer support among individuals with severe mental illness: a review of the evidence. Clinical Psychology: Science and Practice, 6, 165–187. DOI:10.1093/schbul/sbj043

Davidson, L., Drake, R. E., Schmutte, T., Dinzeo, T., & Andres-Hyman, R. (2009). Oil and water or oil and vinegar? Evidence-based medicine meets recovery. Community Mental Health Journal, 45, 323–332. DOI 10.1007/s10597-009-9228-1

Davidson, L., & Roe, D. (2007). Recovery from versus recovery in serious mental illness: One strategy for lessening confusion plaguing recovery. Journal of Mental Health, 16(4), 1–12.

DiNitto, D. M., Webb, D. K., Rubin, A., Morrison-Orton, D., & Wambach, K. G. (2001). Self-help group meeting attendance among clients with dual diagnoses. Journal of Psychoactive Drugs, 33(3), 263-272.

Drake, R., & Bond, G. (2008). Supported employment: 1998 to 2008. Psychiatric Rehabilitation Journal, 31(4), 274-276. doi:10.2975/31.4.2008.274.276.

Eisen, S. V., Normand, S. L. T., Belanger, A., Spiro, A., III, & Esch, D. (2004). The revised Behavior and Symptom Identification Scale (BASIS-24): Reliability and Validity. Medical Care, 42, 1230-1241.

Falzer, P. R. (2011). Comparing an intervention with treatment as usual. Psychiatric Services, 62(7), 807.

Fenger, M., Mortensen, E., Poulsen, S., & Lau, M. (2011). No-shows, drop-outs and completers in psychotherapeutic treatment: Demographic and clinical predictors in a large sample of non-psychotic patients. Nordic Journal of Psychiatry, 65(3), 183-191.

First, M. B., Spitzer, R. L., Gibbon, M., & Williams, J. B. W. (1997). Structured Clinical Interview for DSM-IV Axis I Disorders (Patient ed., Version 2). New York: Biometrics
Research Department, New York State Psychiatric Institute.

France, D. G., & Dugo, J. M. (1985). Pretherapy orientation as preparation for open psychotherapy groups. Psychotherapy, 22, 256-261.

Fukui, S., Davidson, L., Holter, M., & Rapp, C. (2010). Pathways to Recovery (PTR): Impact of peer-led group participation on mental health recovery outcomes. Psychiatric Rehabilitation Journal, 34(1), 42-48. doi:10.2975/34.1.2010.42.48.

Goldberg, R., & Resnick, S. (2010). US Department of Veterans Affairs (VA) efforts to promote psychosocial rehabilitation and recovery. Psychiatric Rehabilitation Journal, 33(4), 255-258. doi:10.2975/33.4.2010.255.258.

Hebert, M., Rosenheck, R., Drebing, C., Young, A. S., & Armstrong, M. (2008). Integrating peer support initiatives in a large healthcare organization. Psychological Services, 5(3), 216-227. DOI: 10.1037/1541-1559.5.3.216

Hibbard, J. H., Stockard, J., Mahoney, E. R., & Tusler, M. (2004). Development of the Patient Activation Measure (PAM): Conceptualizing and measuring activation in patients and consumers. Health Services Research, 39, 1005-1024.

Hilbe, J. M. (2007). Negative Binomial Regression. Cambridge, UK: Cambridge University.

Ilardi, D. L., & Kaslow, N. J. (2009). Social difficulties influence group psychotherapy adherence in abused, suicidal African American women. Journal of Clinical Psychology, 65(12), 1300-1311. doi:10.1002/jclp.20628

Jonikas, J.A., Kiosk, S., Grey, D. D., Hamilton, M. M., McNulty, J., & Cook, J. A. (2010). Cultural competency in peer-run programs: Results of a web survey and implications for
future practice. Psychiatric Rehabilitation Journal, 34(2), 121–129.

Kazis, L.E., Miller, D.R., Clark, J.A. et al. (2004). Improving the response choices on the veterans SF-36 health survey role functioning scales. Results from the Veterans Health Study. Journal of Ambulatory Care Management, 27, 263-280.

Kelly, J. F., & Moos, R. (2003). Dropout from 12-step self-help groups: Prevalence, predictors, and counteracting treatment influences. Journal of Substance Abuse Treatment, 24, 241–250.

Laudet, A.B., Magura, S., Cleland, C.M., Vogel, H.S., & Knight, E. L. (2003). Predictors of retention in dual-focus self-help groups. Community Mental Health Journal, 39(4), 281-295.
Luke, D. A., Roberts, L., & Rappaport, J. (1993). Individual, group context, and individual-group fit predictors of self-help group attendance. Journal of Applied Behavior Science, 29, 216-238.

McKisack, C., & Waller, G. (1996). Why is attendance variable at groups for women with Bulimia Nervosa? The role of eating psychopathology and other characteristics. International Journal of Eating Disorders, 20, 205-209.

O'Connell, M., Kasprow, W., & Rosenheck, R. (2010). National dissemination of supported housing in the VA: Model adherence versus model modification. Psychiatric Rehabilitation Journal, 33(4), 308-319. doi:10.2975/33.4.2010.308.319.

Ogrodniczuk, J. S., Piper, W. E., & Joyce, A. S. (2006). Treatment compliance in different types of group psychotherapy: Exploring the effect of age. Journal of Nervous and Mental Disorders, 194, 287–293. DOI: 10.1097/01.nmd.0000207366.49820.85

Paulson, R., Herinckx, H., Demmler, J., Clarke, G., Cutter, D., & Birecree, E. (1999). Comparing practice patterns of consumer and non-consumer mental health service. Community Mental Health Journal, 35, 251-269. DOI: 10.1023/A:1018745403590

Rapp, C., & Goscha, R. (2004). The principles of effective case management of mental health services. Psychiatric Rehabilitation Journal, 27(4), 319-333.

Resnick, S. G., Armstrong, M., Sperrazza, M., Harkness, L., & Rosenheck, R. A. (2004). A model of consumer-provider partnership: Vet-to-Vet. Psychiatric Rehabilitation Journal, 28, 185-187.

Resnick, S. G., & Rosenheck, R. A. (2008). Integrating peer support and mental health services: A quasi-experimental study of recovery orientation, confidence and empowerment. Psychiatric Services, 59, 1307-1314.

Resnick, S. G., & Rosenheck, R. A. (2010). Who attends Vet-to-Vet? Predictors of attendance in mental health mutual support. Psychiatric Rehabilitation Journal, 33, 262-268.

Ridgway, P., McDiarmid, D., Davidson, L., Bayes, J., & Ratzlaff, S. (2002). Pathways to Recovery: A Strengths Recovery Self-Help Workbook. Lawrence, KS: The University of Kansas School of Social Welfare.

Rogers, E. S., Chamberlin, J., Ellison, M. L., & Crean, T. (1997). A consumer-constructed scale to measure empowerment among users of mental health services. Psychiatric Services, 48, 1042-1047.

SAS Institute Inc. (2008). SAS software, Version 9.2. Cary, NC, USA.

Saunders, J.B., Aasland, O. F., Babor, T. F., De La Fuente, J.R., & Grant, M. (2006). Development of the Alcohol Use Disorders Identification Test (AUDIT): WHO collaborative project on early detection of persons with harmful alcohol consumption-II. Addiction, 88, 791-804.

Schneider, R., Burnette, M., & Timko, C. (2008). History of physical or sexual abuse and participation in 12-step self-help groups. The American Journal of Drug and Alcohol Abuse, 34: 617–625.

Sells, D., Davidson, L., Jewell, C., Falzer, P., & Rowe, M. (2006). The treatment relationship in peer-based and regular case management for clients with severe mental illness. Psychiatric Services, 57, 1179–1184.

Sheeran, P., Aubrey, R., & Kellett, S. (2007). Increasing attendance for psychotherapy: Implementation intentions and the self-regulation of attendance-related negative affect. Journal of Consulting and Clinical Psychology, 75(6), 853-863. doi:10.1037/0022-006X.75.6.853

Sherbourne, C. D., & Stewart, A. L. (1991). The MOS Social Support Survey. Social Science & Medicine, 32, 705-714.

Sledge, W. H., Lawless, M., Sells, D., Wieland, M., O'Connell, M. J., & Davidson, L. (2011). Effectiveness of peer support in reducing readmissions of persons with multiple psychiatric hospitalizations. Psychiatric Services, 62(5), 541-544.

Snyder, C. R., Harris, C., Anderson, J. R., Holleran, S. A., Irving, L. M., Sigmon, S. T., et al. (1991). The will and the ways: development and validation of an individual-differences measure of hope. Journal of Personality and Social Psychology, 60, 570-585.

Solomon, P., & Draine, J. (2001). The state of knowledge of the effectiveness of consumer provided services. Psychiatric Rehabilitation Journal, 25, 20–27.

Spaniol, L., Koehler, M., & Hutchinson, D. (1994, 2009). The recovery workbook: Practical coping and empowerment strategies for people with psychiatric disability, Revised edition. Boston: Boston University, Center for Psychiatric Rehabilitation.

SPSS Inc . (2009). SPSS for Windows, Rel. 18.0. Chicago, IL.

Starnino, V., Mariscal, S., Hotler, M., Davidson, L., Cook, K., Fukui, S., & Rapp, C. (2010. Outcomes of an illness self-management group using wellness recovery action planning.
Psychiatric Rehabilitation Journal, 34(1), 57-60.

Swarbrick, M., Schmidt, L. T., & Pratt, C. W. (2009). Consumer-operated self-help centers: Environment, empowerment, and satisfaction. Journal of Psychosocial Nursing, 47(7), 41-47.

Uniformed Mental Health Services Handbook (VHA HANDBOOK 1160.010. June 11, 2008).

Weiss, R. D., Griffin, M. L., Gallop, R., Luborsky, L., Siqueland, L., Frank. A., Onken, L. S., Daley, D. C., & Gastfriend, D. R. (2000). Predictors of self-help group attendance in cocaine dependent patients. Journal of Studies on Alcohol, 61(5), 714-719.

Weiss, R. D., Griffin, M. L., Gallop, R. J., Najavits, L. M., Frank, A., Crits-Christoph, P., Thase, M. E., Blaine, J., Gastfriend, D. R., Daley, D., & Luborsky, L. (2005). The effect of 12-step self-help group attendance and participation on drug use outcomes among cocaine-dependent patients. Drug and Alcohol Dependence, 77, 177–184.

Yanos, P. T., Primavera, L. H., & Knight, E. L. (2001). Consumer-run participation, recovery in social functioning, and the mediating role of psychological factors. Psychiatric Services, 52(4), 493-500.

Zemore, S.E., & Kaskutas, L.A. (2008). Services received and treatment outcomes in day-hospital and residential programs. Journal of Substance Abuse Treatment, 35, 232–244.

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 2
July 2011– June 2012

‘Building Babies Brains’: A mental health program for promoting parenting skills for parents of ‘at risk’ children.

Dr Pam McGrath, B.Soc.Wk., MA., Ph D
Director International Program of Psycho-Social Health Research (IPP-SHR)
Centre of National Research on Disability and Rehabilitation Medicine
Griffith Health Institute LO5, Level 1 Logan Campus Griffith University Meadowbrook
Qld 4131 Queensland, Australia Postal Address:
PO Box 1307 Kenmore Qld 4069 Australia
E-mail: pmcgrathgu@gmail.com or p.mcgrath@griffith.edu.au

Ms Nicole Rawson-Huff, BSc (Hons)
Project Officer
International Program of Psycho-Social Health Research (IPP-SHR)
Centre of National Research on Disability and Rehabilitation Medicine
Griffith Health Institute LO5, Level 1 Logan Campus Griffith University Meadowbrook
Qld 4131 Queensland Australia Email: nicolelhuff@yahoo.com.au

Mr Hamish Holewa, B. Sc (Comp Sci), B Ed, GradDipHEcon
Research Associate
Institute of Health and Social Science
CQUniversity
Brisbane Campus
160 Ann St
Brisbane Q 4000
AUSTRALIA Email: h.holewa@cqu.edu.au

Citation:
McGrath P, Rawson-Huff N & Holewa H (2012). ‘Building Babies Brains’: A mental health program for promoting parenting skills for parents of ‘at risk’ children. ***International Journal of Psychosocial Rehabilitation. Vol 16(2) 106-113***

Acknowledgements

The authors would like to thank the many participants who gave their time and insights to this research project. The authors would also like to thank Mr Neil Alcorn & Ms Teresa Vant and the staff at the Mater Parent Aide Unit, Mater Hospital. The authors wish to acknowledge team members that contributed to this report, including: Ms Mary-Anne Patton, Ms Bo McGrath, Ms Elaine Phillips & Mr Michael Bouwman.The authors acknowledge the support of the Institute of Health and Social Sciences and the Faculty of Sciences, Health and Engineering, CQUniversity and Centre of National Research on Disability and Rehabilitation Medicine, Griffith University.

Abstract

The Building Babies' Brains (BBB) program aims to educate new parents, particularly parents of children considered psychologically 'at risk', about the vital impact their interactions have on their child's brain development and mental health. BBB offers a comprehensive support package which includes recruitment into the 'Getting to Know You' (GTKY) parent education workshops, 12 months Mater Aide follow-up support and 18 months subscription to Noah's Ark services. This paper presents research findings on an evaluation of the GTKY workshop that indicates that such a program has the potential to be a significant proactive mental health initiative for parents and infants. Factors associated with positive outcomes include the provision of social support and normalisation of the parenting experience, self-esteem and confidence building through networking with peers, self expression in a non-judgemental group environment, and parental education through information provision. Limitation and suggestions for further developments of the program are included. The hope and expectation is that the findings will help encourage the further development of such programs elsewhere.

Keywords: Mental health, rehabilitation; parents; infants; psychosocial; communication.

Introduction

As Bayer and associates (2007) note, mental health problems are a public health issue affecting as many as 20% of children in modern communities. The quality of parent-infant communication has long-lasting effects and is seen as an important factor associated with the mental health of the developing child (Hotelling, 2004). Attachment studies of families at social risk demonstrates that disorganized attachment behaviours in infancy are important precursors to later psychological and mental health disturbances (Baradon, 1999; Lyons-Ruth et al., 2006). This early vulnerability is related to patterns of parent-infant affective communication observable by the end of the child's second year. Thus, interventions that promote positive parent-infant interactions are noted as strategies that can help to reduce the risk of poor developmental outcomes for the child (Leitch, 1999). Literature indicates that good infant mental health places the child at a lifelong advantage for sound teenage and adult relationships.

The Building Babies' Brains (BBB) program aims to educate new parents, particularly parents of children considered psychologically 'at risk', about the vital impact their interactions have on their child's brain development and mental health. BBB offers a comprehensive support package which includes recruitment into the 'Getting to Know You' (GTKY) parent education workshops, 12 months Mater Aide follow-up support and 18 months subscription to Noah's Ark services. This paper presents research findings on an evaluation of the GTKY workshop, independently conducted by the International Program of Psycho-Social Health Research (IPP-SHR), that indicates that such a program has the potential to be a significant proactive mental health initiative for parents and infants.

The Building Babies Brains (BBB) Program

The Mater Parent Aide Unit (MPAU) at Mater Children's Hospital, Brisbane, Australia, in conjunction with Noah's Ark Children's Resource Centre has been conducting a pilot project titled, 'Building Babies Brains' (BBB). BBB aims to educate new parents, particularly parents of children considered psychologically 'at risk', about the vital impact their interactions have on their child's brain development and mental health. This is in response to peer-reviewed recognition of the need to promote emotional availability and secure attachment during a baby's first 12 months of life (Berlin & Cassidy, 2001). As Hotelling (2004) details, educational strategies are now available to facilitate and improve the basis of effective communication for parents and their infants. BBB is a support and education package based on presentation and discussion of a training DVD delivered to new parents who have been referred to the Mater Parent Aide Unit from the Community Hospital Integration Nurse and who have difficulty being 'emotionally' available to their newborn. The program offers enrolment in the 'Getting to Know You' (GTKY) workshops, 12 months support services offered by the Parent Aide Unit and membership to Noah's Ark play group.

The GTKY workshops are run over a 7 week period and are designed to educate and support new parents who have difficulty being 'emotionally available' for their newborn. The program teaches parents to recognise and respond more appropriately to their infant's earliest communications, including: enhancing the infant's brain development, promoting emotional wellbeing and facilitating the development of 'secure attachment'. The program is offered to 4 groups of parents over a 12 month period and started on the 21st of July 2008. The GTKY program has been designed and developed by the NSW Institute of Psychiatry. Theoretically the GTKY workshops are based on the Transactional Model (Sameroff, 1975; Sameroff & MacKenzie, 2003) that respects the dual contribution to the child's development of both nature and reaction to events in the environment. In the Transactional Model the infant is perceived as developing in maturational sequences fostered or hindered by their relationship to significant others responsible for physical, emotional and social support. The GTKY program recognises the value of early interaction to brain and behavioural development through an understanding of a phenomenon known as 'neural plasiticity', which is a process by which experience is incorporated into the structure of the brain. As detailed by Nelson and Bosquet (2000), neural plasticity means that both positive and negative experiences can alter the structure and function of the brain, and as a consequence affect cognitive, social and emotional functioning during infancy.

Methodology

The study was an evaluation of the GTKY workshops based on a qualitative methodology. Human Research and Ethics Committee approval was obtained from both hospital and university HREC prior to commencement of data collection and full consent obtained from participants. The data collection was conducted at CQ University and analysis and write up completed at Griffith University.

Interviews were conducted after the participants had completed the course. The program evaluation focused on the individual positive and negative experiences with the program and the perceived changes that participants experienced in their parenting skills, relationship with their infant and in the infant's development.

Potential participants were identified by a MPAU member, who was independent of the course , with the assistance of an IPP-SHR Project Officer. A MPAU member promoted and provided project information about the study during the end of the GTKY courses. Included in this information was a project description and potential requirement if agreeing to participate. Participants were informed that they may be contacted by an IPP-SHR project officer and if they did not wish to participate, that they could either tell the MPAU member or IPP-SHR Project Officer. If they agreed to participate, the IPP-SHR Project Officer arranged an interview time. Participants were selected from the five Building Babies Brains' courses. Twenty-three potential participants were contacted, with ten declining participation or being unable to be contacted. Thirteen parents participated in the in-depth interviews, consisting of twelve mothers and one father. Participants ranged in age from 21 to 43 years. A diverse family composition was represented in the cohort with nine married, two separated and two single parent families. Twelve of the families had one child whilst one had a family composition of two children.

Interviews were conducted by an IPP-SHR research member. The interviews were audio recorded, transcribed verbatim and de-identified. Once transcribed, the interviews were loaded into the QSR NVivo computer package and coded (free nodes). The coding was conducted by IPP-SHR project officers experienced in the NVivo computer package. The naming and development of the codes was driven by the exact words of the participants. All data collected were entered into codes. The data were then thematically analysed by collapsing the free nodes down into broad thematic categories and used to provide an evaluation of the BBB program.

Project management and collaboration was managed using Quadrant™, an online Qualitative collaboration software tool.

Results

The Course Experience

Most participants were referred to the course by Mater Parent Aide staff, with some referrals originating from the Young Women's Program and from other health care professionals at the Mater Hospital. Most participants indicated that they wanted additional support and appreciated the referral to the program:

- ***I kind of went along because I felt that I needed as much support as I could get.***

Participants noted that attending the course after the birth of their baby was beneficial as it allowed them to raise issues associated with their newborns as they happened. Participants indicated the informality of the course and the small class sizes gave them confidence in expressing issues to the group, for example:

- ***Cause it was only two mothers we had a bit of time just to talk generally, just about us rather than the course and so in that sense I think I got my needs met in that I was able to talk about those issues, yeah.***

The participants also appreciated the non-judgemental environment, for example:

- ***(Interviewer) Was there an accepting feel within the room that you could pretty much throw anything out there? (P) Yeah yeah it was pretty open for it, yeah it was fine yeah, it is nice to feel that space.***

For courses that did not have a high attrition rate, the ability to socialise following the formal component of the course was also valued, for example:

- ***The best thing I liked was very, very friendly. It's not like formal meeting sort of thing [unclear] having sandwiches and then tea, watch DVD and then talking about things with other mums.***

However, even in such a supportive environment, one participant indicated that participating in a group is a difficult experience, for example,

- ***Yeah for me personally I found it quite difficult, I've had a pretty tough time throughout, yeah having both of them so yeah I find the whole group thing quite -difficult personally but not because they're not lovely and everything.***

For some, the continuing relationships between course participants led to the development of a playgroup after the course had finished.

- ***Yep, yeah so it's been really good because … we decided you know we all got on so we made like a baby group that we see every fortnight.***

However, for courses in which the majority of attendees failed to attend, participants indicated that the course did not offer many social opportunities. For some, travel distance or return to work inhibited relationships with course participants after the cessation of the course despite participants mentioning that it may be beneficial.

Two participants indicated that their male partners attended the course and that they were appreciative that the course was open to partners. One participant also appreciated the learning opportunity that the course provided for her partner, particularly as this was the first child for her partner. However, due to the lack of other fathers present in the course and the consequently high number of mothers present, two participants indicated that, after the initial welcoming experience, their male partner felt intimidated and ceased course participation.

Course Structure and Delivery

The BBB course is based on the viewing of a DVD on baby development followed by informal discussion of the content and the distribution of relevant written material. Tea and refreshments were offered as part of the informal group experience. There was some disagreement on the suitability of course structure and delivery.

Some participants indicated that the DVD was the correct length as due to fatigue from caring for a newborn, they were not able to remember much material and appreciated the reduced information and content:

- ***…weren't very long at all. That was great because you know if they had've given us a big lengthy DVD, you know, lots of material, I basically wouldn't, I wouldn't of been able to concentrate cause I was only really able to concentrate for short periods you know.***

However, a few participants indicated that it would have been better to have a more structured and organised course with much more content. In particular, participants indicated that the DVD was not long enough and did not cover enough content for the time dedicated to the course.

There was a strong indication that the amount of written information provided to course participants was adequate, with many indicating that they already felt overburdened with information and written material from other sources.

Practical Issues to Course Attendance

The team at BBB organised transport for the course attendees. A majority of participants indicated that the provision of transport, and communication with BBB concerning the arrangement of transport facilitated course attendance. Some participants indicated that the provision of transport assisted them in leaving the house with their baby and decreased isolation, apprehension and anxiety, for example:

Yeah they did, they did at first cause otherwise I'm not allowed to drive for a couple weeks (Interviewer) yes cause your operation, yes. (P) yeah that was really helpful, so I wouldn't feel confident drive myself and the baby at that time, really nervous as well.

Participants also noted the ease of parking helped in maintaining course attendance.

Social Support and Normalisation

A majority of participants indicated that the BBB's course allowed them the opportunity to leave their domestic premises and attend a social function which catered for themselves and their infants, for example:

- ***It does help because I know a lot of people they won't really go out. If they have some sort of social interaction they've got more of a reason to you know be social with their babies and that.***

Indeed, social contact and creating a network was mentioned as a strong factor for continued attendance, for example:

- ***It was more the social side of things, I think that's why I kept going.***

Many participants found that being able to attend a social situation in a safe and relaxed environment assisted in creating confidence to be able to leave their house with their new born. A majority of participants indicated that they felt an affinity with staff and described them in positive terms. Participants noted that this helped them to continue participation in the course, for example:

- ***I mean it was lovely, they were all lovely you know and they provided lunch and that was nice.***

Participants indicated that the informal method of the course and strong social environment assisted in raising questions to peers, learning from others and normalising their own experience of caring for an infant. Sharing experiences of parenting allowed participants to reflect on their practices and gain confidence and lessen anxiety associated with their perceived parenting abilities, for example:

- ***No I really enjoyed it, I enjoyed all those little moments because of it and you know I knew things were normal and I was doing things right so it just made me more relaxed and happy with what I was doing.***

This was particularly important for parents that did not have many other parents in their immediate social network. Participants also noted that it was helpful to compare and observe babies of similar age and their development. Many participants indicated that the information provided by the course made them more confident parents, enabling them to better interact with their newborn, for example:

- ***No just keep on doing that and yeah, just keep helping out other mothers who, like me who you know, haven't had a lot to do with kids and sort of been thrown into the deep end so yeah it's good. Yeah I did, I actually was very thankful that I did that course because I was, when I was telling other people about the course they were like, wow I wish I had done that when my kids were little so you know, yeah so.***

Baby Development Issues and Bonding

Most participants indicated that the course helped in understanding development, nurturing and the importance of interaction. Participants indicated that the course enabled them to understand cues and gestures made by their infant and how to respond appropriately to such communications, for example:

- ***Oh like you know maintaining, just like you know some of the things like eye contact and learning how when they're tired and when they're hungry and how they communicate and you know that smile that they give right at the beginning isn't wind, it's actually, you know they're actually smiling at you. I got some beautiful smiles and I appreciated that when she said that cause when (baby) did smile it was like, 'yes she's smiling, it's not wind' you know.***

Understanding subtle cues associated with infant fatigue was also commonly noted and appreciated by course participants, for example:

- ***What I do particularly remember was like we were talking about looking out for baby signs, like baby messages. Like when they're tired, when they blink a lot and when they're you know because of their attention span they, it's quite small, yeah I never really knew much about that.***

Likewise, it was noted that the participants learnt the importance of activities such as eye-contact and its impact on infant neural development, for example:

- ***I saw DVD, even really brand newborn baby can see who's their mum through contact them with eyes, things like that. I really didn't expect that, I didn't know that so that was I think, that was you know the biggest information that I got from.***

The course also assisted participants in understanding the impact that a positive social and caring environment had on brain development, for example:

- ***They showed us a diagram that was quite recent about a baby's brain and how to make it positive and you know a good childhood how many things in the brain there was whereas if they had I don't know, I guess parents that were mean to them and like from an abusive childhood the development would go back because the first five years are the most important as childhood like with the developmental and foundations and making them safe and that.***

Content associated with learning baby cues and signs were appreciated as participants indicated the material had not been covered in other parenting classes.

Recommendations

Participants provided discussion on a number of limitations of the present course and made recommendations for the future development of the program. Many participants indicating that not only would they have liked to know about the course before birth, but to have had the chance to meet and develop relationships with other expectant parents and develop familiarity with the course convenors. Early contact would provide parents with a good opportunity to obtain information regarding the immediate time after birth.

Participants felt that the title 'Building Babies Brains' was incorrect as it did not reflect the course's primary emphasis on understanding babies cues and the impact that positive relationships have on neurological development. The need to explain the course content and objectives before enrolment was emphasised.

Numerous participants felt the DVD and course content was too basic and condescending. Some participants felt that the information presented in the course was already readily available and wished that they had been informed of the content before participation. In particular, a majority of participants indicated that they would have appreciated more discussion regarding the reality of caring for a newborn and the time and energy required. Participants indicated they would appreciate information and the opportunity to discuss issues associated with fatigue, time management and relationship information. This is particularly important as many participants indicated they had fragmented relationships and unstable living situations. In addition, every participant expressed a desire to obtain more information regarding breastfeeding and would have appreciated the support and advice of a lactation consultant. A strong recommendation from the research is that a lactation consultant and child health nurse be integrated in the class content and delivery.

There were problems with the program for those who attended groups with small numbers. Indeed for some, the group numbers were sometimes as small as two attendees. For those with a male partner, there was agreement on the need to incorporate greater partner involvement. Such participants thought that a group specifically designed for fathers would assist in their parent confidence and skills, understanding their baby and contribute to having a greater involvement in parenting.

Discussion

The findings indicate that the BBB program assisted parents to better understanding infant brain development and methods of infant communication. Participants indicated that they were better able to apply this new knowledge and understood the importance of positive nurturing and interaction with their infants. Leitch (1999) had similar findings with regards to the use of videotaped educational information as a method of facilitating very early mother-infant interaction. The findings resonate with the work of Censullo (1994) who found that there was a significant increase in the level of responsiveness and parental self-esteem scores after the intervention based on a parent/infant interaction coaching procedure.

Participants indicated that this social component and knowledge gained from the course assisted in raising their confidence levels regarding their parenting skills and ability. The provision of transport, venue location and easy parking was also noted as a positive practical component to course attendance. Participants also indicated that the course provided opportunity to socialise with other parents who were also experiencing similar phases of development with their infant. This social component normalised their parent experience and alleviated social isolation. Scott and associates' (2001) research on parent-focused education groups similarly found that social contact was an important aspect of the group experience and provided evidence of continuity of this contact after the completion of the groups. Scott and associates (2001) concluded that such programs may be an important vehicle for enhancing social support during the transition to parenthood and thus be a useful primary prevention strategy.

The range of recommendation for future development of the course are useful not only for the convenors of the present BBB course but for other readers seeking to run such a program.

Conclusion

The findings from the BBB program provide fresh insights on the potential for parental support and education groups as a proactive mental health strategy. The hope and expectation is that the research findings can be used by others in the field of mental health for further program development as a resource that can reach a wide diversity of parents.

References:

Baradon T. (1999) Directions. Nurturing nature. Mental Health Care, 2,6:208.

Bayer J., Hiscock H., Morton-Allen E., Ukoumunne O., Wake M. (2007) Prevention of mental health problems: rationale for a universal approach. Archives of Disease in Childhood, 92, 1: 34-8.

Berlin L. & Cassidy J. (2001) Enhancing early child-parent relationships: Implications of adult attachment research, Infant and Young Children, October, 14,2:64-76.

Censullo M. (1994) Strategy for promoting greater responsiveness in adolescent parent/infant relationships: report of a pilot study, Journal of Pediatric Nursing, 9,5:326-32.

Hotelling B. (2004) Tools for teaching. Newborn capabilities: parent teaching is a necessity. Journal of Perinatal Education, 13,4:43-9.

Leitch D. (1999) Mother-infant interaction: achieving synchrony. Nursing Research. 48,1:55-8.

Lyons-Ruth K., Dutra L., Schuder M., Bianchi I. (2006) From infant attachment disorganization to adult dissociation: relational adaptations or traumatic experiences? Psychiatric Clinics of North America, 29,1:63-86.

McGrath P, Holewa, H., Huff, N., & Patton, M., (2011). Participant Feedback and Service Provision Evaluation on Project, “Building Babies’ Brains: A Mater Parent Aide Project in Partnership with Noah’s Ark (BBB)”. International Program of Psycho-Social Health Research, Brisbane, Australia.

Nelson C. & Bosquet M. (2000) Neurobiology of fetal and infant development: Implications for infant mental health. In Handbook of infant mental health. Zeanah C (Ed)., (2nd Ed), Giolford Press, New York, NY, US.

Sameroff A. (1975) Transactional models in early social relations. Human Development, 18, 1-2: 65-79.

Sameroff A. & MacKenzie M. (2003) A quarter-century of the transactional model: how have things changed? Zero to Three, 24, 2: 14-22.

Scott D., Brady S., Glynn P. (2001) New mother groups as a social network intervention: consumer and maternal and child health nurse perspectives. Australian Journal of Advanced Nursing, 18,4:23-9.

The International Journal of Psychosocial Rehabilitation
Volume 16, Number 2
July 2011– June 2012

Coping With Epilepsy: How Do They Influence Health-Related Quality of Life (Hrqol)?

Pei Lin Lua (Ph.D)
corresponding author

Widiasmoro Selamat Neni (Bach. Biomed)

Talib Nor Samira (BPharm)

Centre for Clinical and Quality of Life Studies (CCQoLS)
Faculty of Medicine and Health Sciences
Universiti Sultan Zainal Abidin (UniSZA)
Kampus Kota, 20400 Kuala Terengganu, Malaysia.
Correspondence: peilinlua@unisza.edu.my

Citation:
Lua PL, Neni WS & Samira TN (2012). Coping With Epilepsy: How Do They Influence Health-Related Qualityof Life (Hrqol)?. ***International Journal of Psychosocial Rehabilitation. Vol 16(2) 114-126***

Acknowledgement:
We wish to thank the Director General of Health, Malaysia for permission to publish this paper and the hospital director, Heads of Neurology Department and staff of Hospital Sultanah Nur Zahirah for their cooperation in ensuring the success of this study. Thank you also to the Dean of Faculty of Medicine and Health Sciences, UniSZA, all participants and their families for supporting our study. Our appreciation is also directed to the Pusat Pengurusan Penyelidikan dan Inovasi (PPPI) UniSZA for its financial support [grant no: UDM/10/BR (029)].

Abstract

Health-related quality of life (HRQoL) status of people with epilepsy (PWE) could likely be influenced by their coping mechanisms. Our study aimed to 1) determine the association between HRQoL profiles and coping categories, 2) correlate HRQoL domains and coping mechanisms and 3) compare coping strategies of PWE with different HRQoL levels. A cross-sectional sample of epilepsy out-patients was recruited from the Neurology Clinic, Hospital Sultanah Nur Zahirah, Kuala Terengganu. SPSS 16 was employed for data analysis. Upon written consent, included patients completed the Malay Quality of Life In Epilepsy (MQOLIE-30) and the Malay Brief COPE instruments. Sixty out of 72 patients (response rate = 83.3%) consented participation (median age = 27.5 years; range 18-65 years; male = 53.3%; unmarried = 63.3%; Malay = 90.0%; SPM /Cambridge O' level equivalent education or lower = 81.4%; unemployed = 35.0%; rural residents = 70.0%). Problem-focused coping mechanisms were generally preferred by PWEs compared to emotion-focused strategies ($p<0.05$). Behavioural Disengagement and Self-Blame were significantly associated with almost all HRQoL domains meanwhile Energy/Fatigue and Overall Quality of Life were significantly linked to the most coping strategies. Patients with good HRQoL significantly preferred to cope via Positive Reframing, Planning and Religion compared to their counterparts ($p<0.05$). On the other hand, patients with poor HRQoL significantly favoured Substance Use, Denial, Behavioural Disengagement, Venting and Self-Blame to deal with epilepsy ($p<0.05$). Healthcare providers could incorporate advice on effective coping styles for PWE in an attempt to balance the treatment outcomes in terms of both physiological and psychosocial benefits.

Keywords: coping, health-related quality of life (HRQoL), epilepsy

Introduction

In Malaysia, epilepsy is referred to as "sawan" or "gila babi" and has affected approximately 1-2% of the population in 2004 (Statistics by country for epilepsy, 2004; Neni et al.,2010). Although for 70-80% of patients the disease is successfully controlled using medicine i.e. antiepileptic drugs (AEDs), the negative social stigma of epilepsy along with uncertainty of the disease effects on patients' health-related quality of life (HRQoL) status (Lua & Neni, 2011) could contribute to long-term stress and discomfort, impacting upon their coping patterns and outcomes. Previous studies have shown a high prevalence of psychological and social disorders which have been well documented and are often considered more handicapping than seizures themselves. The problems which have been documented included unemployment (Elwes et al., 1991), financial hardship, social isolation, fear of seizures (Mittan, 1986), anxiety and depression (Betts, 1993), low self-esteem (Collings, 1990), feelings of stigma (Jacoby, 1994) and externality of control (Gehlert, 1994). Consequently, the measurement of psychosocial functioning is becoming a crucial requirement for comprehensive healthcare particularly in a debilitating disease such as epilepsy.

Most literature findings have focused on how individuals cope with a variety of stresses, including those of chronic illnesses (Devins & Binik, 1996; Maes et al., 1996; Morse & Johnson, 1991). However, research on how coping mechanisms influence the HRQoL of people with epilepsy (PWE) is not as widespread. The process theory of coping describes a dynamic process whereby coping changes over time and in response to the situation in which it occurs (Lazarus & Folkman, 1984). Coping is concerned with the thoughts and actions a person makes in response to a taxing situation. The individual's response to the situation is governed by their cognitive appraisal of that situation. In order to ascertain the relative "adaptiveness" or "maladaptiveness" (Lazarus, 1993) of coping behaviour, coping needs to be studied independently from outcomes which are often measured in the form of psychological well-being. HRQoL is generally defined as a multidimensional construct related to "individuals' perceptions of their position in life, in particular to their goals, expectations, standards and concerns" (Trimble & Dodson, 1994). For PWE, HRQoL has come to be seen as an important health outcome consideration (Baker et al.,1993; Baker, 2001). Although there have been numerous definitions of HRQoL, it is generally agreed that it is a largely subjective concept, comprising social, emotional, physical and material factors (Felce & Perry, 1995; Koot & Wallander, 2001) and that a "person-centered perspective" is central to its measurement. Over the past decade, there has been increased interest in how epilepsy and its treatment affect the HRQoL of epilepsy patients. In epilepsy, HRQoL measures have been used not only to characterise disease burden, but also to reflect the effects of AED treatment (Birbeck et al., 2002; Gilliam et al., 2004; Sackellares et al., 2002), seizure severity (Vickrey et al., 2000) and epilepsy surgery (Lowe et al., 2004; McLachlan et al., 2003; Spencer et al., 2003).

Neither seizure-related variables nor psychopathology fully explains the reduction in HRQoL status reported by PWE (Johnson et al., 2004). Several studies have further suggested that an individual's coping resources are an important determinant of their resilience to seizures (Kemp et al., 1999; Rosenbaum & Palmon, 1984; Snyder, 1990). Importantly, previous studies have demonstrated that PWE can be trained to adopt more problem-focused coping styles which are associated with improvements in functioning and overall HRQoL (Spector et al., 1999). Given that coping with epilepsy appears to impose clinical relevance, it is important that clinicians recognize their patients' coping behaviour and considers their coping resources when they make and communicate treatment decisions.

For these reasons, we are interested to study coping behaviours in dealing with epilepsy especially how they may influence HRQoL. Specifically, we intended to compare coping strategies and the frequency of practices between PWE of different HRQoL levels as well as the associations between coping mechanisms and HRQoL dimensions.

Methods

Study design and sample selection

This cross-sectional pilot study was carried out in the Neurology Clinic, Hospital Sultanah Nur Zahirah (HSNZ), Kuala Terengganu, Malaysia for a two-month period. The sample size was determined according to the descriptive observational cross-sectional design formula specific for pilot study which has been devised utilizing examples from Malaysian settings (Naing, 2009). This formula is usually used in prevalence study which is based on whether the parameter is a 'mean' or a 'proportion' (Dobson, 1984; Lemeshow et al., 1990; Lwanga & Lemeshow, 1991). To determine the sample size required to estimate the proportion with the desired level of precision, some idea is required beforehand about the possible proportion which can be obtained from literature or from a pilot study if there was similar study conducted before (Naing, 2009). According to the formula, at least 39 patients were needed at 90% power of study after considering a 20% drop-out.

Formula calculation:
n = [z]2 x 2(1-p)
[Δ]

Where;
n = required sample size
p = anticipated population proportion (stated as %)
Δ = absolute precision
z = value of the standard normal distribution cutting off probability α in one tail for a one-sided alternative
Commonly used values (with 90% power) were;
z = 1.28 for 90% power
Δ = ± 10% as 90% power was selected
p = 2% (epilepsy prevalence in Malaysia estimated at approximately 1-2%) (Statistics by country for epilepsy, 2004).

Hence,
n = [1.28]2 x 2(1-0.02)
[0.1]
= 32.11
Considering a 20% drop-out, 120% x 32.11 = 38.54
Thus the minimum number of patients required for this study, n = 39 patients.

Ethical approval

Before the study began, ethical approval was first obtained from the Medical Research and Ethics Committee of the Ministry of Health, Malaysia via online application. Prior to that, discussions with hospital authorities were made to obtain full cooperation and permission to carry out the study. The study commenced once official clearance was provided by the Ministry of Health, Malaysia [reference: NMRR-10-359-5640/ (2) dlm. KKM/NIHSEC/08/0804/P10-158)].

Data collection procedure

Patients who attended the outpatient neurology clinic at Hospital Sultanah Nur Zahirah, Kuala Terengganu from April to June 2010 were invited to participate if they: have been diagnosed with epilepsy, were 18 years old and above, have been regularly visiting the hospital at least for the past 6 months, were able to either understand, read, speak or write in Malay language and were capable of answering the questions either in written form or by interview. An information sheet was distributed to help them understand the nature of the study as well as to clarify the particulars needed, the instruments used and what was required from their cooperation. Once agreed, participants signed a written consent form before proceeding to complete the set of instruments in this order: Personal Information Form, Malay QOLIE-30 [36] and Malay Brief COPE-27 [36]. Once completed, they were thanked for their participation. Those who were not present on the study day were required to do the same when they visited the clinic. A hospital coordinator was identified and briefly-trained to help with patient identification and medical record examination prior to clinic day.

Assistance in clarifying the questions, reading them aloud or circling the answers was offered whenever there was a need.

Instruments

Two instruments were employed for this study;
1) The Malay QOLIE-30 (Lua et al., 2007) was developed from the original English QOLIE-31 (Vickrey et al., 1993). This is the recommended HRQoL tool choice in epilepsy (Leone et al., 2005). Besides being widely used in patients with epilepsy, it has also been established to be reliable (Vickrey et al., 1993). This tool contains 30 items tapping on 7 domains: Emotional Well-Being (5 items), Social Functioning (4 items), Energy/Fatigue (3 items), Cognitive Functioning (6 items), Seizure Worry (5 items), Medication Effects (4 items) and Overall QoL (2 items) and a single item assessing Overall Health. Responses are scored on a mixture of numerical scale (0-10) and Likert choices (1-3, 1-4, 1-5, 1-6). All scale scores are transformed linearly into scales of 0-100 with higher values indicating better functioning and well-being. The Total HRQoL Score can be derived by weighting and summing the scale scores according to guidelines in the manual (Vickrey et al., 1993).

2) The Malay Brief COPE-27 (Lua et al., 2007) contains 27 items assessing 14 domains as those in the original Brief COPE (Carver, 1997). Similarly, fourteen dimensions of coping are focused in the scales such as Self-Distraction, Active-Coping, Denial, Substance Use, Emotional Support, Instrumental Support, Behavioural Disengagement, Venting, Positive Reframing, Planning, Humour, Acceptance, Religion and Self-Blame. It was constructed from the complete version of 60-item COPE Inventory (Carver et al., 1989) in an attempt to reduce respondent burden during questionnaire completion. Responses are scored on Likert-type scale (1-4) and the instrument can be either self- or interviewer-administered. Individual scale total is computed as an unweighted sum of responses to the four items that make up that scale.

Statistical analysis

This study employed the Statistical Package for Social Sciences version 16 (SPSS 16) for data analysis. All socio-demographic data were analysed descriptively and presented as frequencies and percentages. As data did not conform to normality (Shapiro-Wilks statistics <0.05), non-parametric tests such as Spearman's Rho (rs) was utilized to measure the correlation between HRQoL and coping mechanisms. Coping strategies were grouped into emotion-focused or problem-focused categories by comparing the relative tendencies and preference of each patient in adopting the styles. The association between HRQoL profiles and coping strategies was tested using Chi-Square ($\chi2$) test for relatedness where p-value of less than 0.05 was considered significant. The Mann-Whitney U test was carried out to determine between-group score comparisons (the frequency of various coping practices between PWE with different HRQoL levels). For the purpose of between-group comparisons, patients were regrouped into Good HRQoL and Poor HRQoL. Patients who generated the Total HRQoL Score of higher than the sample median was considered to possess good HRQoL while those with Total HRQoL score of equal to or lower than the sample median was regarded as experiencing poor HRQoL.

Results

Informed consent was obtained from 72 PWE. Of these, 60 completed all instruments giving a response rate of 83.3%.

Characteristics of the patients

The median age was 27.5 years, ranging from 18 to 65 years. The number of male and female respondents were quite balanced. Most of the respondents were Malay (90.0%), Muslim (90.0%), single (63.3%), possessed education level at SPM/ Cambridge O' level equivalent or lower (81.4%), unemployed (35.0%), were earning not more than RM 500/USD 166.5 equivalent (68.4%), and were living with their spouse or family (96.7%) in rural areas (70%). Details in Table 1.

Table 1. Socio-demographic and clinical characteristics of sample respondents (n=60).

Variables	Frequency (n)	Percentage (%)	p value*
Gender			
Male	32	53.3	0.606
Female	28	46.7	
Marital status			
Married	20	33.3	**<0.001**
Single	38	63.3	
Widowed	2	3.3	
Race			
Malay	54	90.0	**<0.001**
Chinese	6	10.0	
Religion			
Islam	54	90.0	**<0.001**
Buddhism	6	10.0	
Education level **			
No formal education	2	3.4	
Primary school	8	13.6	
SRP/PMR or equivalent to lower secondary	6	10.2	**<0.001**
SPM or equivalent to Cambridge O' level			
STPM or equivalent to Cambridge A' level	32	54.2	
Diploma or equivalent	1	1.7	
Degree or equivalent	8	13.6	
	2	3.4	
Occupation			
Professional	2	3.3	
Supportive	5	8.3	
House-wife	18	30.0	**<0.001**
Retiree	7	11.7	
Student	7	11.7	

Unemployed	21	35.0	
*Monthly income ***			
RM 500 and below	39	68.4	
RM 501-RM 1,000	8	14.0	
RM 1,001-RM 1,500	2	3.5	**<0.001**
RM 1,501-RM 2,000	2	3.5	
RM 2,001-RM 2,500	1	1.8	
RM 2, 501 and above	5	8.8	
Living arrangement			
Alone	1	1.7	
With spouse/family	58	96.7	**<0.001**
Rent a room	1	1.7	
Living area			
Urban	18	30.0	**<0.01**
Rural	42	70.0	
Types of epilepsy			
Complex partial seizure	27	45.0	
Generalised tonic clonic seizure	10	16.7	-
Temporal lobe epilepsy	8	13.3	
Idiopathic generalised epilepsy	6	10.0	
Others	9	15.0	
Duration of being diagnosed with epilepsy			
> 5 years	44	73.3	-
6 months to 5 years	10	16.7	
< 6 months	6	10.0	
Type of AED			
Sodium valproate	37	61.7	
Carbamazepine	21	35.0	-
Levetiracetam	11	18.3	
Topiramate	10	16.7	

Phenytoin *Phenobarbitone* *Lamotrigine* *Lorazepam*	6 2 2 1	10.3 3.3 3.3 2.0	

PWE with all subtypes of epilepsy were recruited whereby majority were represented by complex partial seizure (45.0%). Forty-four patients have been diagnosed with epilepsy for 5 years or longer. The most frequently-prescribed antiepileptic drugs (AEDs) was sodium valproate (61.7%) – Table 1.
Association between HRQoL profiles and coping categories.

Coping strategies were categorised into emotion-focused and problem-focused groups whereby their associations with HRQoL profiles were observed. Generally, our respondents preferred problem-focused coping over emotion-focused types in dealing with their diseases irrespective of their HRQoL status ($p<0.05$). Refer to Table 2.

Table 2. Association between HRQoL profiles and coping categories (n=60).

Coping categories	HRQoL [n (%)]	p-value	
	Poor	Good	< 0.05
Emotion-focused	8 (13.3)	2 (3.3)	
Problem-focused	23 (38.3)	27 (45.0)	

Correlation between HRQoL domains and coping mechanisms
Among the HRQoL domains, Energy/Fatigue and Overall QoL were associated with many types of coping mechanisms. For both domains, results were significant for Behavioural Disengagement, Positive Reframing, Planning, Acceptance, Religion and Self-Blame ($-0.343 \le rs \le 0.519$). On the other hand, compared to the other 12 coping skills, Behavioural Disengagement and Self-Blame generated the most significant although negative and weak correlations with HRQoL domains specifically Seizure Worry, Emotional Well-Being, Energy/Fatigue, Medication Effects and Overall QoL ($-0.260 \le rs \le -0.454$). Additionally, Planning showed significant positive associations with Emotional Well-Being, Energy/Fatigue, Cognitive Functioning and Overall QoL. Lastly, Religion was significantly linked to Social Functioning, Emotional Well-Being, Energy/Fatigue, Cognitive Functioning and Overall QoL in a favourable way. Refer to Table 3.

Table 3. Correlation between HRQoL domains and coping mechanisms (n=60).

Mean	***HRQoL***

Coping Mechanisms	*Seizure Worry* (r_s)	*Social Functioning* (r_s)	*Emotional Well-Being* (r_s)	*Energy/ Fatigue* (r_s)	*Cognitive Functioning* (r_s)	*Medication Effects* (r_s)	*Overall QoL* (r_s)
Self-Distraction	-0.029	+0.124	-0.002	+0.121	+0.087	+0.100	-0.047
Active Coping	+0.080	+0.024	+0.117	+0.100	+0.217	+0.045	+0.124
Denial	-0.123	**-0.276***	-0.099	-0.075	-0.219	**-0.375****	-0.150
Substance Use	-0.009	-0.185	-0.191	-0.205	-0.198	-0.167	-0.078
Emotional Support	+0.069	+0.066	+0.132	+0.065	+0.101	**+0.389****	+0.110
Instrumental Support	+0.065	+0.095	+0.159	+0.102	+0.182	**+0.383****	+0.209
Behavioural Disengagement	**-0.260***	-0.246	**-0.430****	**-0.374****	**-0.311***	**-0.288***	**-0.387****
Venting	**-0.340****	-0.186	-0.220	-0.226	-0.207	-0.145	-0.131
Positive Reframing	+0.075	+0.172	+0.192	**+0.301***	**+0.275***	+0.027	**+0.260***
Planning	+0.119	+0.201	**+0.423****	**+0.519****	**+0.400****	+0.194	**+0.431****
Humour	+0.076	+0.020	+0.122	+0.087	+0.094	+0.029	+0.031
Acceptan	+	+0.2	**+0.**	**+0**	+0.2	+0.1	**+0.30**

ce	0.078	00	300*	.391**	21	34	9*
Religion	+0.060	+0.298*	+0.451**	+0.332**	+0.416**	+0.230	+0.374**
Self-Blame	-0.265*	-0.344**	-0.454**	-0.343**	-0.212	-0.318*	-0.444**

*Correlation is significant at the 0.05 level (2-tailed).
**Correlation is significant at the 0.01 level (2-tailed).
r_s = Spearman's Rho correlation coefficient

Comparison of coping mechanisms between PWE with different HRQoL profiles.
The proportion of patients with both good and poor HRQoL were almost balanced (good HRQoL=29, poor HRQoL=31). However, in terms of the types of coping skills and frequency of practices between the two HRQoL groups, PWE with poor HRQoL were discovered to significantly prefer Denial, Substance Use, Behaviour Disengagement, Venting and Self-Blame to deal with epilepsy and its consequences ($p<0.05$). On the contrary, Positive Reframing, Planning and Religion were significantly favoured by their counterparts ($p<0.05$). Generally but not significantly, compared to those with poor HRQoL, PWE with good HRQoL demonstrated a trend of coping more frequently via employment of Self-Distraction, Active Coping, Emotional Support, Instrumental Support, Humour and Acceptance ($p>0.05$) – Figure 1.

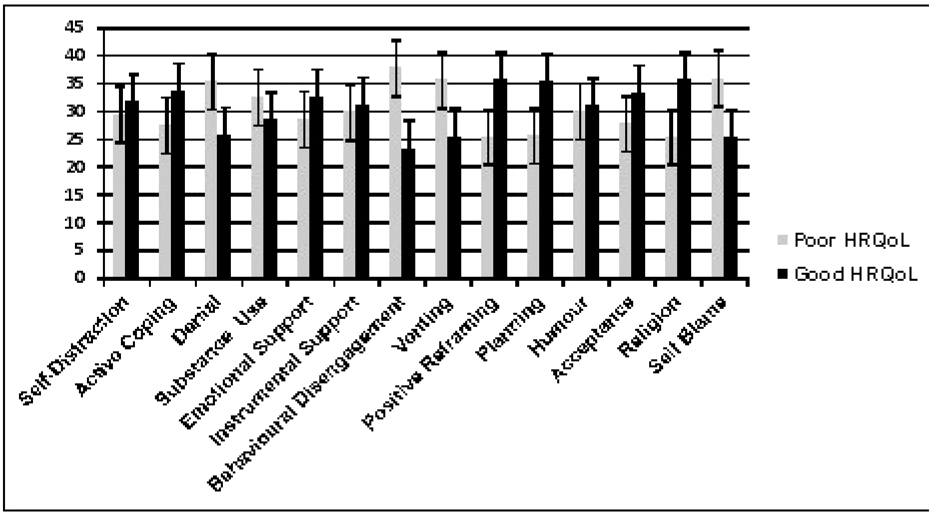


Figure 1. Comparison of coping skills and the corresponding frequency of practices between PWE with different HRQoL profiles. Error bar: 5% error, SD=1. (*p<0.05 **p<0.01)

Discussion

Studies concerning HRQoL and how patients cope with epilepsy have been identified and widely carried out but most have investigated these issues separately. Due to the possible relationships and interactions between the two aspects, our study intended to compare coping strategies by different HRQoL groups and correlate between these two parameters pertinent to the lives of such patients.

The general preference of our respondents towards problem-focused coping over emotion-focused methods showed their tendencies of perceiving the former strategies to be more effective in dealing with epilepsy. Supported by a previous study, problem-focused or approach coping mode has been shown to be more functional whereas the emotion-focused or avoidant coping method was rather dysfunctional and could lead to withdrawal, fatalistic attitudes and avoidance of problems (Herman-Stahl et al., 1995). These coping methods were directed at efforts to solve or manage problems in more practical ways, including strategies for gathering information, making decisions, planning and resolving conflict (Folkman & Moskowitz, 2004). It has also been suggested that long-term, enduring stressors such as epilepsy require problem-focused strategies because continuous use of avoidant tactics would only prevent change and consume substantial effort, which over time, could deplete the individual's psychological and physical resources (Chronister & Chan, 2007).

Nevertheless, emotion and problem-focused coping approaches could sometimes either facilitate or impede each other i.e. patients may need to learn to control their emotion before adopting problem-focused strategies (Folkman & Moskowitz, 2000; Moskowitz et al., 1996). Consequently, problem-focused coping strategies could probably serve as the best options for PWEs in dealing with epilepsy while maintaining emotional-focused approaches as alternative options depending on situation, timing and social resources (Folkman & Moskowitz, 2000).

Interestingly, significant but negative correlations were found between HRQoL domains and coping mechanisms specifically Denial, Behavioural Disengagement and Venting. This could be interpreted to imply that emotion-driven ways were less-likely to be practiced once patients were in better states of well-being. However, those with poorer HRQoL on the other hand have favourably resorted to these negative emotions expressing strategies. PWE especially those with poor HRQoL frequently reported diminished socialization, negative self-image, feeling of stigmatisation, reduced earning potential and diminished hope and ambition (Gilham et al., 2000; Jacoby et al., 2005). Due to all such negative attributes, many failed to accept the situation and encountered adjustment problems. Denial may not eliminate negative mood states but may help patients distance themselves from negative thoughts and feelings (Saniah & Zainal, 2010). PWE could have expressed the negative emotions by venting out the anger and dissatisfaction to the people surrounding them. Consequently, probably due to feeling of lost and hopeless, some PWE decided to disengage behaviourally in order to reduce the amount of effort in dealing with epilepsy, even by giving up efforts to accomplish objectives with which the disease is interfering with (Carver et al., 1989).

Lastly, HRQoL domains were significantly and positively associated with Emotional Support, Instrumental Support, Positive Reframing, Planning, Acceptance and Religion. The more favourable the HRQoL profile, the more frequent patient seek for help, advices and emotional support. It could be that religious approaches have effectively "persuaded" them to gradually accept their condition, hence encouraging them to plan and reframe the problem to become more positive-minded. Like many other studies of such nature, religious belief was the major coping strategy used to confront this particular chronic disease (Ebadi et al., 2009; Hassankhani et al., 2009; Ismail et al., 2005; Taleghani et al., 2006). These strategies seemed to help patients reform their views on the illness and consequently, facilitate them to overcome its related problems. Some PWE also considered the disease as their "destiny" and "God's test", therefore surrendering themselves to their fate (Hosseini et al., 2010). Similar to a previous study, the participants were seeking emotional and instrumental supports which emphasize the role of families' emotional and instrumental backings in helping PWE to adapt to the situation (Ismail et al., 2005).

In general, findings showed that PWE with poor HRQoL significantly chose to cope via Denial, Substance use, Behavioural Disengagement, Venting and Self-Blame more frequently compared to PWE with good HRQoL. All these coping styles are emotion expressing strategies. Similar to a previous study, patients have been found to use an emotion expressing strategy that included anger, aggression and crying to pacify themselves (Livneh et al., 2001). This was supported by another study which claimed that PWE with more severe seizures, those with poor HRQoL, those who were more resistant to medications and those who felt hopeless tended to employ such mechanisms (Hosseini et al., 2010). Emotion is part of the coping process and reflects the weight that the person gives to experiences which can be considered as part of a person's long-term attempts to survive (Raty et al., 2007). All of these attributes could have possibly encouraged our patients to favour such coping strategies which suited their characters as well as the disease conditions.

On the contrary, respondents with good HRQoL significantly preferred to cope via Positive Reframing, Planning and Religion. This suggests that their more positive views on the illness were reflected through their preference. Positive Reframing and Planning are categorized in the problem-focused coping strategies (Piazzini et al., 2007). Among the more specific coping strategies, PWE who adopted problem-focused and cognitive restructuring modes were reported to experience relatively favourable psychosocial outcomes, including better mental health, increased psychological well-being, decreased psychological distress and lower levels of reported depression and anxiety which could all lead to improved HRQoL (Livneh et al., 2001).

It is acknowledged that the findings from this study should still be approached with caution due to the relatively small number of participants whom may not have adequately represented the larger PWE population, due to the recruitment process being conducted in only one general hospital. This sample may have therefore differed from community-based samples recruited by the general practitioners. Because of the limited number too, more powerful statistical analyses were not appropriate at this point to substantiate the outcomes. A comparison of hospital-based and community-based samples of PWE may be an important area for future research to determine if coping strategies may have been affected by the type of services they receive.

Conclusions

Several coping strategies were shown to demonstrate significant associations with HRQoL profiles whereby patients generally possessed the tendencies to cope via problem-focused styles rather than the emotion-focused ones. Groups of PWE with different HRQoL profiles largely differed in their preference and frequency toward coping mechanisms. Those with good HRQoL status chose positive (adaptive) coping styles while their counterparts preferred the opposite. Significant but weak association between HRQoL domains and coping strategies suggested that further research needs to be carried out with larger sample sizes to strengthen our findings. Enhanced awareness and a clearer perception of the ways to help PWE to cope more effectively with their problems will enormously benefit both patients and caregivers in the constant pursuit of improved health outcomes.

References:

1. Baker, G.A., Smith, D.F., Dewey, M., Jacoby. A., & Chadwick, D.W. (1993). The development of a health-related quality of life measure for patients with intractable epilepsy. *Epilepsy Research*,16, 65-81.

2. Baker, G.A. (2001). Assessment of quality of life in people with epilepsy: some practical implications. *Epilepsia*, 42, 66-69.

3. Betts, T.A. (1993). Neuropsychiatry. In J. Laidlaw, A. Richens, & D. Chadwick, (Ed.), *A Textbook of Epilepsy*. Churchill Livingstone.

4. Birbeck, G.L., Hays, R.D., Cui, X., & Vickrey, B.G. (2002). Seizure reduction and quality of life improvements in people with epilepsy. *Epilepsia*, 43, 535-538.

5. Carver, C. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioural Medicine*, 4, 92-100.

6. Carver, C.S., Scheier, M.F., & Weintraub, J.K. (1989). Assessing coping strategies: a theorically based approach. *Journal of Personality & Social Psychology*, 56, 267-283.

7. Chronister, J., & Chan, F. (2007). Hierarchical Coping: A Conceptual Framework for Understanding Coping Within the Context of Chronic Illness and Disability. In E. Martz, & H. Livneh, (Ed.), *Coping with chronic illness and disability: Theoretical, empirical, and clinical aspects* (pp. 49-71). Springer Science.

8. Collings, J.A. (1990). Psychosocial well-being and epilepsy: an empirical study. *Epilepsia*, 31, 418-426.

9. Devins, G.M., & Binik, Y.M. (1996). Facilitating coping with chronic physical illness. In M. Zeidner, & N.S. Endler, (Ed.), *Handbook of Coping: Theory, Research, Applications* (pp. 640-696). Toronto: John Wiley & Sons, Inc.

10. Dobson, A.J. (1984). Calculating sample size. *Trans. Menzies Foundation*, 7, 75-79.

11. Ebadi, A., Ahmadi, F., Ghanei, M., & Kazemnejad, A. (2009). Spirituality: a key factor in coping among Iranians chronically affected by mustard gas in the disaster of war. *Journal of Nursing & Health Sciences*, 11, 344-350.

12. Elwes, R.D.C., Marshall, D., Beattie, A., & Newman, P.K. (1991). Epilepsy and unemployment: A community based survey in an area of high unemployment. *Journal of Neurology, Neurosurgery & Psychiatry*, 54, 200-203.

13. Felce, D., & Perry, J. (1995). The extent of support for ordinary living provided in staffed housing: the relationship between staffing levels, resident characteristics, staff: resident interactions and resident activity patterns. *Social Science & Medicine*, 40, 799-810.

14. Folkman, S., & Moskowitz, J.T. (2004). Coping: Pitfalls and promise. *Annual Review of Psychology*, 55, 745-774.

15. Folkman, S., & Moskowitz, J.T. (2000). Positive effect and the other side of coping. *American Psychology*, 647-654.

16. Gehlert, S. (1994). Perceptions of control in adults with epilepsy. *Epilepsia*, 35, 81–88.

17. Gilham, R., Bryant-Comstock, L.K., & Kane, K. (2000). Validation of the side effect and life satisfaction (SEALS) inventory. *Seizure*, 9, 4584-63.

18. Gilliam, F.G., Fessler, A.J., Baker, G., et al. (2004). Systematic screening allows reduction of adverse antiepileptic drug effects: a randomized trial. *Neurology*, 62, 23-7.

19. Hassankhani, H., Taleghani, F., Mills, J., Birks, M., Francis, K., & Ahmadi, F. (2009). Being hopeful and continuing to move ahead: religious coping in Iranian chemical warfare poisoned veterans, a qualitative study. *Journal of Religion & Health,* 49, 311-21.

20. Herman-Stahl, M.A., Stemmier, M., & Petersen, A.C. (1995). Approach and avoidant coping: implications for adolescent mental health. *Journal of Youth & Adolescence*, 24, 649.

21. Hosseini, N., Sharif, F., Ahmadi, F., & Zare, M. (2010). Striving for balance: coping with epilepsy in Iranian patients. *Epilepsy Behaviour*, 18, 466-471.

22. Ismail, H., Wright, J., Rhodes, P., Small, N., & Jacoby, A. (2005). South Asians and epilepsy: exploring health experiences, needs and beliefs of communities in the North of England. *Seizure*, 14, 497-503.

23. Jacoby, A., Snape, D., & Baker, G.A. (2005). Epilepsy and social identity: the stigma of a chronic neurological disorder. *Lancet Neurology*, 4, 171-178.

24. Jacoby, A. (1994). Felt versus enacted stigma: a concept revisited. *Social Science & Medicine*, 38, 269-274.

25. Johnson, E.K., Jones, J.E., Seidenberg, M., & Hermann, B.P. (2004). The relative impact of anxiety, depression and clinical seizure features on health-related quality of life in epilepsy. *Epilepsia*, 45, 544-50.

26. Kemp, S., Morley, S., & Anderson, E. (1999). Coping with epilepsy: do illness representations play a role?. *British Journal of Clinical Psychology*, 38, 43-58.

27. Koot, H.M., & Wallander, J.L. (2001). Challenges in child and adolescent quality of life research. In H.M. Koot, & J.L. Wallander J L, (Ed.). *Quality of life in child and adolescent illness concepts, methods, and findings* (pp. 403-424). East Sussex, England: Brunner-Routledge.

28. Lazarus, R. (1993). Coping theory and research: Past, present, and future. *Psychosomatic Medicine*, 55, 234-247.

29. Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer-Verlag.

30. Lemeshow, S., Hosmer, D.W., Klar, J., & Lwanga, S.K. (1990). Adequacy of sample size in health studies. *World Health Organization*, 1-4.

31. Leone, M.A., Beghib, E., Righini, C., Apolone, G., & Mosconi, P. (2005). Epilepsy and quality of life in adults: A review of instruments. *Epilepsy Research*, 66, 23-44.

32. Livneh, H., Wilson, L.M., Duchesneau, A., & Antorak, R.F. (2001). Psychosocial adaptation to epilepsy: the role of coping strategies. *Epilepsy Behaviour*, 2, 533-544.

33. Lowe, A.J., David, E., Kilpatrick, C.J., Matkovic, Z., Cook, M.J., Kaye, A., et al. (2004). Epilepsy surgery for pathologically proven hippocampal sclerosis provides longterm seizure control and improved quality of life. *Epilepsia*, 45, 237–242.

34. Lua, P.L., Cosmas, G., & Md.Nawi, N.H. (2007). *The burden of epilepsy: quality of life and coping strategies*. University Publication Centre (UPENA), Universiti Teknologi MARA, Shah Alam. Selangor: Malaysia.

35. Lua, P.L., & Neni, W.S. (2011). Awareness, knowledge andattitudes with respect to epilepsy: an investigation in relation to health-related quality of life within a Malaysian setting. *Epilepsy Behaviour*, 21, 248-254.

36. Lwanga, S.K., & Lemeshow, S. (1991). Sample size determination in health studies: a practical manual. *World Health Organization*, 1-3.

37. Maes, S., Leventhal, H., & de Ridder, D.T. (1996). Coping with chronic diseases. In M. Zeidner, & N.S. Endler, (Ed.). Handbook of coping: theory, research, applications (pp. 221-251). New York: Wiley.

38. McLachlan, R.S., Sadler, M., Pillay, N., Guberman, A., Jones, M., Wiebe, S., & Schneiderman, J. (2003). Quality of life after vagus nerve stimulation for intractable epilepsy: is seizure control the only contributing factor? *European Journal of Neurology*, 50(1), 16-19.

39. Mittan, R.J. (1986). Fear of seizures. In S. Whitman, B.P. Hermann, (Ed.). *Psychopathology in Epilepsy: Social Dimensions*. Oxford: Oxford University Press.

40. Morse, J.M., & Johnson, J.L. (1991). Towards a theory of illness: the illness constellation model. In J.M. Morse, J.L. Johnson, (Ed.). *The illness experience* (pp. 315-342). London, England: Sage Press.

41. Moskowitz, J.T., Folkman, S., Collette, L., & Vittinghoff, E. (1996). Coping and mood during AIDS-related caregiving and bereavement. *Annals of Behavioural Medicine,* 18, 49-57.

42. Naing, N.N. (2009). A practical guide on determination of sample size in health sciences research: Sample size determination in descriptive studies. Kelantan, Malaysia: Pustaka Aman Press Sdn. Bhd.

43. Neni, W.S., Latif, A.Z.A., Wong, S.Y., Lua, P.L. (2010). Awareness, knowledge and attitudes towards epilepsy among rural populations in East Coast Peninsular Malaysia: a preliminary exploration. *Seizure*,19, 280-290.

44. Piazzini, A., Ramaglia, G., Turner, K., Chifari, R., El Kiky, E., Canger, R., Canevini, M.P. (2007). Coping strategies in epilepsy: 50 drug-resistant and 50 seizure-free patients. *Seizure*, 16, 211-217.

45. Raty, L.K.A., Soderfeldt, B.A., Wilde Larsson, B.M. (2007). Daily life in epilepsy: patients' experiences described by emotions. *Epilepsy Behaviour*, 10, 389-396.

46. Rosenbaum, M., & Palmon, N. (1984). Helplessness and resourcefulness in coping with epilepsy. *Journal of Consultancy & Clinical Psychology*, 52, 244-53.

47. Sackellares, C.J., Kwong, J.W., Vuong, A., Hammer, A.E., Barrett, P.S. (2002). Lamotrigine monotherapy improves health-related quality of life in epilepsy: a double-blind comparison with valproate. *Epilepsy Behaviour*, 3, 376-382.

48. Saniah, A.R., & Zainal, N.Z. (2010). Anxiety, depression and coping strategies in breast cancer patients on chemotherapy. Malaysian Journal of Psychiatry, 19, 2.

49. Snyder, M. (1990). Stressor, coping mechanisms and perceived health in persons with epilepsy. *International Disability Studies*, 12, 100-103.

50. Spector, S., Tranah, A., Cull, C., & Goldstein, L.H. (1999). Reduction in seizure frequency following a short-term group intervention for adults with epilepsy. *Seizure*, 8, 297-303.

51. Spencer, S.S., Berg, A.T., Vickrey, B.G., et al. (2003). Initial outcomes in the multicenter study of epilepsy surgery. *Neurology*, 61:1680–1685.

52. Statistics by country for epilepsy in 2004. http://www.cureresearch.com/e/epilepsy/stats-country.htm. Accessed 5 Sept 2010.

53. Taleghani, F., Yekta, Z.P., & Nasrabadi, A.N. (2006). Coping with breast cancer in newly diagnosed Iranian women. *Journal of Advanced Nursing*, 54, 265-272.

54. Trimble, M.R., & Dodson, W.E. (1994). *Epilepsy and quality of life*. New York: Raven Press.

55. Vickrey, B.G., Berg, A.T., Sperling, M.R., Shinnar, S., Langfitt, J.T., Bazil, C.W. et al. (2000). Relationship between seizure severity and health-related quality of life in refractory localization-related epilepsy. *Epilepsia,* 41, 760-764.

56. Vickrey, B.G., Hays, R.D., Graber, J., et al. (1993). A health-related quality of life instrument for patients evaluated for epilepsy surgery. *Medical Care*, 30, 299-319.