International Journal of Psychosocial Rehabilitation

ISSN 1475-7192

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Volume 14
July 2009 - June 2010

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.

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IJPR Volume 14, Number 1

July 2009 - June 2010

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The International Journal of Psychosocial Rehabilitation
Volume 14, Number 1
July 2009– June 2010

The Effectiveness of Community Support Systems and Psychosocial Rehabilitation Services for Mentally Ill Children and their Families

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Ottawa University

Citation:
Bloom, E. (2009).The Effectiveness of Community Support Systems and Psychosocial Rehabilitation Services for Mentally Ill Children and their Families. ***International Journal of Psychosocial Rehabilitation. Vol 14(1) 5-21***

Abstract

The purpose of this study is to see the level of effectiveness of community support and/or psychosocial rehabilitation services for children and families. This study utilized a sample of participants receiving said services from ninety to 120 days in the form of a fourteen question survey. Results show an increase of functioning for the child(ren) and families receiving community-based services. The results imply that psychosocial rehabilitation and/or community support services are an effective service with high levels of recipient satisfaction and an increased independence from acute care services, however additional research is needed in this area.

Review of literature

With the expense of providing effective services burgeoning throughout the United States it has become increasingly important to obtain treatment completion, outcomes, and efficient utilization of available services. Treatment completion and successful outcomes are increased when the mental health system provides culturally appropriate treatment including habilitation and support services (Barton, 1999). Traditionally, those that have participated as service recipients in the mental health system have languished for want of culturally appropriate care. (Walker, 2001). As the current mental health system evolved in the United States it has repeatedly proven to be unequal and ineffective in meeting the mental health needs of children from ethnically or culturally diverse backgrounds (Walker, 2001). If the status quo continues so that communities maintain a perception that their unique cultural heritage, needs and beliefs are not being addressed, trust for the community mental health system may continue to erode. It is vital to increase service recipient trust and confidence in the mental health system if there is to be an expectation of successful and effective outcomes of said services. Thus, the services provided to children and families must capture family experience, culture, views and beliefs (Granat, Lagander, Börjesson 2002).

There is an increase in effective coping with disorders, both emotional and behavioral disorders in the part of the parent when the family receives psychosocial rehabilitation and/or support services (Davidson, Dosser, 1982). Conversely, when the parent’s ability to cope with the disorders or disabilities of their child(ren) are strengthened and supported through psychosocial rehabilitation then positive outcomes are more frequent and family stability improves. Another benefit to children is that with psychosocial rehabilitation/support services, hospital stays are shortened and successful post hospitalization transitions tend to normalize lifestyle, meaning that children are able to be a productive member of their community (Hughes, 1999). Research supports that children and families who participated in psychosocial rehabilitation services averaged 6.51 days of inpatient care versus an average of 38.74 days when typical mental health care services without psychosocial rehabilitation activity (Hughes, 1999). When mental health service recipients are discharged from inpatient care employing psychosocial rehabilitation services patients decrease their reliance on inpatient services by a significant amount, one study discovering a nineteen percent reduction over a three year period in contrast to those that were discharged without the coordination of psychosocial rehabilitation services (Hughes, 1999). Consequently, the group that did not have psychosocial rehabilitation services at discharge from inpatient mental health services increased their utilization of inpatient services eighteen percent over three years (Hughes, 1999). This drastic decrease of utilization of inpatient services shows that when children and families receive psychosocial rehabilitation and/or support services when they need these services, hospitalization rates decrease. For the mental health system to be effective in treatment planning and implementation a broad spectrum approach must be employed which includes collaboration and active participation in decision making by the family coupled with an array of services including psychosocial rehabilitation (Walker, 2001). As leadership by the family/caregivers develops, the needs for services that are easily accessible and customized for the family receiving services are needed.

The family that is receiving psychosocial rehabilitation and/or support services must feel increasingly comfortable and in charge of the treatment process which builds stronger working alliances and trust between service providers and service recipients. The correlation with the level of success and the comfort level of the caregiver with the staff is substantial (Walker, 2001). The utilization of staff that are based within the community and can provide the services to the individual family's culture will prove to be more comfortable receiving psychosocial rehabilitation services and will show higher treatment outcomes as well as overall stability (Hughes, 1999; Jenson, Hawkins, Catalano, 1986).

The increase of utilization of mental health services for children/families requires a reduction in stigma from the community in which they live. The responsibility of reducing the stigma lies on the system to promote a supportive community through education, skills training and skill development (Hughes, 1999; Feehan, Stanton, McGee, Silva, 1990). The focus of these mental health system programs should develop the feelings of improved self-empowerment, self direction and increase the individual's feelings of autonomy (Hughes, 1999; Barton, 1999, Young, Ensing 1999; Feehan, Et al, 1990). The feeling of autonomy will show the service recipient that their recovery from mental illness is successful. The successes that the service recipient continues to have within their community will increase their level of empowerment (Walker, 2001). The empowerment that comes from driving their own successful treatment and recovery process will create a successful individual living in the community. A community that supports individuals that are recovering from mental illness will decrease the stigma associated with mental illness. As the stigma that is around mental health in various communities' decreases, the trust from the individuals needing and seeking mental health services will improve. When the community supports individuals/families with mental illness the community and the individuals/families can contribute to the community in which they live in a successful manner, the entire community can celebrate the victories around recovery (Hughes, 1999; Barton, 1999; Young, Ensing 1999; Feehan, Et al, 1990). The stigma of mental illness also effects the utilization of services. One study showed that fifty percent of parents with children with mental disorders did not seek help for the disorder. This reluctance to seek assistance decreased with the addition of social support services within the community (Feehan, Et al, 1990).

Support and psychosocial rehabilitation skills need to be individualized to encompass the family culture, beliefs and culture to be an effective service (Stanhope, Solomon, Pernell-Arnold, Sands, Bourjolly, 2005; Walker, 2001). The effectiveness of the service is also dependent on the family's leadership in the collaborative effort to ensure that the family is getting the types of services needed. Support and rehabilitation services are designed to add positive interactions to the child/family's everyday life. When psychosocial rehabilitation services are employed successfully there is a corresponding elevation of quality (Anthony, 1993). The utilization of support and psychosocial rehabilitation services for a family with a child that has a mental illness can advance cohesive family interactions and act as a stabilizing force in the family's overall functioning (Granat, Lagander, Börjesson 2002).

Community support/psychosocial rehabilitation services are general and broad by definition, for this reason they can be tailored to the specific needs and culture of the family allowing flexibility with time and intensity (Barton, 1999; Stanhope, Et al 2005). The psychosocial rehabilitation services that the family receives should also be provided in the place that is least restrictive for the recipient as well as the services should be provided at the time the family requests to maximize the utilization of the tools that the provider(s) are teaching the child and family (Barton, 1999). The psychosocial rehabilitation/support services are delivered in the community that the family identifies with, not just the location of the community. The utilization of services that are based in the family's preference of community allows the family to identify and connect with the various communities that may be apart of the culture or beliefs of the family (Walker, 2001; Granat, Lagander, Börjesson 2002). As services are delivered in the desired settings of the child/family the functioning of the child increases and the parents well being also increases and the family is better able to care for itself, independent of formal mental health services (Walker, 2001; Granat, Lagander, Börjesson 2002).

Psychosocial rehabilitation services are by nature tailored to the specific situations in which the services are appropriate based on the collaboration with the family (Barton, 1999). Psychosocial rehabilitation services focus on autonomy, independence, and stabilization to decrease the use of acute care (Barton, 1999). Psychosocial rehabilitation and support services are often used simultaneously however the two concepts are very different by definition (Barton, 1999). Psychosocial rehabilitation needs to have one or more of the following interventions to be accurately called psychosocial rehabilitation. Behavior skills training is used to increase cognitive functioning through curriculum-based interventions and learning experiences (Barton, 1999; Granat, Lagander, Börjesson 2002). Peer support usually includes community-based programs in non-clinical settings (Barton, 1999).

Vocational services are set by the client's vocational goals. The empowerment to have successful, gainful employment increases the client's motivation to take control of their own recovery (Barton, 1999; Young, Ensing, 1999). The client's community resource development is vital to the success of the client in the community. The community resource development area can include direct support for services such as family education as well as indirect supports to include child/family networking abilities to create autonomy from the community behavioral health system (Barton, 1999).

Many components of psychosocial rehabilitation require skills training as a prerequisite for psychosocial rehabilitation services, or in conjunction with psychosocial rehabilitation services (Barton, 1999). It should be noted that psychosocial rehabilitation services can include training set curriculum for various interventions and this focus is targeted to the specific needs of the family and child(ren) involved (Barton, 1999; Young, Ensing, 1999). This targeting of services allows the recovery process to be clear, concise and exclusive to the goals and objectives of the service recipients (Barton, 1999; Young, Ensing, 1999).

The need for quality programming is increasing as the number of children in out of home placements is increasing (Clawson, Luze, 2008). Studies try to evaluate other psychosocial rehabilitation/support services with limited success (Granat, Lagander, Börjesson 2002). The limited success in measuring psychosocial rehabilitation services is that habilitation is a multi-faceted, broad spectrum of service continuum that is complex to evaluate (Granat, Lagander, Börjesson 2002). To foster ongoing improvement in programming requires continuous, ongoing collection and evaluation of service provisions (Granat, Lagander, Börjesson 2002). Consumer's responses to community based services increases the functionality of services as the demand for quality services increases (Stricker, 2001). The demand of the clients of psychosocial rehabilitation service is to provide quality services throughout the broad spectrum of services available to them (Hughes, 1999; Stricker, 2001). Services are consistently evaluated by stakeholders that interact with the clients as well. The feedback by the stakeholders is also continually evaluated for opportunities for improvement in order to provide services for other children/families in the community (Stricker, 2001; Granat, Lagander, Börjesson 2002).

As families receive the psychosocial rehabilitation services in the setting of the family choice, the caregiver(s) of the child feel more competent in addressing the needs of their family and as this competency grows, the need for high intensity, restrictive and costly services (i.e. repeated hospitalizations) will diminish (Barton, 1999). Families that utilize psychosocial rehabilitation see an increase in treatment outcomes and client stability (Jenson, Hawkins, Catalano, 1986). The increase in client stability increases the family's ability to manage and to function autonomously. A family that receives psychosocial rehabilitation services will have tools to lead a satisfying life that is full of new meaning and increased control (Anthony 1993). Parents reported an increase of stress having a child with behavior problems; however the utilization of support and psychosocial rehabilitation services for families appears to increase the functioning of the child and the well being of the parents which empowers the family's autonomy (Long, Gurka, Blackman 2008; Granat, Lagander, Börjesson 2002).

A child/family that utilizes psychosocial rehabilitation services has an increase of relief and symptom control which creates opportunities for self-sufficiency and autonomy from mental health services (Anthony, 1993; Hughes, 1999). Psychosocial rehabilitation services increase client stability as well as the sense of self and increase self-sufficiency to decrease from expensive, restrictive acute care systems for persons with mental illness (Jenson, Hawkins, Catalano, 1986; Barton, 1999; Young, Ensing, 1999). As symptom control increases for the client, the parent(s)/caregiver(s) are better able to care for the family (Anthony, 1993). As the intensity, frequency and /or duration of psychosocial rehabilitation/ support services are decreased over time, the child/family has increased independence and has tools to better care for the family's needs (Hughes, 1999).

Utilizing psychosocial rehabilitation/support services in conjunction with reinforcement based interventions show better outcomes for changing behavior (Brown, Michaels, Oliva, Woolf, 2008). Changing the behaviors that will help stabilize the family and keep the individual in the least restrictive environment will empower the family toward independence (Brown, Et al 2008; Hughes, 1999). The use of strategies that engage parents in the activities that the child(ren) enjoy, will create a less stressful environment for the family (Pullen, 2008, Gottlieb, 1987). Teaching the recipient(s) of support/psychosocial rehabilitation services aversions to coercive behavior modification strategies will increase independence of the individual to make positive decisions (Swanson, Tepper, 2000).

The way the family communicates is an opportunity for engagement and building of relationships between family members (Pullen, 2008). The utilization of psychosocial rehabilitation/support services increase effective interactions and opportunities of positive, constructive communication between parent(s)/guardian(s), service providers, and children (Walker, 2001). Through different approaches or interventions of communication, taught through psychosocial rehabilitation services that increases the functioning of the child(ren) receiving services; the parent(s)/guardian(s) are able to adapt their style of communication to reach the(ir) child(ren) more effectively (Pullen, 2008; Granat, Lagander, Börjesson, 2002). The utilization of psychosocial rehabilitation/support services improves the mentally ill youth's social interactions with non-impaired youth after receiving services after ten weeks (Lochman, Haynes, Dobson, 1981). The basis of social interaction is communication. The increase of communication directly correlates with the social interactions and social successes of children and families (Lochman, Haynes, Dobson, 1981; Pullen, 2008; Feng, Lo, Tsi, Cartledge, 2008).

Methods

Process

The survey tool is an exploratory survey to establish a baseline to measure the satisfaction and effectiveness of future services. The survey tool was developed through a process of peer collaboration focusing on what outcomes need to be measured, and how to best capture said outcomes. The tool design explores and captures the perception of service recipient families of psychosocial rehabilitation services as delivered in a community setting.

The data was started to be collected ninety through 120 days after the inception of psychosocial rehabilitation services that were provided to the family in the least restrictive, most therapeutic environment for the child. The rationale for the lag in capturing data was to reduce the likelihood of creating multiple confounds. One paradox that was discussed with the peer collaboration team was the program was new in providing psychosocial rehabilitation services. The delivery of services from the first day through the ninety day period focused on rapport building activities and collaborating with the family about their preferences for services. Further discussion of data collection lead to creating an internal work process flow. This process would create ease in the direct support staff to complete the documentation as well as a process in capturing the necessary data from the families. The team found that there needed to be a standard of service delivery for each family. At the service standard implementation, the team found that refinement of the standard needed ongoing refinement to ensure individualized services. The services delivery staff needed adequate training to assure that confounds were not due to the lack of knowledge on the part of service delivery staff. The training captured a broad spectrum of curriculum to create a competency before delivering services.

A Likert scale was selected for capturing data from families. The team agreed upon utilizing the Likert scale for various reasons. The scale creates ease for capturing accurate, meaningful data. The Likert scale is easily understandable by service recipient families. Lastly, a scale is statistically functional in an exploratory research project. Additionally, at the end of the survey, an open response section was provided for personal observations of service recipient families was provided. This information is extremely antidotal and will not be included in this research.

The tool has fourteen different questions that are rated on a Lickert scale of one through five. The rating scale also had a definition of the following (1 Totally disagree, 2 Disagree, 3 Neutral, 4 Agree, 5 Strongly Agree) The peer review team collaborated prior to deployment and discussed the effectiveness of measuring the effectiveness of psychosocial rehabilitation and/or community support services provided to children and families.

Tool development

Question one "My family's culture, values and beliefs were respected.**"** The peer review team was in seventy five percent agreement that this question did appear to measure the level of respect that was shown to each individual family's culture, values, and beliefs. The question's design is to capture information regarding the culture, values, and beliefs of the family is being respected throughout the course of the support and/or rehabilitation services in the home or community where the services are needed. After thorough review by an ethics panel, the question was included.

Question two "The staff was available when I needed them." The peer review team was in fifty percent agreement that of the question effectiveness. The team decided that this question may be ineffective in measuring a "crisis type" situation for the family as staff members are generally not always available if the child/family goes into crisis. The question was intended to measure that services were available at the time when the family needed them most. The question focuses on utilizing services at the times when the family felt they needed them most. The question's significance to the research is deemed that psychosocial rehabilitation services reach their maximum effectiveness when utilized when the family can engage or at the time where the services are needed most on a consistent basis. The ethics review panel discussed the question and the question was included.

Question three "I felt comfortable with staff." The peer review team was in fifty percent agreement that the question was a valid instrument in measuring the level of rapport built with staff. The peer review team established a possible confound to the question in that the the family member that is filling out the survey may have a different level of interaction or rapport with the staff member. The peer review team also concluded that the question can not effectively measure the timliness of the rapport established as each family's dynamic is different. The question's intent is to measure the level of rapport and the timliness of rapport that is being established with the family. The question's significance to exploratory research is that the comfort level with staff dramatically impacts the overall course of the effectiveness of the services being delivered to the family. The ethics review panel, question could show usefulness in the research and was added.

Question four "My (My family's) experience with the program was excellent." The peer review team was in twenty five percent agreement that this question measured the overall effectiveness of the program. The level of effectiveness varies greatly from family to family to meet the family's specific goals and needs. Evaluating the effectiveness of services, especially to children across settings is vital to quality service delivery. The question measures the overall experience of the program's services. Question four's measurement of the overall experience deems vital to the evolution of the program. The ethics review panel's review of the question was positive and consequently added.

Question five "My family received the kind of services needed." The peer review group was in fifty percent agreement that the question would be an effective instrument. The group concluded that families may not know the type or the extent of the services needed to help their family depending on the state of the family at the time that services are agreed upon. Question five's design is to gain the family's perspective regarding the types of services they are receiving. The peer review panel discussed the importance of family perception of services. The utilization of question five also shows the influence of family voice as the type of services that the family needs. The ethics review panel approved the utilization of question five.

Question six "Services were delivered in a timely manner." The peer review team discussed a twenty-five percent agreement that the question is effective in measuring access to care services. The team discussed that putting a timeframe on the question may have made the question more effective. The intention of question six ensured that the services that the family is receiving had been implemented in a timely manner as perceived by those families. The family perception of the timliness of services is importance in measuring the response time to the request of services. The ethics review panel perceived question six as ethical and was added to the tool.

Question seven "Services were adequately explained to my family." The peer review team was in seventy-five percent agreement that this question adequately measures the level of understanding that the family has in regards to the type of services that is available to them through the support services /psychosocial rehabilitation program. The question design measures that the family felt the explanation of psychosocial rehabilitation/support services was clear before service inception for the family. The understanding of services is vital to research. The family's thorough understanding of the program and how the goals of the services are designed will influence the utilization of support and psychosocial rehabilitation services. The ethics review panel is in agreeance and will be utilized in the tool.

Question eight "Overall the program is excellent." The team reached a seventy-five percent agreement that the question adequately measures the family's overall perspective of the program. The question's design is to give the "family voice" perspective to the researcher that the program, the staff, and the goals were excellent. This question's value is to the research is that the family voice is being utilized to give feedback to the effectiveness of the support and psychosocial rehabilitation services program. The ethics panel's review deemed the question's approval and was added to the tool.

Question nine "As a family, we are more in control of problems and feel better able to manage." The review team was in twenty-five percent agreement that the question is effective in measuring the level of control that the family has as a result of the support/rehabilitation services provided. The team discussed that there may be other services in place for the family to learn and utilize new skills in conjunction with the support/rehabilitation services. This question was designed to measure the level of control that the family has as a result of the skills that the family learns to utilize from the support and psychosocial rehabilitation services that are being provided to them. Question nine elicits that support and psychosocial rehabilitation services increases the family's control of their problems. Question nine also elicits that the family is better able to manage their problems as a result of support and psychosocial rehabilitation services. The ethics review panel discerned that the question can be utilized within the tool.

Question ten "My family is more self-sufficient in caring for their needs." The peer review team showed a twenty-five percent agreement that this question is effective in measuring self-sufficiency as a family due to the use of support/psychosocial rehabilitation services. The team discussed that support services/psychosocial rehabilitation services can be utilized in conjunction with other services. The question's importance is crucial to show the increase in self-sufficiency from the utilization of support/rehabilitation services that are being provided to the family. This question passed the ethics review panel and was added.

Question eleven "Discipline efforts with the children are more successful." The peer review team established a seventy-five percent agreement of the question. The team decided that the question adequately measures the increased levels of success of Positive Behavioral Support based discipline techniques. The question elicits to research the increased effectiveness of discipline that utilizes a Positive Behavioral Support approach. Question eleven passed a thorough review by the ethics panel.

Question twelve "Our knowledge of how to change child behavior has improved." The team had a fifty percent agreement rate that question twelve was effective in its design. The team collaborated that the question needed specific information to be a more effective measure of knowledge increase due to psychosocial rehabilitation services. The question's intent is to measure the amount of increase of knowledge that the family has gained while utilizing support/rehabilitation services. Question twelve's usefulness to the research is to indicate that the increase of knowledge to change the target behaviors is a result of support/psychosocial rehabilitation services. The question also went through the ethics review panel and was approved for use.

Question thirteen "My child's behavior and attitude has improved." Peer reviewers were in seventy-five percent agreement of the question's effectiveness. The group showed that support and rehabilitation services are effective in changing behaviors and an increase of positive attitudes. This question shows that the target behaviors that the child displayed have decreased and the child's attitude has improved since the implementation of support/psychosocial rehabilitation services. This question shows that the measure is important as the utilization of support and psychosocial rehabilitation services is being explored. The ethics review panel distinguished the question as ethical and could be utilized for research.

Question fourteen "My family's communication skills have improved." Peer reviewers are in fifty percent agreement that the question measures increased communication skills within a family. The question was designed to measure the increase of communication skills due to support/rehabilitation services in the home. The question's significance to research is the increase of communication within the confines of the family. The utilization of communication skills proves to have an important role in the success of support/psychosocial rehabilitation services. The ethics review panel reviewed the final question and ruled it to be ethical and to be used in the research tool.

Tool deployment

The tool was distributed to 229 families receiving support/psychosocial rehabilitation services for ninety days and over. The research staff collected eighty-four individual surveys at the end of the ninety day collection period that could be evaluated for data reporting. The staff also received twenty-one surveys that could not be evaluated for various reasons including but not limited to: incomplete surveys, poor comprehension by respondent, or language barriers.

Collection of data

The fourteen question survey and a self addressed stamped envelope was distributed by the staff members that work with the family's to ensure proper and timely delivery. The survey tool was then completed by the adult family member/custodial guardian of the child. After completion, the survey was returned via mail.

Results

Key:
100 percent would represent perfect service

Eighty-four total responses from total program participation to date of 229 which is a 36.6percent return rate on surveys

		East	**West**	**Aggregate**
1	My family's culture, values and beliefs were respected.	4.7 of 5	4.7 of 5	4.7 of 5 94%
2	The staff was available when my family needed them.	4.4 of 5	4.5 of 5	4.45 of 5 89%
3	I felt comfortable with the staff.	4.6 of 5	4.6 of 5	4.6 of 5 92%
4	My (my family's) experience with the program was excellent.	4.2 of 5	4.2 of 5	4.2 of 5 84%
5	My family received the kind of service needed.	4.2 of 5	4.1 of 5	4.15 of 5 83%
6	Services were delivered in a timely manner.	4.3 of 5	4.4 of 5	4.35 of 5 87%
7	Services were adequately explained to my family	4.1 of 5	4.4 of 5	4.25 of 5 85%
8	Overall the program is excellent	3.8 of 5	4.4 of 5	4.1 of 5 82%
9	As a family, we are more in control of problems and feel better able to manage.	3.8 of 5	3.8 of 5	3.8 of 5 76%
10	My family is more self-sufficient in caring for their needs.	3.8 of 5	4.8 of 5	4.3 of 5 86%
11	Discipline efforts with the children are more successful.	3.3 of 5	3.7 of 5	3.5 of 5 70%
12	Our knowledge of how to change child behavior has improved.	3.6 of 5	3.6 of 5	3.6 of 5 72%

13	My child’s behavior and attitude has improved.	3.6 of 5	3.6 of 5	3.6 of 5 72%
14	My family’s communication skills have improved	3.6 of 5	3.8 of 5	3.7 of 5 74%

Discussion

The survey tool was designed to measure the effectiveness of the support and/or psychosocial rehabilitation services to children and families. The survey tool proved to be useful in areas of staff development and areas of informal practice improvement. The behavioral health recipient’s name was provided on each survey which assisted in tailoring individual supervision and training practices for staff development. This process was efficient for fine tuning service delivery, but may have created some discomfort on the part of the recipient in making completely factual disclosures. This confound was discovered as families may have felt that if they responded negatively, then the services they were receiving would be taken away. Another confound discovered is that if the response was negative that the information would be shared with the staff and the staff member may have ill will towards the family in service. Results of the tool were not shared with individual staff members nor were the results punitive in any way for the staff. During staff debriefing sessions, general themes across the feedback from the families were addressed for staff development and growth.

The tool seemed able to accurately capture that the family’s culture, values, and beliefs were respected through the process of receiving individualized psychosocial rehabilitation/support services. The support for providing services that capture the culture, and values that are individual to the family receive tools through services that the family can continue to employ after the program is finished. Antidotal evidence that was provided from the families encompassed utilizing community based programs that include the family’s values or belief system throughout the course of the psychosocial rehabilitation/community support services increase the family’s independence and overall functioning. Families also included that the staff that worked within the family’s community and found programs within the family’s community increased the rapport built with the family.

The services that are deployed for each family is individualized and thus the peer review team established that the questions regarding excellence of the program may be ineffective at measuring the desired outcomes. The peer review team also concluded that the tool’s question can not effectively measure the timliness of the rapport established as each family’s dynamic is different. The tool’s intent is to measure the level of rapport and the timliness of rapport that is being established with the family. The family’s antidotal evidence supported that the use of activities within the community increased the alliance between the staff member and the family. It is believed that the faster that a staff member can build the rapport with a family then the services will be more effective at an increased rate. The staff members stated in debriefing sessions that building rapport has been challenging with each family that the staff member has worked with. The main reason stated through the debriefing process is the uniqueness of each family and techniques needed to change to meet the family’s need.

The survey totals show an aggregate score of seventy percent or higher success rate from the family perspective. The family voice is powerful as the driving force of treatment goals and services that are provided for individualized services. The exploratory tool in rudimentary form shows that the families that receive support and psychosocial rehabilitation services show at minimum a seventy percent improvement in at least one area of their family’s lives.

The support and psychosocial rehabilitation services provide an increase in stability and consistency. The results of the deployment of the survey tool show an increase of positive family function. The positive impacts of support and psychosocial rehabilitation services are felt by the family as a whole, not just the one member that is receiving services. The increase in stability for the family can act as the start of their independence from formal mental health services. The stability from support/psychosocial rehabilitation services also increase the family's utilization of community supports and community based services. The antidotal data captured supports the family's independence and successful utilization of community based programs. At staff debriefing sessions, staff also captured that the family shows increased independence over the course of the program and was more willing to try utilizing community services and programs.

Staff availability to serve families when the family needed staff is a powerful force in the effectiveness of the psychosocial rehabilitation/support program. The staff availability to provide services at the time and place that the family needed them increased the overall compliance with the treatment plan which also increased the effectiveness of the services. The ability to provide services in the setting and time that the family needs most increases the likelihood of being able to provide support through the time that the target behaviors are most likely to occur. The antidotal evidence supports that having staff available during the times that the family needs increases the satisfaction with service plans and increased empowerment through skill development in the places that the family may struggle. During the staff debriefment process, the staff expressed that having a collaborative schedule with the family seemed to be more effective than dictating to the family of the staff's availability. Staff stated that the cancellation rate of the families that they serve was minimal throughout the course of the program. Through the process of evaluating the cancellation rate, the program did not account for families that stated they wanted psychosocial rehabilitation/support services through the child and family team process, however the need of the family changed to where the family felt that these services would not be appropriate at the time services became available.

The accuracy of the level of comfort with the staff presented confounds such as possibly feeling that the staff may present ill will towards the families based on the response given. However in analyzing the demographics of the family and the demographic of the staff member were similar, the family's comfort level is significantly higher at the ninety days of service benchmark. The staff also reported that the rapport building process with the family seemed easier when the family receiving services demographic was similar to the staff. This information is antidotal in nature as this area was not critically measured during the study.

The overall excellence of the program is also difficult to define through the data collected. The families surveyed stated that the program overall is excellent, however through the data, the confound of the family's comfort level of answering this question may not accurately capture the data of the family's actual experience with the program. The ongoing process for improvement in the program requires the feedback about the overall experience with the program and the service design. The utilization of the family's experience with the program also has similar confounds around the nature of the question. The need for program to improve and meet the needs of the family relies on the feedback that the family provides through their experience with a psychosocial rehabilitation/support service program.

While the survey tool did not capture hospitalizations, the antidotal data would support fewer hospitalizations and short stays in acute care did occur. The data collected also shows increased family independence from services with the utilization of support and rehabilitation services as part of treatment of mentally ill children. Antidotal data and statements from families with children that have repeated the hospitalizations state that the support and/psychosocial rehabilitation services that are in place create a structured, more stable environment for the child to return home to and create an environment where the child and family can recover from acute care facilities. This stabilization and support for the child and family also creates an environment of empowerment that the child and family can function without the acute care facilities as the families get tools to use and support from the community.

The tool has various areas of improvement to get a more in-depth perspective in regards to support and psychosocial rehabilitation campaigns. The questions that were utilized in the tool show general themes around the family view of support/psychosocial rehabilitation services for children and families. The tool does not take into account the complexity of cases or the level of dysfunction within the family's that participated in the survey. The levels of improvement look different for each family that has been served with support services/psychosocial rehabilitation, which the tool does not account for. The theme of improvement does not rule out any dysfunction or the cessation of any type of dysfunction. The utilization of the tool leaves further research and more options of specific information that can be explored at a later time.

The results have been broken down by each site that the program operates from, and then the data was combined to give an aggregate total for the program. The representation of the data collected represents children with an age range of four through seventeen years of age receiving services within the community behavioral health population. The population does not exclude ages birth to four, however the program did not receive a request to serve any families in said age range.

The tool's design is decipher if the service design is effective in measuring the effectiveness of community support and psychosocial rehabilitation services. The literature that is cited in this work showed that there is still a need for additional research in the role of support and rehabilitation services that are to be delivered in the most therapeutic, least restrictive environment to further the recovery process.

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APPENDIX A

DEFINITION OF TERMS

Psychosocial rehabilitation: A behavioral health service that is provided in the recipients home, in the location where the target behavior is most likely to occur, or in community settings that teaches the recipient about but is not limited to: emotional management, emotional regulation, positive coping mechanisms.

Skills training: A behavioral health service that teaches a service recipient a particular skill that can include, but is not limited to : vocational, social, organizational, personal care, or educational.

Support services: A behavioral health service that is provided in the recipients home, in the location where the target behavior is most likely to occur, or in community settings that teaches the recipient and/or the caregiver of the recipient positive ways to change target behavior(s).

Target behavior: A behavior that is re-occuring that may need to be altered in duration, frequency, or intensity to create a sense of normalcy for the individual or family

APPENDIX B

Survey Tool

Community Support Services
Please check at least one below

☐ **East Valley** ☐ **West Valley**

Client Name: ______________________________
Date: _______________

Instructions:

By filling out this survey, you can help us learn what parts of our program are or have been most helpful to you. Please read each statement on the following page and decide how well it describes you and your family.

- There are no right or wrong answers; just give your opinion
- If you have trouble with a statement, give the first answer that comes to mind
- Your answers are confidential

If you strongly disagree with the statement ---- put an X over ☐
If you disagree with the statement ---- put an X over ☐
If you neutral ---- put an X over ☐
If you agree with the statement ---- put an X over ☐
If you strongly agree with the statement ---- put an X over ☐

		Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
	Since being involved in the program, my family has a better home life.	☐	☐	☐	☐	☐

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1	**My family's culture, values and beliefs were respected.**	☐	☐	☐	☐	☐
2	**The staff was available when my family needed them.**	☐	☐	☐	☐	☐
3	**I felt comfortable with the staff.**	☐	☐	☐	☐	☐
4	**My (my family's) experience with the program was excellent.**	☐	☐	☐	☐	☐
5	**My family received the kind of service needed.**	☐	☐	☐	☐	☐
6	**Services were delivered in a timely manner.**	☐	☐	☐	☐	☐
7	**Services were adequately explained to my family**	☐	☐	☐	☐	☐
8	**Overall the program is excellent**	☐	☐	☐	☐	☐
9	**As a family, we are more in control of problems and feel better able to manage.**	☐	☐	☐	☐	☐
10	**My family is more self-sufficient in caring for their needs.**	☐	☐	☐	☐	☐
11	**Discipline efforts with the children are more successful.**	☐	☐	☐	☐	☐
12	**Our knowledge of how to change child behavior has improved.**	☐	☐	☐	☐	☐
13	**My child's behavior and attitude has improved.**	☐	☐	☐	☐	☐
14	**My family's communication skills have improved**	☐	☐	☐	☐	☐

Your Comments:

What do/did you like best about this program?

What do/did you like least about this program?

The International Journal of Psychosocial Rehabilitation
Volume 14, Number 1
July 2009– June 2010

Neurofeedback Training to Enhance Learning and Memory in Patient with Traumatic Brain Injury:

A Single Case Study

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Citation:
Reddy RP,Rajan J, Bagavathula I, & Kandavel T. (2009).Neurofeedback Training to Enhance Learning and Memory in Patient with Traumatic Brain Injury: A Single Case Study. ***International Journal of Psychosocial Rehabilitation. Vol 14(1). 21-28***

Abstract:

Road traffic injuries are the leading cause (60%) of brain injury. It is estimated that India would occupy third position for Traumatic brain injury (TBI) by 2020. The most vulnerable group of population is the young adults for TBI.

Primary objective: The purpose of the present study was to examine neurofeedback training (NFT) to enhance verbal and visual learning and memory in patient with traumatic brain injury (TBI).

Research design: Single case study was adopted. The neuropsychological profile of the patient was compared pre and post NFT.

Methods and procedures: Patient S, 30 yr male with mild head-injury was given 20 sessions of NFT, 45 min / day, 5 days a week. The training incorporated video feedback to increase the frequency of alpha waves (8-12 Hz): and to decrease theta waves (4-7 Hz). The pre assessment showed impairment in verbal learning and memory.

Main outcomes and results: Results indicated improvement in both verbal and visual learning memory in patient post NFT. The details will be presented.

Conclusions: The present study puts forward that NFT should be taken into account to plan for rehabilitation of patients with TBI for enhancement of learning and memory.

Introduction

Traumatic brain injury (TBI) is defined as an insult to the brain caused by an external force that may produce diminished or altered states of consciousness, which results in impaired cognitive abilities or physical functioning (Menkes, 1990). Primary damage occurs to structures at the point of impact or at the point opposite the impact point (i.e., contrecoup injury) as the brain is pushed against the interior of the skull. Secondary injury results from processes of vasodilation, edema, and increased intracranial pressure that can occur as a result of the primary injury. The frontal and temporal lobes, particularly anterior temporal regions, are the cortical areas most likely to be damaged (Fennell & Mickle, 1992).

TBI constitute a significant burden on health care resources. Road traffic injuries are the leading cause (60%) of brain injury, followed by falls (20-25%) and violence (10%). A vehicular accident is reported every 3 minutes on Indian roads. It is estimated that nearly 1.6 million people in India sustain head injuries annually (Gururaj, 2002). Road crash data from Delhi indicates that 41% of injured are pedestrians, 27% motorcyclists and 14% pedal cyclists. The state witnessed 9,083 road accidents in the year 2004. Data from Kerala indicates that 56% of road crashes involve riders of two-wheeled vehicles. Kerala leads the country in traffic injuries - 29 per 100,000 people (Fitzgerald et al., 2006). There is significant sex difference. Males were two to three times more likely to suffer brain injury than females' low socioeconomic status constitutes independent risk factor for traumatic brain injury (Kraus & McArthur, 1996).

Memory Impairment Following TBI

Memory deficits are the most frequent chronic cognitive disturbance reported by patients and relatives in TBI, long-term memory impairment (Serino, ciaramelli, Santantonio et al., 2005), working memory, verbal and visual memory (Kumar, 1999). Memory dysfunction is characterized by anterograde and retrograde deficits, faulty sequencing of events, inefficient encoding, storage strategies and working memory (McDowell et al., 1997).

Mechanism of Recovery from TBI

The recovery of TBI would be maximized by appropriate rehabilitation, which occurs within months of the damage. The degree of recovery depends on many factors, including age, the brain area and amount of tissue damaged the rapidity of the damage, the brain's mechanisms of functional reorganization, and environmental and psychosocial factors. The mechanisms of recovery are also through regeneration, diaschisis, and plasticity (Ricardo E., et al., 1997). The models of memory account for the relationship between the wider neocortex and the medial temporal lobe structures, which helps in rehabilitation. In the rehabilitation of memory the emphasis is typically on alleviating the impact of the memory impairment and as a consequence improving day-to-day functioning. Within the field of cognitive rehabilitation there is a tradition of cognitive retraining, which typically involves repeated exercise on tasks that make demands on the cognitive functioning being retrained. The methods were to (i) enhanced learning (making more effective use of residual memory skills); (ii) mnemonic strategies; (iii) external aids; (iv) environmental modification. Such restitutive approaches and the compensatory approaches have been shown to be helpful for people with memory impairment; however main problem with such approaches have been lack of evidence of its effectiveness (Goldstein & McNeil, 2004).

Neurofeedback Training (NFT)

Neurofeedback (NF) is based on specific aspects of cortical activity. It requires the individual to learn to modify some aspect of his/her cortical activity (Vernon, 2005). The procedure is based on operant conditioning whereby an individual modifies the amplitude, frequency or coherence of the electrical activity and learn to influence the electrical activity of their brain. The goal of neurofeedback is to train the individual to normalize abnormal EEG frequencies. With the neurofeedback approach, the brain frequencies that are in excess are reduced, and those with a deficit are increased (Hardt, 1975). Site–Frequency Specificity and the Self-Regulating Brain models of NFT address to improved ability to maintain homeostasis and to improve stability when responding to a sudden challenge or insult to the regulatory system (Othmer & Kaiser, 1999). The research has led to the conceptualization of neurofeedback as a mechanism is used to stimulate and or regulate cerebral activity, which in turn influence cognitive processing. Hoffman, Stockdale, Hicks and Schwaninger (1995) reported 80% of mildly posttraumatic head-injured patients demonstrate improvements in self-reported symptoms and neuropsychological measures after an average of 40 sessions of NFT. Thornton (2000) compared three patients' with post-head-injury and reported 68–81% improvement in mean recall to paragraphs after amplitude and coherence NFT. A sample of 20 outpatients with mild to moderately severe closed head injury was treated with, Flexy Neurotherapy System FNS with a 16 20-minute sessions 3 years post trauma, significant improvement was reported (Schoenberger, et.al., 2001). Slowing of EEG, of varying degree and duration, scattered spike activity of varying intensities was frequently reported in patients with TBI (Engstrom & Winkler, 2006).

Case Report

Patient S was a 30-year-old married male from middle socio economic status, employed in a garment factory with nil significant personal, past and family history presented with complaints of poor memory, increased irritability associated with increased distress in meeting the demands of family. He had sustained a mild traumatic brain injury one year earlier following a road traffic accident. S demonstrated significant memory problems on an everyday basis. He frequently left his money at home, forgot information passed on from colleagues, forgot to bring articles from market. He experienced anxiety about his and low mood. Family members were critical about his memory difficulties. The patient's pretraining revealed left hemisphere neuropsychological deficits.

Method

The study protocol consisted of assessment using the Rivermead Post-Concussion Symptoms Questionnaire (King et., al 1995), Rivermead Head Injury Follow Up Questionnaire (RHFUQ) (Crawford et al, 1995), Edinburgh's Handedness inventory (Old field, 1971), Quality of life Scale (WHO-QOL,1992), NIMHANS Neuropsychological Battery (Rao et al, 2004) was carried out three days prior to the start of NFT. S obtained profile scores, suggesting severe verbal memory impairment pre NFT; however there was a significant change in the post NFT sessions for verbal memory. Post assessment was carried out after one month of treatment.

Procedure

S completed a pre-intervention assessment. This baseline period was followed by neurofeedback training. The program consisted of 4 weeks of 45 minutes, 20 individual training sessions. Sessions were conducted in hospital setting. Gold electrodes were applied, with paste according to the 10– 20 International System of electrode placement on O1, O2, with two reference points on the ear lobes and one ground electrode on the forehead. Re-assessment followed completion of the program, along with a structured interview to obtain qualitative feedback from patient. The protocol was to enhance alpha and decrease the frequency of theta waves. The patient received visual feedback from a video monitor.

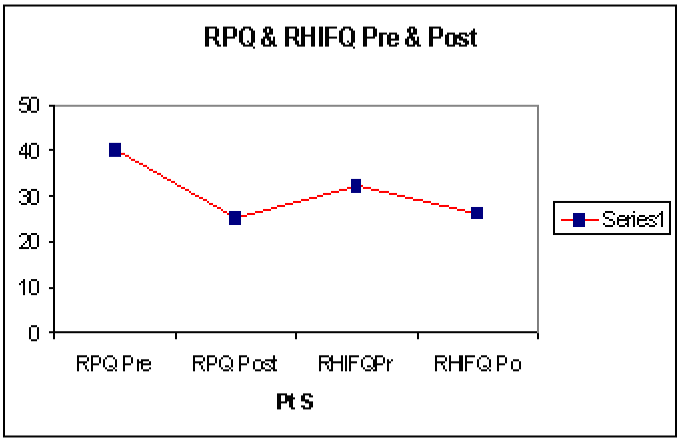
Results:

The post NFT demonstrated marked changes from the pre training in the verbal learning and memory. Tables 1, 2 and 3 are showing the scores on RPQ, RHIFQ, WHO- QOL, verbal and visual learning and memory of the pre- and post training. The patients score

Table 1 shows the scores of Rivermead Post concussion Symptoms (RPQ) & Rivermead Head Injury Follow up Questionnaire (RHFUQ) Pre & Post intervention.

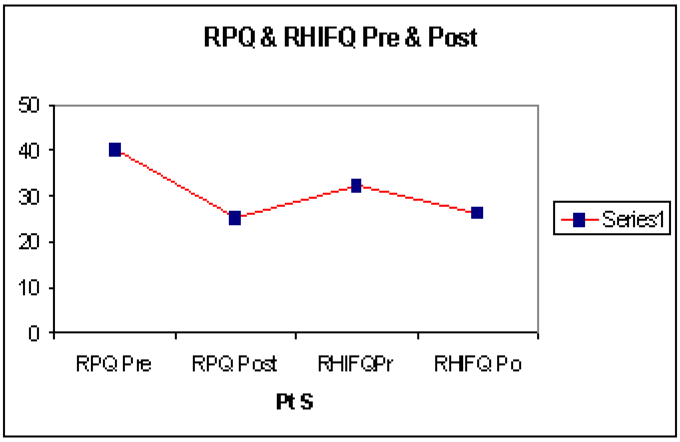
RPQ Pre	RPQ Post	RHIFQ Pre	RHIFQ Post
40	25	32	26

Graph 1 Shows Pre & Post scores of RPQ & RHIFQ



The scores clearly indicate that there was reduction of scores in post concussion symptoms.

Graph 1A Shows the scores of WHO – QOL Pre & Post intervention



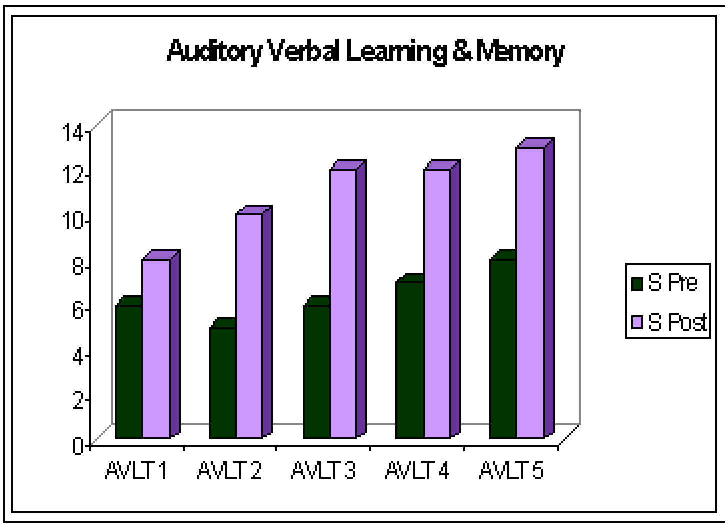
Similar results are shown in quality of life. There were positive results in areas of physical, social, psychological and environmental factors.

Table 2 shows the Percentiles of Auditory Verbal Learning & Memory Pre & Post intervention.

Pt S	Total AVLT		Immediate Recall		Delayed Recall	
	Pre	Post	Pre	Post	Pre	Post
	5	60	5	30	5	75

There was significant improvement for verbal learning and memory which was assessed by AVLT, where as for visual learning and memory which was assessed by CFT had a marginal improvement of scores.

Graph 2 shows the scores Auditory Verbal Learning & Memory Pre & Post intervention across 5 trials.



Graph 3 shows the scores total, immediate and delayed recall in Auditory Verbal Learning & Memory Pre & Post intervention

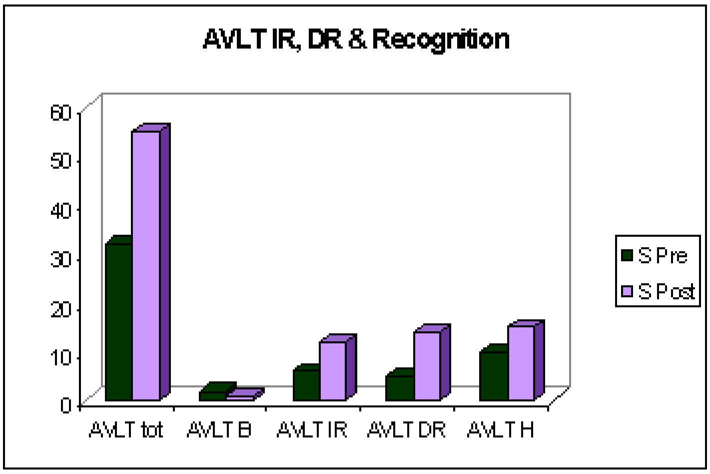
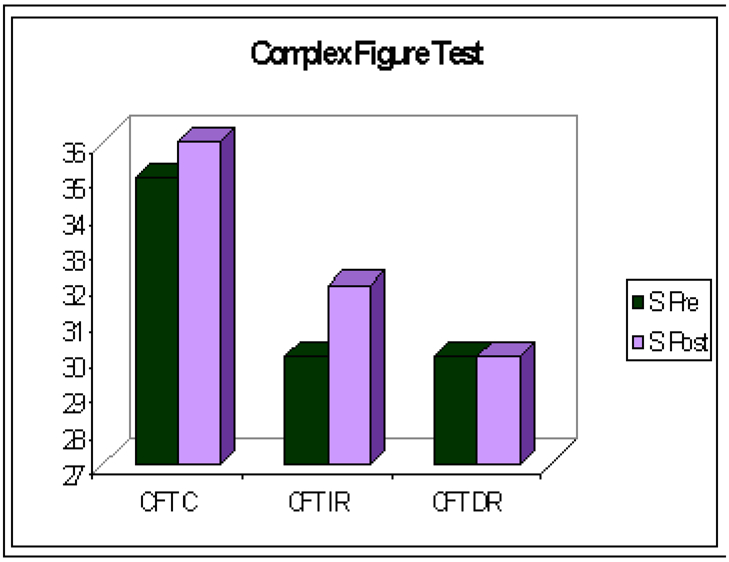


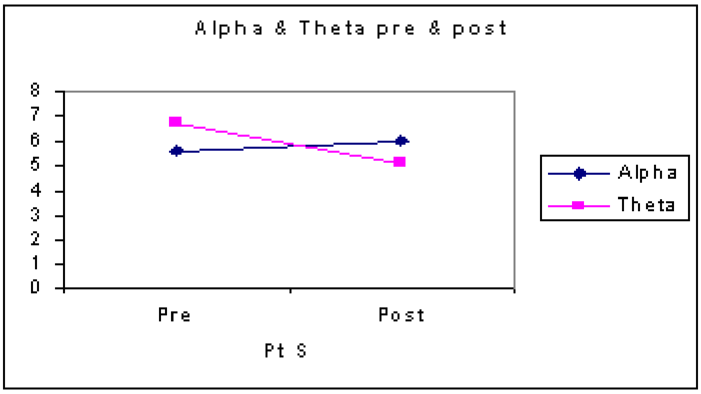
Table 3 shows the Percentiles of Auditory Verbal Learning & Memory Pre & Post intervention

CFT IR Pre	CFT IR Post	CFT DR Pre	CFTDR Post
90	95	90	95

Table 4 shows the scores Complex Figure Test Pre & Post intervention



Graph 5 showing the pre post Alpha & Theta scores



Discussion

The purpose of this study was to examine neurofeedback training in enhancement of verbal and visual memory in TBI. S, a 30 -year-old male who suffered from mild head injury was assessed on measures of handedness, post concussion symptoms, quality of life, verbal and visual memory. The results indicate severe impairment in verbal memory prior to treatment protocol. At the termination of training the patient demonstrated clinical improvements in verbal recall. Pre-and post-intervention scores in Table indicate that S improved in performance on verbal learning and memory and visual learning and memory. Qualitative feedback indicated that S found the training beneficial. At a time when an increasing number of people are concerned with negative effects from relying solely on medication treatments, neurofeedback may offer an additional treatment alternative for many conditions (Hammond, D. C, 2007). Research suggests that theta activity (4–7 Hz) has an influence on the cellular mechanisms of memory through its role in facilitating long-term potentiation (Pavlides, Greenstein, Grudman, & Winson, 1988). The link between recognition memory processes and theta activity is also reported (Burgess & Gruzelier, 1997). Research focusing on alpha (8–12 Hz) show that upper alpha is primarily associated with semantic memory processes. Examination of the interplay between working memory and long-term memory has suggested that theta activity (4–8 Hz) reflects the processes of working memory, whilst upper alpha (9.5–12 Hz) reflects retrieval from long-term memory (Klimesch et al., 1997).

The aim of rehabilitation is to optimize independence while ensuring that environmental support is available to assist for those areas that the individual is unable to achieve independently (Burke et al., 1994). This case study has demonstrated that for S the use of neurofeedback training improved ability to perform day to today tasks and better quality of life. Neurofeedback is an emerging neuroscience-based clinical application. The study has demonstrated the importance of NFT for the memory enhancement to aid to the patient's needs. However there is greater need for further work which is required using group designs to establish training methods. Additional neurofeedback studies with control groups, large numbers of neurotherapy patients, and long-term follow-up are necessary to fully ascertain the effectiveness of this therapy.

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The International Journal of Psychosocial Rehabilitation
Volume 14, Number 1
July 2009– June 2010

Organisational views of the Mental Health Support Worker role and function.

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International Journal of Psychosocial Rehabilitation. Vol 14(1). 29-33

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Abstract

Following on from recent research (Gallaway & Smith, 2005; Pace, 2009) in a further attempt to assist Support Workers forge an identity in mental health service in New Zealand, a thematic analysis of job descriptions was conducted across six services which provide mental health rehabilitation and recovery programmes. Job descriptions were coded for 1. Roles and responsibilities, 2. Skills and knowledge, and 3. Qualification requirements.

Keywords: Mental Health Support Work, Residential and Community Support Services. Organisation, New Zealand.

Introduction

The role of a mental health support worker is not clearly defined and even within their job title 'support worker' there is ambiguity surrounding the role (Gallaway & Smith, 2005). This lack of definition leads to support workers performing numerous tasks and functions outside their job descriptions (Pace, 2009). These deviations can be attributed to a number of factors including the shortage of health staff and increasing demands for services (Baldwin, Roberts, Fitzpatrick, White, & Cowan, 2003).

Recently published research (Pace, 2009) investigated how support workers perceived their role within the mental health sector in order for the group to develop a sense of 'professional' self. The research involved a series of semi-structured interviews to explore how New Zealand Mental Health Support Workers perceived their role. The findings suggested a range of duties, including developing and maintaining therapeutic relationships, working alongside service users, community reintegration and administrative tasks. The discussion which followed suggested further exploration into how health professionals viewed support workers and how best the different disciplines could compliment one another. What was not considered was how mental health and support organisations viewed the role and function of mental health support workers. As a continuation of the line of investigation in order to provide parameters for mental health support workers, the current investigation sought to identify the key duties of support workers as perceived from an organisational/employer perceptive.

Method

Selection criterion used for the current research stated that the agencies provided mental health / psychiatric recovery and rehabilitation services, which employees paraprofessionals in the role of support workers. Six organisations meeting this criterion from the Waikato region in New Zealand agreed to participate in the research project. The sample comprised of four community-based non-government organisations (NGO's), one clinical-based government funded agency, and a Kaupapa Maori-based NGO. Kaupapa Maori services are design to cater for the specific needs of Maori clients.

A thematic analysis (Braun & Clarke, 2006) was conducted for eight Community Mental Health Support Worker job descriptions. Common themes in role, responsibility and function were identified and subsequently divided into three fields: 1. Roles and responsibilities, 2. Skills and Knowledge, and 3. Qualifications. The organisations values and mission statements were collected and compared to the content of the job descriptions to determine the principle focus of the organisation: clinical, or community/whanau-based. Statistical analysis was conducted to determine the relative strength of the Role/Responsibilities, Skills and Knowledge, and Qualifications required across the mental health organisations examined.

Results

The results indicted that the support worker role, from an organisational perceptive, comprises of eight commonly occurring roles, and seven key skills (Table 1). Key responsibilities indicated across service types included; 1. The development and subsequent maintenance of the therapeutic relationship with the identified client group. 2. The ability to meet key performance indicators as set by the agencies. 3. To advocate on behalf of the client group and offer support as required. 4. To be able to work as part of a team, and 5. To adhere to Health and Safety legislation and organisational policy. Supervision was also identified as a requirement of support workers for five of the six organisations. However, the roles and responsibilities required were not consistent across the organisations particularly with reference to support workers collecting client information and reporting accordingly. Likewise for liaising with other professional staff engaged in the client's welfare.

Required knowledge and skill revolved around two key aspects: Communication and Social and Cultural Needs. Each organisation clearly identified the need for support workers to be able to communicate effectively with those individuals in their care, as well as significant others such as family members. Alongside communication skills was the expectation that support workers will maintain a high level of client confidentiality. Secondly, each organisation referred to the need for support workers to have a working knowledge of the Treaty of Waitangi and the ability to demonstrate cultural sensitivity and appropriate safety. Organisational and planning skills were also deemed as a significant skill set.

The largest variation across the organisations related to the required level and type of minimum qualification. Three of the six agencies required the National Certificate in Mental Health (Level 4) as a minimum qualification, with two agencies stating no mental health or health care qualification was needed. The clinical based service required at least a National Diploma in Mental Health (level 6), a relatively new qualification to New Zealand. All agencies required support workers to have both a current drivers licence and first aid certificate.

Table 1. <u>**Results matrix**</u>

		Organisation 1* (Community)	**Organisation 2** (Clinical)	**Organisation 3** (Community)	**Organisation 4** (Community)	**Organisation 5*** (Kaupapa Maori)	**Organisation 6** (Community)	**Average**
Role and Responsibilities	Development Therapeutic Relationships	X	X	X	X	X	X	1
	Meet Key Performance Indicators	X	X	X	X	X	X	1
	Advocacy and Support	X	X	X	X	X	X	1
	Information gathering and reporting	X	X	X	-	-	X	0.66
	Supervision	X	X	X	-	X	X	0.83
	Liaison with clinical staff	X	X	X	-	-	X	0.66
	Teamwork	X	X	X	X	X	X	1
	Health and Safety	X	X	X	X	X	X	1
Skills and Knowledge	Communication and Listening Skills	X	X	X	X	X	X	1
	Planning and Organisational Skills	X	X	X	-	X	X	0.83
	Understanding of Social and Cultural Issues	X	X	X	X	X	X	1
	Analytical and Evaluation Skills	X	X	X	-	-	X	0.66
	Assessment Skills	X	X	X	-	-	X	0.66
	Culturally Sensitive	X	X	X	X	X	X	1
	Client Confidentiality	X	X	X	X	X	X	1
Qualification	National Certificate in Mental Health (Mental Health Support Work)	X	n/a	X	-	-	X	0.66
	National Diploma in Mental Health (Mental Health Support Work)	-	X	-	-	-	-	0.16
	First Aid Certificate	X	X	X	X	X	X	1
	Drivers Licence	X	X	X	X	X	X	1

* Two or more job descriptions reviewed

Discussion

From the information collected we are able to extract and refine the core competencies employers are look for in mental health support workers. Core skills, roles and responsibilities are able to be clearly identified across the service type's suggestions that the following can be viewed as fundamental requirements for Mental Health Support Workers in New Zealand. 1. The ability to develop and maintain therapeutic relationships with their client group. 2. Be able to communicate effectively with their clients. 3. Be able to offer support and advocate on their behalf as required. 4. Be able to conducted themselves in a manner which support confidentiality and cultural sensitivity. 5. Attend supervision as required or stated by the organisation. 6. Is able to work as part of a team and conduct tasks and duties as required including planning and meeting key performance indicators.

Areas which appear less consistent across services types revolved around what can be perceived as clinical-based duties, including gathering, assessing and reporting client-based information and liaising with clinical staff. Consideration of the skills required to carry out these duties lends itself to question the required qualification and level of competence to do so, indicating the boundary between professional and paraprofessional staff. This leads to the consideration of qualification required as indicated by mental health services.

The greatest variation across the sample is seen with regards to the type and level of qualification required, ranging from no required qualification other than a current drivers licence and first aid certificate through to a National Diploma in Mental Health. The National Diploma in Mental Health being a pre-bachelors level qualification. This apparent lack of educational requirement surrounding mental health support work within New Zealand health care and rehabilitation providers is of potential concern, particularly considering the population support workers are working alongside.

Further analysis of the data, comparisons to Pace (2009), and the inclusion of educational/training requirements allows for the development of a clear scope of practice for New Zealand mental health support work. Common occurring themes can be identified through the comparison of organisational job description and the support workers own perception of their roles and duties. Preliminary analysis shows fours commonalities between the findings given within the current paper and Pace (2009): the development and subsequent maintenance of the therapeutic relationships; support and advocacy on behalf of the client; effective communication skills; and the ability to create and maintain trust and confidentiality.

Based on research to date we can start to build an initial conceptualisation of the mental health support worker role, and define its scope of practice. Information shown through organisational support worker job descriptions indicates the clinical limitations of support worker practice suggesting support work to be a pre-clinical profession. Primary roles of support and advocacy as suggested within the job title form the principle function of support work based on the successful development of therapeutic relationships, with a strong emphasis on strengths-based practice and recovery principles. In order to further the development of the support workers function and scope of practice the initial conceptualisation needs to be tested and refined. Investigations of other mental health professionals and service user's perceptions of mental health support worker, would add further vital information. Using these multiple views, the final conceptualisation will hold greater validity, with a higher probability of capturing the essence of the support worker role.

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[1] Kaupapa Maori is the conceptualisation of Maori knowledge

[2] New Zealand's indigenous population

[3] A foundation document in New Zealand identifying the country's bicultural nature.

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The International Journal of Psychosocial Rehabilitation
Volume 14, Number 1
July 2009– June 2010

The EMILIA project: The impact of a lifelong learning intervention on the sense of coherence of mental health service users.

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Abstract

Objectives: The EMILIA project provides formal learning and employment opportunities to mental health service users. This study evaluates this intervention in terms of its effect on participants' sense of coherence (SOC).
Method: This study employed a within subjects design with a measure of SOC and a qualitative assessment at follow-up. A combined analysis was employed to establish a deeper understanding of the quantitative results and to investigate factors, mechanisms and processes of the project associated with SOC and recovery.
Results: Among the 22 participants there was a significant increase in SOC. Qualitative analysis revealed factors, mechanisms and processes linking lifelong learning, recovery and SOC.
Conclusions: The findings suggest that projects that provide lifelong learning and employment opportunities can increase participants' ability to cope, adapt and recovery. The study adds to evidence for funded provision of formal learning and employment opportunities for mental health service users
Conflicts of interest: None.

Key words: sense of coherence, recovery, lifelong learning, social inclusion, empowerment.

Introduction

Context

EMILIA (Empowerment of Mental Illness: Lifelong learning, Integration and Action) is a Framework 6 European Union project, funded at €3.4 million over a four and a half year period. The main aim of the EMILIA project is to facilitate social inclusion and empowerment of its mental health service user (MHSU) participants through specifically designed lifelong learning and employment opportunities.

Sense of Coherence

Aaron Antonovsky's (1923-1994) work formed part of the movement in medicine towards studying the origins of health. His sense of coherence (SOC) theory relates to the adaptive capacity of humans. Antonovsky defined SOC as "a global orientation that expresses the extent to which one has a (A) pervasive, enduring, though dynamic feeling of confidence that stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; (B) the resources are available to one to offset the demands posed by these stimuli; and (C) these demands are challenges worthy of investment and engagement" (Antonovsky, 1987, p. 19). He labelled these components A) coherence, B) manageability, and C) meaningfulness. The development of the meaningfulness component was greatly influenced by the work of Frankl (1978; 1992). SOC can be regarded as a crucial element in the structure of an individual's personality that facilitates the coping and adaption process (Antonovsky, 1979; 1987).

Those who are experiencing mental disorder face constant challenges and setbacks, both small and large, and the success of their recovery, at a biological, psychological and social level, is determined by their ability to cope with, overcome and recover from these challenges and setbacks. This ability depends on, according to Antonovsky's theory, the strength of an individual's SOC which is determined by an individual's general resistance resources (GRRs) and their effective deployment. GRRs can be physical (e.g., a strong physic, strong immune system, genetic strengths), artefactual (e.g. money, food, power), cognitive (e.g., intelligence, education, adaptive strategies for coping), emotional (e.g., emotional intelligence), social (e.g., support from friends and/or family), or macrosocial (e.g., culture and shared belief systems). There has been extensive research in to the SOC concept (e.g. Bengtsson-Tops & Hansson, 2001; Carstens & Spangenberg, 1997; Cederblad & Hansson, 1996; Eklund, Hansson, & Bengtsson-Tops, 2004; Johnson, 2004; Volanen, Lahelma, Silventoinen, & Suominen, 2004; Volanen et al. 2006; Wolff & Ratner, 1999). Feigin & Sapir's (2005, p. 63) literature review found that "the concept of SOC has a broad theoretical base and a growing and impressive body of empirical evidence supporting its utility".

EMILIA, recovery and sense of coherence

Lifelong learning and mental health recovery can be viewed as inseparable interrelated processes (Griffiths & Ryan, 2008). This is because mental disorder brings change to an individual's life and new learning is required to enable that individual to cope and adapt in the recovery process. Lifelong learning and recovery can be involved in a cycles of development and progression (Feinstein & Hammond, 2004). Learning can aid recovery, and the process of recovery can lead to new learning.

The interconnections between these two concepts contribute to the research prediction that exposure to the EMLIA lifelong learning project would increase the ability to cope, adapt and recover (capsulated here as SOC). Eriksson & Lindström (2007) stated that the SOC concept can be applied to the process of learning – that the learning process is facilitated when it is structured, comprehensible and meaningful: "The salutogenic framework facilitates the learning process and simultaneously promotes health" (p. 941). The qualitative analysis aspect of this article aims to investigate factors, mechanisms and processes linking lifelong learning, recovery and SOC in the EMILIA project. It also seeks to understand any changes in SOC from baseline to follow-up.

A review of research literature reveals that there are many factors, mechanisms and processes involved in formal learning that could lead to an increase in SOC. Hammond (2004, p. 551) found that learning can have positive impact "upon psychosocial qualities; self-esteem, self-efficacy, a sense of purpose and hope, competences, and social integration." Research into specific examples of formal learning for those with mental disorder has found that they can bring benefits on a wide variety of measures, for example, improvements in measures of coping skills, stress management, goal setting, quality of life, and well being (Griffiths, 2006).

Formal lifelong learning can contribute to increased comprehensibility, manageability and meaningfulness and hence strengthen SOC (Landsverk & Kane, 1998). A direct positive effect of formal learning on individuals' SOC has been shown by Suominen, Blomberg, Helenius, & Koskenvuo's (1999) study which found that the degree of occupational training was strongly and positively correlated to SOC. SOC can be strengthened by factors such as teaching and reinforcing coping skills, the facilitation of social support and by enabling individuals to identify, access, and mobilize resources that are available to them (Landsverk & Kane, 1998).

EMILIA, as a lifelong learning and employment opportunity project, has the potential to increase the SOC strength of its participants through increases in a sense of hope, meaning, well being and self-esteem (Borg & Kristiansen, 2008) and also through social aspects (Antonovsky, 1979; 1987). Social aspects include interpersonal support from study peers, opportunities to express and validate concerns and questions, and being able to understand that you are not alone in your experience of mental illness (Ascher-Svanum & Whitesel, 1999). It also has the potential to increase SOC through increased empowerment (NIACE, 2004; Frankl, 1992), through the development of new areas of interest (NIACE, 2004), increased purpose in life by defining and setting personal goals (Frankl, 1978; 1992), and increased structure in life (Antonovsky, 1979; 1987). What's more, the service users who help deliver the learning modules can act as role models, allowing an individual service user to see that others can cope with and be successful despite their mental illness and this can have a positive effect on SOC (see Ascher-Svanum & Whitesel, 1999).

The components and practical delivery of the EMILIA learning modules can also had the potential to increase participating individual’s SOC. For example, EMILIA sought to meet participant expectations and adapt to them; it promoted peer to peer support; allowed learners to express and validate their concerns and questions; tried to create a cohesive learning group; employed a format that enabled participant interaction; sought to develop effective learner teacher relationships; employed teachers who believed in the learning potential of their students and who tried to instil hope and belief and be sensitive to the participants learning needs (see Ascher-Svanum & Whitesel, 1999; Emer, McLarney, Goodwin, & Keller, 2002; Hayes & Gantt, 1992; Mather & Atkinson, 2004).

The EMILIA learning intervention developed learning goals that were attainable to help facilitates success (Koplewicz & Liberman, 2003). It did this by allowing participants to complete assessment at Middlesex University levels from zero (below 1st year undergraduate) to level 4 (masters). Furthermore, it sought to provide solutions to everyday concrete practical problems of the participants through content grounded in reality of participant’s existence - so that the modules connected with participant’s lives and goals (Koplewicz & Liberman, 2003).

It is difficult to achieve a load balance (which Antonovsky described as essential in strengthening SOC) in a group that has various types and severity of mental disorder and different levels of educational attainment, ability, and experience. Of crucial importance in respect to the underload/overload balance is the learning support that the EMILIA project provided its participants. There was a high tutor to student ratio and the EMILIA tutors actively sought to identify students requiring additional support, clarification and counselling during the training sessions.

In conclusion the research prediction was that participation in the EMILIA project will cause a significant strengthening in the SOC levels of participants and that qualitative analysis will reveal insights into the factors, mechanisms and processes linking lifelong learning, recovery and SOC.

The intervention

The EMILIA project intervention provided a set of three core learning modules and one additional learning module, a certificate of completion, learning support, the option of academic assessment to obtain Middlesex University credits and opportunities and training for paid employment at Middlesex University (teaching and assessing student mental health nurses). The titles of the core learning modules were ‘Building on Strengths and Personal Development Planning’, ‘Empowering People in Recovery’, and ‘User Leadership and Advocacy’. The additional module was entitled ‘User Research Skills’. All teaching was conducted by MHSUs who were leaders in the mental health community.

Research Methods

Combined qualitative and quantitative analysis

A combined quantitative and qualitative approach was adopted. The employment of a combined qualitative-quantitative approach meets the recognition among many researchers of the need to establish the qualitative grounding of empirical research in order to increase its scientific value (see for example, Henwood & Pidgeon, 1992).

Qualitative analysis

This research utilised a deductive ‘top down’ approach and in doing so it employed theoretical thematic analysis. Thematic analysis is a method for identifying, discovering, analysing and reporting patterns (themes) within data. A seven phase analysis in a recursive process based on the guidelines provided by Braun & Clarke (2006) was employed. The results of this analysis were used to explore the effects of the EMILIA experience in relation to SOC theory.

A priori themes identified

Eight lifelong learning related themes were identified through a literature review before the research study was conducted: learning, employment, social networks, success, failure, mental health issues, goals, and motivation.

Design

The study employed within-subjects pre- and post-test design.

Participants

There were 22 participants, 8 males and 14 females (see table 1). All participants had a current diagnosis of mental disorder, at least three years of using mental health services and did not have ‘real world’ employment (regular paid work of more than 18 hours a week) or a diagnosis of learning disabilities or dementia. Their ages ranged from 28-62 years, with an average age of 46. The number of years of contact with mental health services ranged from 3 to 36 years, with an average of 14 years. All of the participants were living in North London, UK at the time of the intervention.

The majority of the participants (over three quarters) who provided information for the follow-up measures completed the entire set of the core learning modules and over half completed the additional learning module. At the time of follow-up only two of participants had started taking up the paid opportunities offered through the EMILIA project.

Table 1. Participant information

Name (names changed to protect identity)	Mental health disorder diagnosis		Age	Sex	Marital status	Years of contact with mental health services	Country of birth
Alvita	Bipolar disorder		47	F	Single	7	UK
Cathy	Personality disorder + depression + anxiety		46	F	Married	29	UK
Dawoh	Bipolar affective disorder		51	M	Married	11	Sierra Leone
Eric	Schizophrenia		39	M	Single	18	UK

Freya	Clinical depression		41	F	Single	4	UK
Grace	Schizoaffective disorder		41	F	Divorced	16	UK
Hilda	Bipolar affective disorder		37	F	Single	8	UK
Isabel	Bipolar disorder		40	F	Single	12	UK
Jameela	Bipolar disorder		28	F	Single	3	UK
Kay	Schizoaffective disorder		43	F	Single	23	UK
Lokesh	Schizophreniform illness		55	M	Married	12	Pakistan
Maria	Anxiety		48	F	Single	6	UK
Norris	Bipolar affective disorder		35	M	Single	9	UK
Olive	Premenstrual dysphoric disorder (PMDD)		61	F	Married	36	UK
Paulette	Bi-polar affective disorder		48	F	Divorced	29	UK
Rena	PTSD		62	F	Divorced	20	UK
Steven	Bi-polar + clinical depression + anxiety		43	M	Single	18	Canada
Tracy	PTSD		51	F	Married	5	Ireland
Una	Schizophrenia		60	F	Single	15	UK
Vincent	Depression		43	M	Single	3	UK
Warren	Anxiety + depression		48	M	Married	10	Ireland
Zack	Depression + anxiety		53	M	Married	5	UK

Orientation to Life Questionnaire measure

According to Eriksson & Lindström's (2007) systematic review a measure of SOC is applicable in the evaluation of education/training and for use with both healthy people and people with serious illness and disabilities. The SOC measure employed for this research is the Orientation to Life Questionnaire abbreviated version SOC-13 (Antonovsky, 1987). The SOC-13 is measured on a 7-point Likert-type scale where each item has two fixed contradictory responses at opposing ends of the scale.

Feldt, Leskinen, Kinnunen, & Ruoppila (2003) reported that the SOC-13 measure has relatively high structural validity and high stability, Hart, Hittner & Paras (1991) reported high validity, and Antonovsky (1993a), Callahan & Pincus (1995), and Pallant & Lae (2002) all reported a high level of reliability and content, face and construct validity. More specifically, internal consistency testing has shown Cronbach alpha scores ranging from .74 to .95 (Antonovsky 1993, 1996a, Gallagher, Wagenfeld, Baro, & Haepers, 1994; Lundman & Norberg, 1993; Post-White et al. 1996; Volanen et al. 2006). In 1996(b) Antonovsky reported that the scale showed reliability and validity across social classes, different cultures, ethnic groups, ages and both genders.

Qualitative measures

A series of ten open-ended questions were designed for the project and these focused on education, training, employment, unpaid activities and social networks in the preceding 12 months and also on barriers, difficulties, problems, and goals in the present and future. They were labelled as self reports. Five of the participants also completed semi-structured interviews; these people are labelled in the project as ‘key informant service users’. They were selected on the basis that they met a diagnosis of schizophrenia F20 (ICD-10), schizoaffective disorder F25 (ICD-10), or bipolar disorder F30-F31 (ICD-10). The first five participants that met these diagnoses were selected. They were requested to answer 16 questions within a formal interview; these open-ended questions focused on aspects of quality of life, social inclusion, personal goals and the project itself.

Procedure

Ethical approval was obtained from the Institute of Psychiatry and Camden and Islington Mental Health & Social Care Trust. All participants provided informed consent and completed the SOC-13 measure and self reports and the ‘key informant service users’ completed the semi-structured interviews at baseline and at a ten month follow-up. For the ‘key informant service user’ interviews the format employed was a digitally recorded face to face interview. The interview was semi-structured to encourage two-way communication and to enable fuller answers to be provided and clarification of any answers given. For the self reports the participants were given the choice of writing the answers on a piece of paper, typing them into a computer or having their answers digitally recorded in a face to face interview. If an interview approach was chosen then the same procedure was employed as for the ‘key informant service user’ interview.

Results

Quantative results

The impact of the EMILIA intervention on participant’s scores on the abbreviated SOC checklist: SOC-13 was evaluated. Paired sample t-tests revealed that there was a significant increase in SOC-13 scores from baseline (M=29.54, SD=12.23) to a 10 month follow-up point (M=34.82, SD=10.80), t(21)=-2.58, p=.017 (two-tailed). The mean increase in SOC-13 scores was 5.36 with a 95% confidence interval ranging from -9.69 to -1.04. The eta squared statistic (.24) indicated a large effect size.

Table 2. Comparison of SOC means

	General population mean SOC*	Participants baseline mean SOC	Participants follow-up mean SOC

All participants	65.16	29.45	33.07
Male only	65.6	33.25	37.88
Female only	64.8	27.29	34.82

* Population means are from Konttinen, Haukkala, & Uutela (2008). This is a Finnish study - no recent large scale population figures were available from the UK.

Discussion

Quantitative

SOC significantly increased following the EMILIA intervention, matching the research prediction. This indicates that the project may have enhanced participants' ability to manage potentially stressful situations. The results provide evidence for the direct positive effect of formal learning on individuals' SOC shown by Suominen et al. (1999). They are a demonstration of the wider benefits of the intervention because SOC is negatively associated with psychopathology and negative affectivity, and positively associated with well-being, mastery, quality of life, general health, global well being, global psychosocial functioning and self-esteem (Bengtsson-Tops & Hansson, 2001).

Even though the average SOC scores increased significantly the mean scores of the participants were still below the mean scores for a general population (Konttinen et al. 2008). Not one of the participants in the study reached the mean score for a general population. This points to the continuing negative effect that having severe and enduring mental illness can have on SOC strength.

Combined quantitative and qualitative results discussion

Qualitative analysis revealed evidence for each of the a priori categories. The following discussion will use extracts from the qualitative analysis to describe the possible effects of the EMILIA intervention on the SOC strength of participants.

There were extracts relating to factors which have been identified as pathways through which SOC can be strengthened such as teaching and reinforcing coping skills, enabling individuals to identify, access, and mobilize resources available and the facilitation of social interaction and support (Landsverk & Kane, 1998). One participant relayed that:

Rena: "Doing the EMILIA course has given me more confidence in myself and I've realised I can do things even though I struggled."

Having confidence is clearly a valuable resource which enables an individual to mobilise and access other resources. Also within this quote is the mention of persistence despite difficulties, which is a coping strategy often vital to ensure success in life. It is positively linked with confidence, hope and an active optimistic style labelled as 'fighting spirit' (Olason & Rodger, 2001). What's more, fighting spirit is linked to adaptive health behaviour and coping with disease (Pettingale, Morris, Greer, & Haybittle, 1985; Spiegel, 2001), and positively correlated with SOC (Johnson, 2004). Also in terms of psychological resources a participant mentioned an increase in dignity and a sense of importance:

Una: "I think that it [EMILIA training] has given me some dignity in my situation [having mental difficulties] and I absolutely hate receiving benefits and I think that it [EMILIA training] has given someone in my position the dignity to feel a bit important anyway."

A sense of dignity is part of the human need to achieve and maintain various forms of integrity and it is linked to a sense importance, intrinsic worthiness and self esteem; and a sense of self esteem has been found to be positively related to SOC in a population at risk of psychiatric disturbance (Cederbald & Hansson, 1996). Deegan (1988, p. 15) described the mental health recovery as process "to re-establish a new and valued sense of integrity…" Dignity is an internal resource that can be viewed as forming a part of a person's SOC.

Social support is a key GRR in the SOC model. Representing the sentiment of many participants one participant simply stated that: "I have made more friends" (Ben). Another participant expressed the feelings of many when they stated that EMILIA was very useful in terms of: "…drawing on the support and strengths within the community" (Dawoh). The following participant expressed the value to them of the social interaction with other service users that contributed towards more positive feelings and their recovery:

> *Norris: "I consider my participation in the EMILIA project to have gone well and enabled me to meet and interact with people with similar mental health issues in a positive and constructive way, that at the time it was happening made me feel better in myself and better able to face up to life in general."*

The qualitative analysis revealed comments relating to possible enhanced motivation and this is an indication of increased SOC (Antonovsky 1979; 1987). For example, "[Motivation] It developed, it progressed during the training" (Isabel) and "[EMILIA gave me] more motivation to pursue and maintain new social contacts" (Steven). The EMILIA project tried to motivate its participants to pursue and complete the learning programme by connecting the intervention with an individual's personal goals. The following statement is representative of comments expressed in relation to this:

> *Dawoh: "It's all positive stuff. I found that very very useful in terms of focusing and setting my goals and stuff. It helped to firm up my ideas and goals, I found it very useful."*

Many participants developed or found goals related to the mental health issues explored in the training, examples of which is provided through the following extracts:

> *Ben: "I want to do some voluntary training in order to eventually get paid employment in the mental health field."*
> *Isabel: "I may do something in mental health in the future because I am so passionate about it, you see."*

There were many other statements which revealed insights into the development of goals in other areas. Whilst no claim is made that the project installed all of these goals in the participants it did help many participants discover and set their own goals. The EMILIA teachers helped participants to understand how the information taught related to real-life issues and the participant's life goals and roles (Parnell, 1994). This aspect is likely to be part of the contribution towards stronger SOC (see Antonovsky, 1979; 1987). Deegan, (1988, p. 15) stated that mental health recovery partially evolves through "the aspiration to live, work, and love in a community in which one makes a significant contribution". Antonovsky (1979) explained that if individuals are engaged in goal orientated behaviour that encourages success then this can strengthen their SOC.

Connected to the formulation of goals is future orientation. Frankl's (1985, p. 37) work demonstrated the importance of being "oriented toward the future, toward a meaning to be fulfilled… in the future" in order be able to successfully adapt and cope in life. The project may have reduced the negative effect of future-orientated uncertainty caused by the experience of mental disorder (McCann & Clark, 2004). There were a number of extracts describing future orientation, for example: "I started to think: 'what do I need to do in the next year or so?'" (Ben) and: "Yeah. I am more hopeful for the future" (Alvita). One participant provided a direct reference to increased meaningfulness in their lives that had emerged from their experience of the EMILIA project:

> *Alvita: "It [EMILIA] has made me feel that what I went through was not in vane if you see what I mean. Because I went through what I went through and I was lucky enough to come out the other end I can help others and that is where I'm from if you see what I mean…*"

Helping to achieve a realisation that their experience of mental illness had provided participants with strengths, coping skills and expert knowledge of the health system that can help them in their lives, and also that they could use this experience to help others in their recovery, was one of the core themes of the 'Strengths' module and a goal of the project overall.

In addition, the increase in SOC recorded could also be partially due to increases in empowerment as all of the modules were partially aimed at achieving this. Empowering an individual to take greater responsibility for his or her life and health can strengthen an individual's SOC meaningfulness factor (Frankl, 1992). Furthermore, taking action to help to develop agency and empowerment can facilitate recovery (Green, 2004). There were many comments made in relation to empowerment, for example:

> *Steven: "I have been able to begin to break the social restrictions I grew up with, and take ownership of my life, to build healthier boundaries."*
> *Isabel: "And also being honest with myself and being able to ask for help when I need it. Because I never used to do that."*

Increased empowerment may have enhanced self directedness (defined as how responsible, purposeful and resourceful a person is in working to achieve their goals and values) and this is factor has been found to explain variations in SOC (Eklund et al. 2004). Empowering an individual to take greater responsibility for his or her life unlocks resources and helps create hope for the future (Langeland et al. 2007). Representing the feelings of many one participant expressed the following: "Yeah. I am more hopeful for the future" (Alvita).

A sense of hope is vital for recovery and hope is positively related to the SOC component of meaningfulness (Mascaro & Rosen, 2005). Having hope for the future increases meaningfulness and it suggested that having a strong sense of meaning in life provides stronger immunity against hopelessness (Mascaro & Rosen, 2005). "Having some hope is crucial to recovery [from mental disorder]; none of us would strive if we believed it a futile effort" (Leete, 1989, p. 32).

Other aspects of the project that may have contributed to the increased SOC scores include the project's paid employment opportunities (Volanen et al. 2004; Linhorst, 2006). How much contribution that this has made to the group's overall SOC scores is questionable because at the time of the follow-up only two of the participants had been involved in EMILIA generated employment. However, many of the participants gained employment outside of the project, both paid and voluntary, in the 10 months from baseline. For example, four of the participants started to play an active role at a mental health charity, one became an administrator, trustee and legal advisory to a major mental health charity and another successfully helped set up a mental health related social firm. One participant described the benefits that they derived from their new employment:

> *Grace: "…it is all about getting back to the helping aspects and I like that. If I do something good in the day it makes me feel good. It makes me feel better."*

The analysis revealed that exposure to the EMILIA project also lead to the development of existing and new areas of interest for many of its participants; for example, interest in the service user movement, mental health research, and the process of recovery. This is likely to have stimulated minds (increasing comprehensibility), enriched lives (increasing meaningfulness) and lead to feelings of personal satisfaction (which can be important in a feeling of confidence which Antonovsky described as essential for strong SOC levels). It is likely that the development of new areas of interest will have made a contribution to the finding of increased SOC strength.

Many of the extracts in relation to goals, empowerment and areas of interest provide evidence that the EMILIA teachers were able to get participants to see both the specific objectives of learning and the larger meaning as it relates to real-life issues and to participant's actual roles in life. This is what Parnell (1994) describes as essential in effective teaching. It also helps demonstrates that the modules had meaning for those who completed them, that they connected to the participants' needs, problems, preferences, real-world existence, goals and ambitions (Parnell, 1994; Boree, 1991).

Increased levels of employment, working towards goals and new areas of interest are all a part of active engagement in life. There is a dynamic positive relationship between active engagement in life and meaningfulness strength (Carstens & Spangenberg, 1997; Frankl, 1985; Mascaro & Rosen, 2005; Yalom, 1980), and hence SOC.

Increased levels of employment, working towards goals and new areas of interest are also connected to purpose in life. As Mascaro & Rosen (2005) explained if a person finds increased purpose in life then it is likely that this would strengthen aspects of his or her mental health such as hope, well-being and self confidence. An increased sense of purpose helps explain the increased SOC found following the EMILIA intervention as it is linked to meaning in life (Antonovsky, 1979; 1987; Yalom, 1980; Frankl, 1985). The analysis helps confirm Hammond's (2004) literature review which revealed that learning can have a positive impact on an individual's sense of purpose and hope.

The increase in SOC found in this study points to the value of various components and practical delivery of the EMILIA learning modules. The analysis revealed extracts relating to eight different examples of this:

1. EMILIA's efforts to develop effective learner teacher relationships.
2. Allowing learners to express and validate their concerns and questions.
3. Creating a friendly supportive environment.
4. Providing constructive feedback.
5. Providing opportunities for self reflection.
6. The projects efforts to take into account the needs of MHSUs by allowing frequent breaks during the training.
7. The size of the group (approx 10-12 students), which participants generally responded well to.
8. EMILIA group teaching style and its use of variety of methods of delivery of material.

The qualitative analysis also highlighted the positive effects of employing MSHUs as trainers which helps confirm Rummel et al.'s (2005) findings that peer led education for MHSUs is effective. MHSU trainers may have acted as role models, allowing participants to see that others can cope with and be successful despite their mental illness (see Ascher-Svanum & Whitesel, 1999). Young & Ensing's (1999) literature review found that learning through role models and peers with a similar experience can have an especially large positive effect on recovery. The following extract is representative of participant comments:

> *Alvita: "It was good that the teachers were in the same position as us as well [i.e. mental health service users]. That was very good. I think that that helped [us] to open up. I think that if the teachers hadn't experienced mental ill health I think that I would have probably opened up but perhaps some other people may not have done. That was a very good [aspect to the training]. It gave me more of a push to achieve as well."*

Most participants stuck with the project despite the challenges and problems which they faced. Challenge and overcoming challenges is crucial in the development of a strong SOC (Antonovsky 1979, 1987; Wolff & Ratner, 1999). Research suggests that successful coping can lead to the development of further adaptive coping resources (Aldwin, 2000). There is evidence from the qualitative analysis that EMILIA had a positive effect on mental health recovery:

> *Dawoh: "EMILIA had an [positive] impact. It came at a time when I was transitioning and it helped with the transition. The EMILIA strengths training help[ed] with my transitioning and focus on positive goals drawing on community supports."*
> *Norris: "I consider my participation in the EMILIA project to have gone well… that at the time it was happening made me feel better in myself and better able to face up to life in general."*
>
> *Isabel: "Sharing in the group activities, learning things about myself that I didn't know. I thought I had lot things down in my mind about how I was and how I came to be here but I didn't really. And learning different things and challenging myself. Things that I never thought I would do. It is changing and it is a positive change.*"

The recovery associated extracts support the findings of Borg & Kristiansen (2008) that employment, learning, and social interaction are all important in generating a sense of hope, meaning, well being and self-esteem. The extracts also reflect the core recovery processes identified by Green (2004): development, learning, healing and adaption. Lifelong learning and recovery are both part of the process of managing and forging a meaningful, coherent understanding of the experience of mental disorder.

Strengthening SOC can play an important part in the mental health recovery process. Charmaz (1991) describes recovery as involving the development of an understanding of abilities and limitations (comprehensibility factor), making adaptations and day-to-day life management decisions (manageability factor) and setting long term goals that take into account the reality faced in terms of strengths and capabilities (meaningfulness factor).

The results of this study link recovery, social inclusion, lifelong learning and SOC. They add to the findings of Hammond (2004) that learning can have positive impact upon factors that include self-esteem, self-efficacy, a sense of purpose and hope, competences, and social integration. They support the findings of Feinstein & Hammond (2004) that participation in formal learning is an important element in positive cycles of personal and social development and progression.

To foster recovery mental health services need to: "understand how to help people maintain resources, how to facilitate resource development, or how to help people prevent and stop loss spirals" (Green, 2004, p. 305). It follows that there needs to be an understanding of how to generate 'gain spirals', positive spirals in which people gain GRRs and hence strengthen their SOC. This present study's results show that lifelong learning and employment opportunities can help provide gain spirals. The results show that EMILIA type interventions can: "provide opportunities for developing necessary competencies" in the recovery process (Green, 2004 p. 302).

In summary, the results showing an increase in SOC and meaningfulness and extracts related to motivation, goals, empowerment, optimism, hope, self-confidence, success, etc. demonstrate that EMILIA can strengthen MHSUs ability to effectively respond to the needs and demands of their lives. The results also reflect EMILIA participants increased ability to be flexible, to generate of alternative solutions and to be self-directed (Antonovsky, 1979). This study's results indicate that recovery, the strengthening of SOC and lifelong learning can be viewed interlinked processes.

Limitations

There were a number of limitations associated with this study. There was no control group and the sample size was relatively small which limits the quantitative results generalisablity due to a lack of statistical power. Countering this was the use of triangulation: the qualitative results supported the quantitative. The participants can be considered to be reasonably representative of the MHSU population but self selection is likely to mean that the participants tended to be more stable, empowered, and socially included, and have higher self confidence and self efficacy than the average MHSU. The self selective method is also likely to have meant that the sample was skewed to those who had more of an interest in learning and employment than the average MHSU. This means that the participants were more likely to be motivated to do well, provide positive feedback, complete the training and take up employment opportunities than the average MHSU.

Conclusion and implications

This research points to the possibility of developing learning interventions based on SOC theory and salutogenic principles. SOC theory can be regarded as a theoretical framework for designing interventions for MHSUs that seek to enhance recovery, social inclusion and empowerment.

MHSUs, for the most part, live within the community. For them to prosper, take part in and contribute to the community they require access to lifelong learning and employment opportunities. This study's results support the funding and delivery of programmes such as EMILIA which can be considered part of the responsibility of society to create the conditions that promote SOC strength (Antonovsky, 1979, 1987). It can be part of the vision of a salutogenic society.

Projects such as EMILIA enable an opportunity to participate in a normalising activity and thus help to reduce the problem of social marginalisation experienced by so many people with severe and enduring mental health disorders. The findings provide evidence for continued and embedded use of the modules designed for the EMILIA project and for extending EMILIA's underlying principles and practical application to further groups of MHSUs. Project such as EMILIA could be implemented across and beyond Europe.

An EMILIA style opportunity could be an integrated part of mental health services. MHSUs could be offered a choice of different learning modules, and on completion of these they could be offered help in finding a job and supported in any employment found in the competitive market place. To provide embedded EMILIA style opportunities requires adequate funding, cooperation between health services, education providers, etc., and integrated and progressive systems that are sensitive to the individual, their needs and their right to be socially included in terms of learning, employment, etc.

Bergstein, Weizman, & Solomon (2008, p. 288) explained the "necessity of an integrative biopsychosocial treatment approach, which would include interventions aimed at enhancing elements of SOC." Projects such as EMILIA could be part of a comprehensive, coordinated, compassionate, service user-oriented, and service user involved integration of treatment and rehabilitation for MHSUs. This integration should be based on a combination of salutogenic and pathogenic principles (Antonovsky, 1979; 1987).

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The International Journal of Psychosocial Rehabilitation
Volume 14, Number 1
July 2009– June 2010

Experienced Long-Term Benefits Of Group Psychoeducation Among Forensic and Challenging Non-Forensic Patients with Schizophrenia

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Citation:
Aho-Mustonen K, Miettinen R, Räty H & Timonen T. (2009). Experienced Long-Term Benefits Of Group Psychoeducation Among Forensic and Challenging Non-Forensic Patients with Schizophrenia. ***International Journal of Psychosocial Rehabilitation. Vol 14(1).*** 51-63

Abstract

This study examined the long-term benefits experienced in a brief group psychoeducation pilot program among forensic and challenging non-forensic patients with schizophrenia in a forensic hospital setting. Data was obtained by semistructured thematic interviews with six long-term schizophrenia patients who attended an eight-time pilot psychoeducation group four years earlier at the Niuvanniemi Hospital in Kuopio, Finland. Using Antonovsky's Sense of Coherence Theory as a theoretical framework, deductive content analysis was used to analyze the data. Participants experienced benefits from psychoeducation especially in regard to learning new information about the illness and reflecting it to their own situation. Participants also experienced a sense of "shared fate" and noticed that they were not alone in their problems. The aim of providing new strategies for stress management and coping with their illness was not sufficiently fulfilled.

Key words: group psychoeducation, schizophrenia, forensic setting, Sense of Coherence Theory

Introduction

The main principle of psychoeducation is that everyone has the right to receive information about the illness and treatment in order to take more active role in relation to the illness instead of being a passive recipient of care (Cross & Kirby, 2001; Deegan, 1996; McGorry and Edwards, 1997; Mueser et al., 2002). Schizophrenia patients sometimes know very little about their diagnosis despite long-term illness (Hornung et al., 1996). Patients usually want information about their illness, and information should also be provided to those patients who have suffered from schizophrenia a long time (Chien et al., 2001; Wiersma et al. 1998). It has been shown that even quite brief interventions can lead to functional improvements in patients with persistent psychiatric disorders (e.g. Goldman & Quinn, 1988). Chaplin and Timehin (2002) have concluded in their four-year follow-up of a patient education trial concerning tardive dyskinesia that patients can retain a small but significant amount of information several years after an intervention. Psychoeducation also constitutes a foundation for more comprehensive and individualized treatment forms for schizophrenia patients (Bäuml et al., 2006; Mueser et al., 2002). Psychoeducation can be regarded as a specific form of psychotherapy (Bäuml et al., 2006) but as Klimitz (2006) has pointed out, if psychoeducation is seen only within a deficit model of illness and regarded as merely compliance training, people may only learn to accept the illness; from the standpoint of recovery psychoeducation can, then, not be regarded as psychotherapy.

Sibitz et al. (2007) have recently studied the perspectives of non-forensic schizophrenia patients concerning psychoeducation groups and found that participants specifically emphasize the information received, reflections on the new information about the illness and life, exchanging information with other patients, and learning that they are not alone in their situation, as positive experiences in group psychoeducation.

It is recommended that structured psychosocial group interventions also be integrated into the treatment of forensic patients, i.e. offenders with psychiatric illness; psychoeducation is nowadays considered an important component in the comprehensive treatment of these patients (Cross & Kirby, 2001; Duncan et al., 2006). Schizophrenia patients in forensic psychiatry are often hospitalized for many years and the treatment poses many challenges as a result of the severity of the patients' illness, the often persistent symptomalogy, and many related problems, such as aggressive behaviour. Individualized treatment programs with individually adapted components are needed to target the problems of different kind of forensic patients (Hodgins, 2002). Cross and Kirby (2001) have postulated that in forensic settings many patients feel quite hopeless about the prospect of change, and the main purpose of psychoeducation is therefore to combat stigma, and help forensic patients take more responsibility for their own care and thus live more meaningful lives. The effectiveness of patient psychoeducation has only rarely been studied among forensic schizophrenia patients (see Aho-Mustonen et al., 2008; Jennings et al., 2002).

Recovery can be conceptualized as an attitude or life orientation (Resnick et al., 2005), and although forensic patients are often treated differently than other patients and may have limited opportunities for recovery (see Porporinio & Motiuk, 1995), a recovery orientation to psychiatric illnesses has also recently been adopted in the field of forensic psychiatry (see for example Barsky & West, 2007). Maintaining and instilling hope is an essential feature in the recovery process of the people with severe psychiatric illnesses (Byrne et al., 1994; Clayton & Tse, 2003; Coleman, 1999; Czuchta & Johnson, 1998; Kelly & Gamble, 2005; Kirkpatrick et al. 1995; Kylmä et al., 2006; McCann, 2002; Spaniol, 2008). Interventions in psychiatric settings can serve as recovery goals directed towards persons with psychiatric illness, for example, in terms of social and instrumental support, learning and practicing coping strategies to manage their illness and achieving individual goals, and supporting the self-efficacy and self-esteem of the patients (Corrigan, 2003; Mueser et al., 2002; Mueser et al., 2006). For example Anderson et al. (2001) have earlier presented a recovery oriented brief psychoeducational group therapy program for the dually diagnosed patients in inpatient and residential settings.

The present study adopted the view that recovery from psychiatric illness is a process of taking back control and living a satisfying life despite of the illness, whereas wellness can be experienced in spite of symptoms, and at any point of the process of recovery (Anthony, 1993; Deegan, 1996; Hutchinson et al., 2006; Kelly & Gamble, 2005;

Mullen 1986; Spaniol et al., 2002; Spaniol, 2008; Thornton, 2000). Feeling that one has no control over one's illness can cause hopelessness and eventually lead a person to abandon responsibility and active coping strategies; hence, this has a significant role in the efficacy of treatment and rehabilitation, and the long-term course and outcome of schizophrenia (Birchwood et al., 1993; Deegan, 1996; Hoffmann, Kupper & Kunz, 2000). It is important that interventions aimed at recovering from mental illness emphasize a hope-promoting environment, processes and strategies such as acceptance of the illness (Hatfield & Lefley, 1993); access to objective information and education (Kirkpatrick et al. 1995; McCann, 2002); viewing persons with psychiatric illness as people, increasing their dignity, self-esteem, self-efficacy, and self-worth, and promoting meaning, mastery and motivation (Coleman, 1999; Kirkpatrick et al., 1995; McCann, 2002; Snyder et al., 2000). It is also important to validate patients' coping strategies, experiences, and help them with problem-solving, illness management and self-management (Kirkpatrick et al., 1995; Snyder et al., 2000).

Coffey (2006) has pointed out that we still do not know much of the experiences of people who use forensic mental health services. The present study was the pilot phase of larger study of the effectiveness of group psychoeducation among forensic patients and the results have been utilized in designing a larger controlled study about the efficacy of group psychoeducation among these patients. The present study sought to examine experiences concerning benefits of group psychoeducation four years after the intervention from a participant perspective. The study questions were: 1) what kind of recollections do the participants have concerning the psyhoeducation group they had attended four years earlier and 2) what are the experienced long-term benefits of group psychoeducation program that participants express and attach to their group experience.

Theoretical framework

Landsverk and Kane (1998) have postulated that the processes that result in an effective outcome in psychoeducation are still unknown and therefore proposed the Sense of Coherence Theory developed by Antonovsky (1979, 1987) as a potentially useful framework for conceptualizing the effectiveness of comprehensive psychoeducational programs. They have also recommended that psychoeducation programs should be aimed at schizophrenia patients with persistent illness in institutional settings, since in this context intentionally modified changes in SOC may be possible.

According to Antonovsky (1987), individuals move back and forth on a health-disease continuum through life; he calls this orientation the salutogenic model of health. Of major importance in determining a person's relative position on this continuum is his/her Sense of Coherence (SOC). The sense of coherence construct relates to how individuals assess and cope with stressful situations; the sound management of stressors, explained by Antonovsky, is salutogenesis. The three elements of the SOC are: (1) Comprehensibility – which refers to the cognitive controllability of one's environment, that the world is interpreted as rational, understandable, structured, ordered, consistent and predictable; (2) Manageability - the extent to which individuals believe they have personal access to adequate resources for coping with challenges, demands or problems in the environment; (3) Meaningfulness - the subjective feeling that life makes sense and that at least some parts of our life are worthy of commitment and engagement. Meaningfulness can also be considered as an emotional component of the SOC (Antonovsky, 1987).

Landsverk and Kane (1998) have proposed that an effective psychoeducational model encompasses the three main components contributing to SOC, and in this way psychoeducation works to maintain and enhance an individual's sense of coherence. Bengtsson-Tops and Hansson (2001) have also suggested that the salutogenic perspective might contribute to well-being among patients with schizophrenia in many advantageous ways. Therefore Antonovsky's theory was applied as a theoretical tool in the present study for studying the experienced benefits of group psychoeducation for schizophrenia patients.

The compatibility of the SOC theory with psychoeducation and the treatment of schizophrenia concerns the relationships between stress, health and coping. Schizophrenic disorders are nowadays understood on the basis of the vulnerability/stress model of mental disorders, first time proposed by Zubin & Spring (1977). In treating schizophrenia a fundamental aim is to reduce vulnerability to life stress and chronic symptom recurrence, as, for example, Nuechterlein & Dawson (1984), have postulated. Since patients in this study suffered from a difficult, long-term illness with persistent symptoms, the salutogenic orientation also seemed relevant in this context. Thus, the goals of the intervention were not to find a cure for the illness, but to improve the patients' situation and move closer towards positive end of the health-disease continuum. The benefits of psychoeducation have also been postulated to be largely due to non-specific treatment factors (e.g. social support and facilitation and promotion of a shared fate and hope) than due to specific active therapeutic ingredients (Ascher-Svanum & Whitesel, 1999; Bäuml et al., 2006; Sibitz et al., 2007). The SOC theory with its three components is therefore conceptually feasible as it captures both the possible specific and non-specific experienced effective aspects of group psychoeducation.

Method

Participants in the present study were 4 male forensic patients, i.e. mentally disordered offenders who had found to lack criminal responsibility for crimes committed and instead admitted to an involuntary psychiatric treatment, and 2 difficult to treat or dangerous non-forensic long-term patients, who met the *DSM-IV* criteria (American Psychiatric Association, 1994) for a primary diagnosis of schizophrenia, and who had attended the psychoeducation pilot group four years earlier. Also the non-forensic patients in the present study were in involuntary treatment. The pilot intervention was conducted in summer 2001 at the Niuvanniemi Forensic Mental Hospital in Kuopio, Finland. 5 of the 7 patients who initially participated in the intervention were still hospitalized at Niuvanniemi Hospital, and 2 were treated in psychiatric rehabilitation homes. One participant who was no longer hospitalized was not allowed to be interviewed due to his psychiatric state at that time. Participants had severe illness, and at the time of pilot intervention they had been hospitalized in Niuvanniemi Hospital continuously on average over seven years. The mean age of the group was 39.2 years (SD=5.8 years), and the mean GAF, assessed by the doctor in charge of each participants care, was 35.5 (SD=8.5). Clinical characteristics of the group participants at the time of pilot intervention in 2001 are presented in Table 1.

Table 1. ***Clinical characteristics of the group participants at the time of pilot intervention in 2001.***

Participant	Age	Current treatment started	Admission status	Primary diagnosis	Substance abuse
Aaro	45	1986	Forensic patient/ Attempted homicide	Other schizophrenia	Alcohol dependence
Samuel	34	1995	Forensic patient/ Aggravated robbery	Undifferentiated schizophrenia	Multiple drugs dependence
Juha	31	1995	Difficult to treat patient/ Violence	Hebephrenic schizophrenia	No
Leo	44	1998	Difficult to treat patient/ Aggressiveness	Hebephrenic schizophrenia	Multiple drugs dependence
Tatu	38	1988	Forensic patient/ Attempted homicide	Undifferentiated schizophtneia	Alcohol dependence
Ilkka	43	2000	Forensic patient/ Attempted homicide	Undifferentiated schizophrenia	Alcohol dependence

The eight-time psychoeducational program used in pilot study was adapted and modified from Ascher-Svanum and Krause's (1991) "Psychoeducational Groups for patients with Schizophrenia". The group intervention goals sought to provide information about schizophrenia and coping with the illness. Maintaining and instilling hope was emphasized, and sharing one's thoughts and group discussion were encouraged. Topics covered in the group sessions included: orientation, definition of schizophrenia and common symptoms, diagnosis and etiology of schizophrenia, course of illness, outcome of schizophrenia and warning signs of relapse, causes of schizophrenia, stress-vulnerability model and the influence of stress, substance abuse in schizophrenia, antipsychotic medication, treatment of schizophrenia, and legal issues. In addition program contained cognitive-behavioral elements, and participants were, for example, assigned homework between group sessions. A normalizing rationale to explain symptom emergence in schizophrenia was used. The group met once a week and the sessions were 45-60 minutes long. The sessions were conducted by two psychologists (the first and second authors of this article). The intervention group utilized a leader manual.

The follow-up data was obtained by semistructured individual thematic interviews which contained questions about the participants' recollections and experiences of the intervention group four years earlier. The participants were first asked to describe in their own words what they could recall from the group. Then complementary thematic interviews were conducted, where more specific questions about their experiences and memories of the group were asked. Interviews were conducted by the first author during the summer of 2005 and were 45-90 minutes long. All but one was audiotaped. Because one participant refused permission to audiotape the interview, his interview was conducted by making extensive notes.

The interviews were transcribed verbatim. In the analyses deductive content analysis, where the structure of the analysis is based on previous knowledge (see Elo & Kyngäs, 2008), was applied. The three major categories were derived from Antonovsky's Sense of Coherence Theory. The interviews were read and reread by the first author and the expressed benefits were extracted from the text and classified under the three main components of SOC. The categories captured the experiences of the participants very well, as they could be seen to represent a wide range of possible aspects of the intervention (cognitive, behavioral, emotional). Although in previous research comprehensibility has sometimes been seen as a cognitive, manageability as a behavioral, and meaningfulness as a spiritual and emotional component of SOC (see, e.g., Rabin et al., 2005), there is some overlap between categories. For example, in the present study "gaining information" could be categorized to be an experienced benefit in terms of both comprehensibility (more understanding about the illness) or manageability (information as a resource to cope better). Gaining information or understaning were categorized under comprehensibility but if the answer referred more to new skills and behavioral aspects, for example, "learning to search for new information" it was categorized under manageability. Citations from the interviews were used to increase the reliability of the findings (see Coffey, 2006; Elo & Kyngäs, 2008; Graneheim & Lundman, 2004).

Ethical considerations

Ethical approval for the research was obtained from the Research Ethics Committee of Kuopio University Hospital. All participants were told that they were free to withdraw at any time and this would have no bearing on their treatment. Written informed consent was obtained from all participants for both the interview and research, as well as for information to be obtained from their treatment records. To guarantee confidentiality and anonymity, the interviews were coded and no citations that could reveal the identity of the informant were used. The names of the participants were changed. Due to the vulnerability of the group participants and the very sensitive, difficult issues discussed in the interviews, the participants were guaranteed that no person other than the main researcher would have access to the original interviews.

Results

To guarantee confidentiality and anonymity of the participants their names were changed. In text participants are called Aaro, Samuel, Juha, Leo, Tatu and Ilkka.

All the participants could remember the interviewer, who had acted as a group leader in the psychoeducation group. Aaro, Juha and Ilkka had the most specific memories about the group. Samuel and Tatu could summon up memories about the group in mainly general terms and could share their experiences of the group only after focusing the themes and questions in more specific terms. Leo was the only one who could not recall the intervention at all. Participants who remembered the group considered it to have been helpful in their situation.

The benefits of group psychoeducation for each patient were assessed by using the following overall categories derived from Antonovsky's SOC theory with its three main components as categories (Table 2). "Comprehensibility" referred to cognitive aspects of experienced benefits and included themes such as gaining new information about schizophrenia and its treatment and restructuring one's experiences as experienced benefits of the group. "Manageability" included themes involving different resources and skills gained and experienced as helpful in the group, and the emphasis was on behavioral aspects considered to be beneficial. Gaining new skills concerning coping with stress, managing with persistent symptoms, monitoring of early warning signs, seeking help and information, and peer support were included in this category. "Meaningfulness" included motivational and emotional aspects and themes, for example, answers involving hope, identification with appropriate role models, sharing, empowerment, reasonably challenging activities and optimism. When a participant expressed benefits from more than one category, the primary and secondary benefits experienced were determined by making the category with more accounts the primary category.

Table 2. ***Experienced benefits of group psychoeducation in the study group.***

	Comprehensibility	Manageability	Meaningfulness
Aaro	++	-	+
Samuel	++	-	+
Juha	++	-	+
Leo	-	-	-
Tatu	+	-	-
Ilkka	++	+	+

Note. ++ = primary experienced benefit, + = secondary experienced benefit, - = no experienced benefit

Comprehensibility

The results show that the benefits gained from the psychoeducation group came mainly in terms of new information and improved comprehensibility, although participants emphasized that they had forgotten a lot about the group during the four intervening years. The group seemed to work as a new, confidential forum where it became possible for the participants to obtain new information about the illness, ask questions, and get them answered. Aaro, Samuel and Juha mentioned that getting new information was the very best thing in the whole group experience. Respondents also emphasized their belief that this new information appeared to be reliable. The need for information was evident: Aaro, Juha and Tatu felt that before the group they had "some knowledge of schizophrenia", but not enough. Samuel reported that before the group his level of knowledge was "zero".

Human beings have an innate need to understand and have control over their lives. As Aaro stated in the interview "there should be an explanation, a reason for everything". Psychotic illness and symptoms can often be very confusing and even frightening and people have a need to know what is happening to them. Aaro gave an example of fears that troubled him:

> I have had fears that I would become disabled, break a limb or something, or maybe something unexpected happens … I would have to be in a hospital for the rest of my life or suffer some injuries, immobility … Or maybe I would lose my mind for good. These are the things I wonder about.

It was hoped that the information offered would give the patients a chance to reinterpret and reorganize their experiences. It was evident in the interviews that participants were able to reflect on this new information in their personal situations and structure their experiences:

> The information that was given about the symptoms, I think it was all true … I found out things about my own life … and thought about those things again and remembered things I had not remembered before … I was able to dredge up memories from my past. I think that without this group I would have never been able to talk about those things, here or elsewhere either. (Aaro)

> Yes, yes. I found out that there can be almost same diseases, it was something really good to hear … you get a social phenomenon there that helps in healing…I was able to realize that earlier I didn't understand my own thoughts, that was the feeling I got, what it really is to be in psychosis. … I think I realized that even before, but now I am sure ... I need help. (Juha)

Manageability

One of the main aims of the intervention was to provide the participants with new strategies for coping with their illness and ways of handling stress better. In research interviews the participants were asked about the new coping skills and strategies they had learned. Only Ilkka could refer more specifically to the coping strategies he had learned in the group:

> For example, how do you know that you could get so seriously ill, and what the first symptoms and signs are … how you can prevent the worsening of symptoms and when you should go to the doctor or notice that things are getting worse.

The participants were also assigned homework between group sessions to help them practice new skills for coping. In the interviews, all the participants said that they had done at least part of the assignments but, on the other hand, none of them could recall the exact contents of these assignments:

> I guess I scrawled something on the papers, as far as I can recall. (Aaro)

Meaningfulness

One aim of the intervention was encourage sharing in the group, and in the light of the interviews this supportive environment was clearly realized. Group rules were created to support the structure of the group and help build an atmosphere of confidence and sharing for the participants. For example, Samuel emphasized that "keeping one's mouth shut" was the most important rule in the group and admitted that without such a rule he would not have even participated in it. Other patients stressed the importance of confidentiality in the interviews as well:

> It was quite good that you get a chance to (speak)...confidentially, you don't have to be afraid that you hear those things while walking down the corridors. (Aaro)

The participants believed that confidentiality worked well. For example, Aaro was able to share the very sensitive and personal difficult experiences of his illness. Samuel also shared his experiences about psychosis, alcohol abuse, and side-effects of his medication with the group, even though his medical records from that time postulated that he could not discuss his mental problems at all. The atmosphere of mutual understanding and confidentiality were probably of great importance in permitting him to dare to share his feelings and experiences.

Patients with schizophrenia often believe that their condition is very rare and uncommon. A normalizing rationale for explaining the emergence of symptoms in schizophrenia was therefore used in the group. Medical analogies were used to normalize mental illness and show schizophrenia to be a treatable illness. Patients found hope in the notion that they are not alone in their situation:

> I found out that my illness is not that bad after all ... I can speak about it with other patients in my ward ... we won't be here forever ... some day I'll get out of the hospital...They had the same problems, almost, almost the same kinds … I felt that I am not alone after all, that others have the same things. (Aaro)

Sharing one's experiences can be empowering and foster hope, but it can also be emotionally difficult for the patients:

> I have had discussions about my mental illness so many times with doctors and psychologists ... they have asked whether I hear voices ... everything about ... how I felt and how I was doing when I stabbed that guy ... Sometimes it feels very bad ... now I can tell you that when the stabbing happened, I actually heard voices, I really was a sick man. Sometimes I just feel that I don't want to talk about it all the time ... those are such bad memories, really bad. (Ilkka)

Despite this statement, Ilkka noted in the interview at the end of the group that he had a positive feeling about it. Also Aaro and Samuel said that sharing experiences was sometimes difficult and made them feel bad; on the other hand, an opportunity to share and listen to the experiences of others was viewed as interesting, and the information about the universality of schizophrenia and the experiences of others were considered to be a relief. A shared experience of illness or "shared fate" was evident also in following quotation:

> We are all fellow sufferers here. All people have their own things, but we all have got to the hospital ... I think what we have in common is that everyone of us walks the same road, schizophrenia is the reason why we have to stay here. (Tatu)

If patients are offered a sufficient level of challenge, it could imply their sense of meaningfulness (Bengtsson-Tops & Hansson, 2001). Therefore these challenges of learning new things were offered in the group, but always kept in mind the participants' personal abilities and limitations. For people, who appreciate and can easily adopt the school-like structure, the group format with its lessons and written material can be very important. Juha, who had graduated from upper secondary school before he became ill, stated:

> The written material was the number one thing, for me at least.

The meaningfulness of the group experience can also be understood as an active attempt to take part in one's own treatment: For example, Leo, who did not even recall attending the psychoeducational group, brought out in the interview that he has serious memory problems; despite this, he said he wants to take part in all kinds of therapeutic activities in the ward because he wants to "rehabilitate the brain". He explained:

> But my brain just doesn't work … it is ramshackle … it doesn't work at all … this situation comes near to brain damage … and probably is brain damage ... I take part in different interventions just because of interest, and of course I hope that maybe they could help me in some way … interest is the main reason (to participate).

Although Leo could not recall the group, he emphasized that groups are in general important and meaningful to him in terms of active participation in his own treatment and help him maintain hope in his difficult situation.

Discussion

The present study sought to examine the experienced benefits of group psychoeducation four years after the intervention from a participant perspective. The findings suggested that participants had fairly positive experiences, especially in regard to comprehensibility, and were able to take in information about the illness and adapt it to their own situation. The study supported the findings of previous research that psychoeducation has beneficial effects and also long-term psychiatric patients need and want information about their illness, consider that information to be helpful in their situation and give them hope even if they have suffered from schizophrenia for several years (Bäuml et al., 2006; Chien et al., 2001; Griffiths, 2006; Wiersma et al. 1998). Participants were able to reflect on this new information in their personal situations and structure their experiences in such a way that the information became the participant's personal knowledge, in the same way as Kilkku et al. (2003) found in their study. Participants, however, emphasized that they had forgotten a lot about the group during the four intervening years, which is consistent with some previous findings that patients can internalize information, but booster sessions are probably needed to consolidate learning (Macpherson, Jerrom, & Hughes, 1996; Zygmunt et al., 2002).

Most participants in this study also experienced benefits related to meaningfulness and perceived the group as beneficial since it gave them a new sense of hope for the future. The benefits from psychoeducation included a sense of “shared fate” and a chance to note that they are not alone in their problems; all of these issues are related to the individual’s sense of coherence. The opportunity to share and listen to the experiences of others was viewed as interesting, and the information about the universality of schizophrenia, i.e. the notion that they are not alone in their situation, and shared discussions were experienced as important and mitigating. These findings concur with what Kilkku et al. (2003) found studying the meaning of information-giving to patients with first-episode psychosis. Sharing difficult experiences can reduce the feeling of isolation and enhance the sense of belonging, but it can also be emotionally difficult for patients. This issue was illustrated in present study as the group was seen as difficult but helpful.

As Spaniol et al. (2002, 2008) have noted, gaining control over the illness requires having effective coping skills and strategies for dealing with symptoms and stressors. Although one of the main aims of the intervention was also to provide the patients with new strategies for stress management, coping with their illness and ways of handling stress better, this aim was not sufficiently fulfilled. Still, all the participants who remembered attending the group expressed satisfaction with the group experience and considered group psychoeducation to have been helpful in their situation. It has been proved that forensic schizophrenia patients can also develop skills and roles when provided with meaningful rehabilitation (Schindler, 2005). Compared to those studies where the effectiveness in terms of skills has been proved, the group program presented here was of short duration. Clearly longer and more intensive interventions are needed to help these patients adopt new active coping strategies for managing their symptoms and illness.

It has been recommended that we also give patients whose illness affects their cognitive functioning an opportunity to participate in psychosocial interventions (Bengtsson-Tops & Hansson, 2001; Välimäki et al., 1996). In this study, participants’ cognitive deficits and disturbances were taken into account when planning the intervention, and visual aids and other techniques were used. Leo, who suffered from substantial cognitive problems and thought disorder, could still not even recall he had attended the group four years earlier. Massive formal thought disorder has been, in fact, been defined in recent research as one of the few mandatory contraindications to psychoeducation (Bäuml et al., 2006), but the aim of the present study was to also give those patients, who prior to this group very seldom had a chance to participate in any psychosocial group interventions, an opportunity, as it has been postulated that interventions with unconditional support and zero exclusion as principles can provide hope to patients with persistent illness and support individuals’ recoveries (Bäuml et al., 2006; Mueser et al. 2002).

Findings in the present study are largely similar to those of Bäuml and his colleagues (2006), who have found that the specific effective factors of psychoeducation seem to be the illness-related key information and emotional topics, and those obtained from Sibitz et al. (2007), who found that participants especially emphasized the information received, reflecting the new information about illness and life, exchanging information with other patients, and learning that they are not alone in their situation, as positive experiences in group psychoeducation.

Participants expressed very few benefits connected to manageability or the behavioral level of the outcomes. These results are also in line with previous research. It has previously been recognized that even though behavioral changes are not achieved, psychoeducation can still enhance the participants’ quality of life by offering information and a chance to share experiences, and that it creates a useful foundation in the treatment of schizophrenia. Other and more comprehensive long-term treatment efforts and methods need to be applied in addition to brief pychoeducational groups, especially in the treatment of patients with persistent illness (see, e.g., Bäuml et al., 2006; Kilian et al., 2001; Mueser et al., 2002) but psychoeducational programs can serve as a basic therapeutic component even though more individualized treatment are needed to target the specific problems of forensic patients (Hodgins, 2002)

Because of the nature of the participants' illness and the criminal offenses they had committed, durations of inpatient treatment are often very long and most of the participants in the present study were still hospitalized four years after the intervention. It is therefore impossible to estimate whether the intervention shortened the duration of treatment among these participants. Participants still found the intervention helpful and expressed benefits from it even four years after attending the group.

There are limitations concerning the present study. As indicated above, due to ethical reasons the inter-rater reliability of the analysis was not possible to assess, and the issues of credibility and transferability were taken into account by using quotations from the original interview material in the text. The sample in this study, due to the study's pilot nature, was also very small, which may reduce the transferability of the present findings to other contexts.

Conclusions

Comprehensibility, manageability and meaningfulness proved to be useful concepts for understanding the experienced benefits, related both to the active treatment factors and more non-specific effective treatment factors that psychoeducation produces for the participants. The findings of the present study support the idea that long-term psychiatric inpatients gained new information about their illness from the psychoeducation group and considered the information obtained to be helpful in their situation and gave them hope, even though they had suffered from schizophrenia for several years. Our results indicated that for some participants the group acted as a forum where a new understanding of their situation was gained. It would be advantageous that as many patients as possible be given a chance to participate in psychoeducation groups, because psychoeducation groups with a recovery orientation may provide their participants a new sense of hope and empowerment, and for some people even a unique context to discuss the very sensitive issues that would be difficult to discuss in other circumstances. Further research with a larger sample will be conducted based on results obtained from the present study.

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The International Journal of Psychosocial Rehabilitation
Volume 14, Number 1
July 2009– June 2010

‘I have to Get Really Honest with Me’: Findings on Recovery from Mental Illness.

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Citation:
McGrath P. (2009). ‘I have to Get Really Honest with Me’: Findings on Recovery from Mental Illness. **International Journal of Psychosocial Rehabilitation. 14 (1), 65-75**

Introduction

The primary focus in present day psychiatry on symptoms and their neurobiological basis, although of significant, is now increasingly viewed as insufficient (Hoffman et al., 2000). There has been a conceptual shift to view people with serious mental illness as consumers rather than patients, and to appreciate the need to understand their views as essential to the recovery process (Torgalsboen 2001). Psychosocial issues associated with care and recovery are now posited as of core significance (Yanos et al., 2001).

Consequently, increasingly there are calls in the literature for in-depth information on appropriate psychosocial care for individuals coping with a mental illness (Fenton & Schooler, 2000; Heinssen et al., 2000). As one response to these calls, this article presents insights gathered from an Australian qualitative research project with the primary aim of exploring factors that contribute to recovery in mental illness from a consumer’s perspective. Further findings from the study (McGrath et al., 2007), highlight many negative aspects of the drug imperative within the Australian psychiatric system. The present article focuses on the findings associated with consumers’ strategies for recovery that are not dependent on drug therapy.

The Research

The findings are from a sub-project of a larger research project funded by a Central Queensland University Merit Grant that followed up clients from Project 300, a mental health, disability and accommodation package established by Queensland Health in 1995 to assist 300 clients with psychiatric disabilities. The aim of the sub-project was to explore, through qualitative methodology, the factors that contribute to recovery from mental illness. This research involved interviews with individuals chosen because they were articulate about their recovery from mental illness. Qualitative research methodologies have been instrumental in ensuring that the voice of the consumer is heard in a way that contributes to changes in conceptual understanding of recovery in relation to mental health care practice (Mancine et al., 2005; Ramon et al., 2007).

Full ethical clearance was obtained for the research from the university ethics committee. The interviewees were provided with a written project description, informed verbally of their rights as a research participant and signed a written consent form at the point of agreeing to participate.

Methodology

The ten (*n*=10) participants for this arm of the study represent a purposive sample of individuals who were chosen on three criteria: first, they had an official DSM-IV psychiatric diagnosis for a mental illness; second, they were able to demonstrate recovery from that illness; and third, they were articulate and sufficiently motivated to express in words the experience of recovery. Each participant documented their own criteria for recovery which included evidence of remaining symptom-free, of maintaining a support and friendship network, of engaging successfully in meaningful occupation or study and of investing energy as a volunteer into assisting others coping with a mental illness. Participants were enrolled through the snowballing techniques of networking within the mental health consumer network. The intent behind such a purposive sample was to provide an opportunity for articulate mental health consumers to provide leadership in providing insights on recovery for those who were less able to express themselves.

Data was collected through a non-directive Rogerian interview that proceeded at each interviewee's pace, with constant checking by the interviewer that the material dealt with remained within the comfort zone of the participant. The interviews started with the question – "Could you talk about your recovery process, taking as much time as you need and talking about issues that you think are important?" At times the interviewer would ask for clarification of statements and would also make summaries of the progress of ideas to confirm that the interviewer understood the ideas expressed correctly. The interviewer did not impose a structure on the interviews but rather engaged with the flow of the discussion in the direction established by the interviewee. The interviews lasted for approximately two hours. They were audio-recorded and transcribed verbatim. The language texts were then entered into the NUD*IST computer program and analysed thematically. A phenomenological approach was taken to the recording and analysis of the data. The aim of phenomenology is to describe particular phenomena, or the appearance of things, as lived experience (Streubert & Carpenter, 1995). The process is inductive and descriptive and seeks to record experiences from the viewpoint of the individual who had them without imposing a specific theoretical or conceptual framework on the study prior to collecting data (Polit & Hungler, 1995). All of the participants' comments were coded into free nodes ('free nodes' is a technical term for the categories created on the QSR NUD*IST N5 program to store statements that relate to a similar topic), which were then organised under thematic headings. There were 141 free nodes created from the interviews of which the data from the free nodes on factors facilitating recovery are presented here.

Findings

Recovery takes time

A caveat to the following discussion is the idea that even with the right conditions recovery is a protracted process that can take years. As can be seen by the following, the participants emphasised this point:

- *It was a journey [and it] took some time to get it right.*
- *It's taken me years.*
- *You're just learning as you go along…*

Factors initiating recovery

Personal crisis and significant life change as turning points

The participants gave detailed examples of personal crises they experienced and how the experience initiated or gave them the motivation for the recovery process. For reasons of confidentiality the details of these experiences will not be provided, but the point that a crisis can initiate recovery is recorded. As one participant explained:

- *When I went through that stuff, it was something I made a commitment to myself: That I would never, never, ever, ever walk down that road again.*

There were also examples of positive life changes initiating recovery, such as finding a supportive partner and doctor, as one participant explained:

- *It's very hard. It takes a lot of determination, and you need some feeding and fortunately my feeding came from [remarrying] again. My current wife, and my doctor who at that time I was seeing weekly, he was just encouraging. Just straight out simple, non-scientific encouraging. And away I went.*

For others, it was the responsibility of providing the best emotional environment for their children, for example:

- *What every parent wants is to know that they... have done... the best thing by their kids. I want to emphasise that, you know, that's probably one of my driving forces.*

Taking personal responsibility for recovery

A key factor mentioned by all of the participants in relation to initiating and sustaining the recovery process is that of taking personal responsibility for dealing with their illness. As seen by the following, without self-responsibility recovery is seen as unlikely to take place:

- *Look, you should go to all the amount of lectures, and medication and psychiatrists, and courses. Yet till you are ready to accept something in your own mind, then it just won't work.*

Accounts were provided of how previously participants had 'given away' their sense of control to others, for example:

- *... You know until I had my own hand there directing; you know all the other times... I gave my control over to the partner I was with, or the parents... The worst I was at was when I let other people [take control].*

At the core of personal responsibility is the idea of 'owning' the illness, for example:

- *Put it this way, I owned the stuff that was my stuff.*

Self-control incorporated taking advice from others, for example:

- *I made my own decisions about myself, and my life. And she'd give me some guidance at times, and different suggestions, and things like that. But it was always my choice.*

Although discussed in full in findings published elsewhere (McGrath et al., 2007), it is important to note that participants stated that the mental health system does not adequately support this healing direction. For example, one participant who had been involved in the system for over six years with 15 hospital admission before any health professional gave advice about the importance of taking personal responsibility for recovery, stated:

- *But one of the major criteria I feel, and I feel even more strongly now, is that the system has to be encouraging towards that [taking personal control of illness].*

It was seen as possible for a sense of personal responsibility, albeit limited, to even be initiated during a psychotic phase of the illness, for example:

- *I guess when you're deep in a psychosis there's not a lot you can do... But you have to come to a bit of an insight that you're unwell.*

Confronting mental illness

At the core of the process of taking self-responsibility is that of confronting and accepting the fact of one's mental illness, as one participant explained:

- *And being a real to the fact that it exists... and finding a way to think of it differently.*

Fear is an emotion that can block such a process, as one participant expressed:

- *... Sheer fear of it... I guess it's something that you've got to face and accept. And you know, I think... the reason I was able to do it, was because I wasn't afraid of losing anything.*

It was noted that the act of confronting the illness helps to control it, for example:

- *... If you're going through something, handle it. Sit down if you have to. Handle it, and it goes away.*

Self awareness and insight

Participants indicated that self-awareness and insight are essential in the process of confronting the illness in order to initiate and sustain recovery.

- *... And it's using that word… which is quite vital within recovery: 'insight'.*

As one participant explained, honesty with the self is a key aspect of insight:

- *And what I have to do is I have to get really honest with me.*

The process is active and requires ongoing focus and attention, as the following example of mood control indicates:

- *I've been told... that I have a quite an insight into my moods. I don't let it get out of hand. I could bring it back down. I think I'm very aware of my mind.*

Accepting the limitation imposed by the illness is also seen as a part of insight, for example:

- *I'm not over-confident. I don't want to be that. But I'm… more understanding than ever before that I still have to be mindful that there is… an inherent weakness. But it's not a handicap.*

An important point made by the participants is that insight is not just restricted to the illness but must embrace an exploration of the whole person. As one participant explained:

- *So often I did a lot of my own logical thinking around, or rational thinking around some of the experiences I'd get on a daily basis... So I guess the thing that is going to help me along the way is working on myself, my human self. "Okay, that's just part of my illness."*

Self-acceptance and self-forgiveness – getting over the mental illness label

Self-forgiveness is an important part of accepting the limitations of the illness, for example:

- *You look at some actions and behaviours that you do when you're ill, and they just don't fit into your self perception. But that's hard to accept. And that's where, if people want to get better, they have to… cut themselves some slack, and then forgive themselves for not acting the way they wish they'd acted all the time.*

Along with self-forgiveness, there needs to be a sense of self-acceptance, for example:

- *And I used to lie a lot, about who I was, and because I... didn't feel like I was up to par with everyone else. And now it's like, 'Here I am, if you don't like me, that's fine'.*

An important part of this process is the act of letting go of the illness label. Participants talked about how prior to recovery they had related to others through their 'illness label' but had to let go and embrace a sense of self-respect, for example:

- *And I really… wanted to be me…I didn't want to be known as 'the poor little schizophrenic; be nice to her because she's ill'.*

As another participant explained, it is the act of redefining the self:

- *... Recovery to me is about understanding, and getting familiar the sense of self that I... had given away to somebody else to define, so redefining that for myself.*

Obtaining useful information

Information on all aspects of the mental illness was noted to be of considerable assistance for the recovery process, as one participant expressed:

- *... Helpful information, I'm really loving it... there are concepts that are really helpful, and there are others that are really useless.*

Information about how other 'consumers' deal with recovery was seen as particularly helpful, for example:

- *I do think another thing is that sharing information between consumers or advocates does help. Because I think that information helps you. Yes, and it's not something any professional would ever teach you.*

Many of the participants indicated that they actively read a wide range of books to seek out the information they needed, for example:

- *I read a lot. I read stuff on the internet. I've got a folder full of stuff that I read over and over again, trying to find some similarity to what I experience.*

Reading provided insights on mental illness, strategies for coping, hope and inspiration from the stories of others going through similar experiences.

People support – a safety net

The support of others was noted as vital to recovery, but a caveat is that it is important to be selective about the people to include in the support circle, as one participant explained:

- *But I actually found out that it's actually better to have many people in your life, [more] than just one in particular, but also be cautious and careful about who you have in your life.*

In particular, it was seen as important to be cautious about sharing the diagnosis with others, for example:

- *I chose to disclose my diagnosis to about half a dozen people, the range of people I felt safe with.*

Strategies found successful for moving forward

The participants discussed a wide range of strategies they found successful in assisting with their recovery. Focusing on aspects of their experience that they could control was one such strategy, as one participant explained:

- *I guess I break it down to things that you have control over, and things that you don't.*

The strategy associated with taking control is to view obstacles with an openness of what to learn from the experience, for example:

- *... It's not seen as obstacles, but it is: 'Now what can I learn from this…'*

An important part of the focus on control is goal setting, as one participant explained:

- *I started to set goals. I started to set goals of things I wanted to do.*

Another strategy is to not dwell on negative thoughts or problems as this will re-enforce an inward focus, but rather to look outside the self:

- *And try not to dwell - if you find out you've got problems or anything, have a look around you. Don't dwell on what it is. Dwelling on your problems, some people might shut off, become reclusive, sit on a lounge all day smoking. If you dwell on negative thoughts, or… irrational thinking, then it's going to consume you.*

Engaging in activities that affirm the person's strength assists with a positive focus, for example:

- *I used to swim a lot, and I was a fairly good swimmer. And that was another space, that's kind of where I knew I was okay. Because I had to have something I could work with, something I could do, something I could change… If you're just flat with schizophrenia… it's kind of like almost a death sentence, you know?*

This may include any diversional activity, such as learning a new skill, for example:

- *Diversional [activities], taking my mind off my problems, onto more positive stuff. Like learning new skills, like playing tennis, or planning.*

For some, their employment or studies helped affirm their positive sense of self and provided diversional activities.

Where possible, the participants found it important to keep in touch with positive feelings about the future, as one participant explained:

- *... I'll lay down here when I'm going through a hard time. I know that things are going to get better, and I'm going to have good times again. I had this sense that I'd get it right again.*

Finding a meaningful perspective can re-enforce the positive, for example:

- *... I think the only thing I know... is that some of the people in my life that have helped me unpack it in ways that help me create meaning.*

Looking back at the progress made also helps to affirm the positive, for example:

- *It's wonderful to be able to value how far you're coming.*

Indeed, one participant found that to write their life story helped to put things in perspective:

- *Writing my story probably did it for me.*

Humour

Humour was mentioned as a key ingredient in the recovery process for a variety of reasons including being a 'safe way' of talking about difficult issues, a medium for feeling good and a way of making aspects mental illness accessible to others.

Recovery reinforces recovery

Participants spoke of the positive perspective that the recovery experience gave them and how they felt nourished by their recovery journey, as one participant explained:

- *What it's taught me now, is that I don't feel that way anymore. And I love that. It's a complete new experience. I don't believe you ever gain back what you had. I think you just grow into something different. And better.*

It was noted that the positive aspect of the journey of recovery is not widely recognised, for example:

- *The richness of the journey - people don't go into that. You don't see people going, 'Oh God, I wish I hadn't gone through that'. I think I've been very much blessed.*

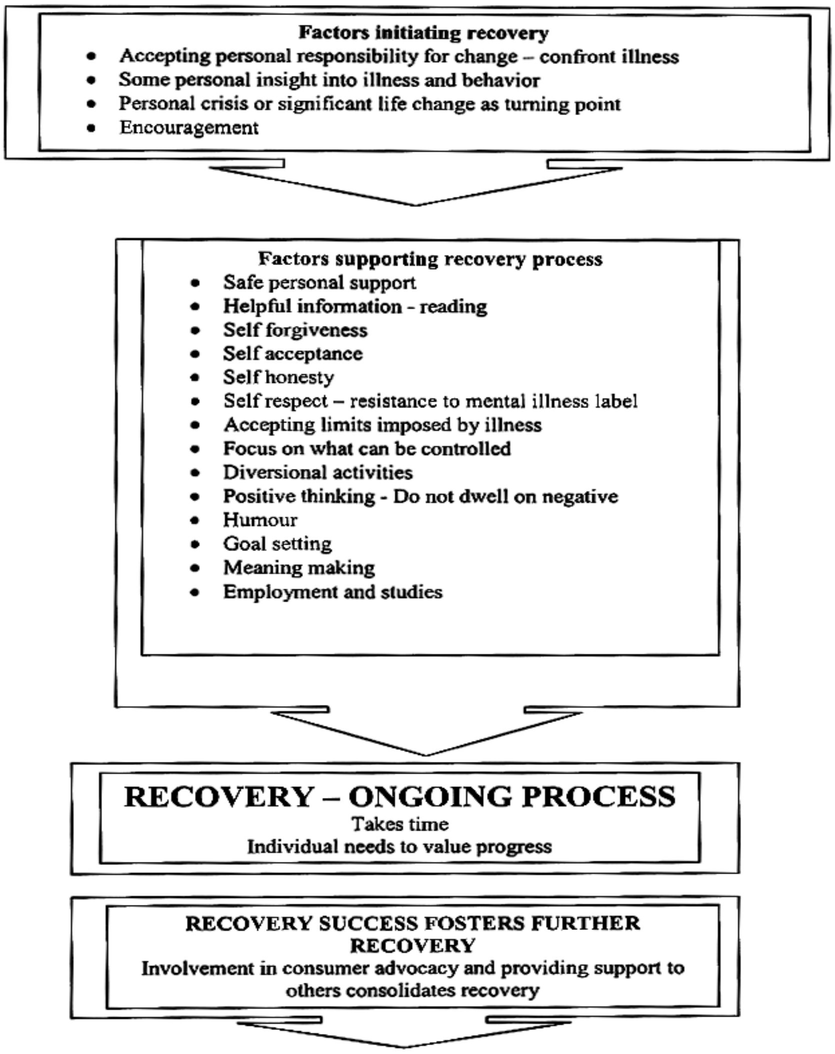
Most of the participants used the insights from their own recovery journey in their advocacy work in mental health. This advocacy work was seen as further strengthening the recovery process, for example:

- *Advocacy has given me a lot of satisfaction. It's wonderful to be able to value how far you're coming. You don't realise that till you see somebody who is just [been diagnosed] and all of a sudden you realise what a hole that they're in, and you remember how hard it was. Yeah... I tend like to think of it as turning your weakness into a strength.*

Discussion

As outlined in Figure 1, the findings presented in this paper focus on the generic factors that participants perceived as facilitating their recovery process. This discussion needs to be set in the context of the notion that the process is protracted and can take many years.

Figure 1: Overview of Findings



The findings indicate that the process of recovery can be initiated by either a personal crisis or a significant positive life change such as finding a life partner or having children.

Taking responsibility for the process of recovery by ‘owning’ the illness is seen as essential for recovery. However, further published findings from the study (McGrath et al., 2007) indicate that this can be difficult in a mental health system that does not adequately support this healing direction. Part of the process of ownership is the act of confronting and accepting the fact of the mental illness, a process that can be blocked by the emotion of fear. Young and Ensing (1999) refers to this as ‘stuckness’ and the challenge in relation to recovery is to overcome ‘stuckness’ through self-empowerment.

The findings from the present study indicate that self awareness, insights and self-honesty are essential attributes initiating and sustaining the recovery process. Importantly, the findings indicate that recovery is seen to be an active process that requires focus and attention. A case study published from the study (McGrath & Jarrett, 2004) outlines in detail the focus and attention required for a therapeutic alliance to assist recovery. As Ridgway (2001) emphasises, recovery is a process of active coping rather than passive adjustment, in which the individual needs to move away from withdrawal in the disempowered role of psychiatric patient to engage actively with life. The present findings indicate that accepting the limits imposed by the illness and focusing on the strength of the whole person rather than just the illness are important dimensions of this process. In the literature this is referred to as the 'strengths perspective' where the focus is on the person's capabilities rather than on a limited illness model (Ramon et al., 2007; Rapp, 1998; Saleeby, 1992). The present findings indicate that this requires a degree of self-acceptance and self-forgiveness. The point is to focus on the whole person and re-define the self by moving beyond the mental illness label. Davidson (2003) refers to this process as living outside the illness and resonates with Ramon and associates (2007) concept of 'self-agency' which is increasingly being recognised as a key element in recovery.

Obtaining useful information on mental illness, and in particular on how other individuals deal with recovery, is noted as an important factor contributing to recovery. Hence, reading widely is valued as it provides insights on mental illness, strategies for coping, hope and inspiration.

The support of significant others is essential to recovery. The importance of connection and belonging are documented elsewhere (Laliberte-Rudman et al., 2000). However, the findings also indicate that a sense of safety and acceptance is essential so it is important for individuals seeking recovery to be selective about people included in the support circle and cautious about sharing information about their diagnosis and personal story.

The findings point to a number of successful strategies that can be used in the recovery process such as focusing on aspects of the experience that can be controlled; viewing obstacles with an openness; goal setting; not dwelling on negative thoughts; engaging in self-affirming and diversional activities; maintaining positive towards the future; seeking a meaningful perspective; and looking back on progress achieved. All processes are made easier by the use of humour. Making choice, maintaining control and goal setting are all factors affirmed in the literature (Dhillon and Dollieslager, 2000; Laliberte-Rudman et al., 2000). Willpower, as Torgalsboen (2001) demonstrates, is a potent factor contributing to recovery. The reverse has also been documented, with poor self-concepts, low expectations and external loci of control negatively influencing the individuals coping strategies and leading to hopelessness and chronicity (Hoffmann et al., 2000).

The positives gained from recovery are seen to further re-enforce the continuing process of recovery. The insights gained enable individuals in recovery to engage in mental health consumer advocacy, a process described as satisfying that provides further nourishment for the individual. A positive outcome of the recovery journey is reported to be a sense of evolving to a new person which includes feelings of achievement and appreciation. The work of Deegan (1996) affirms this idea – her writings describe recovery as a transformative process in which a new sense of self emerges.

Conclusion

The hope and expectation in sharing the insights from a group of individuals who have found successful strategies for recovery is that it will affirm the way forward and provide inspiration for others on a similar journey. As Hoffman and associates (2000) demonstrate, it is so important for recovery to maintain a positive approach and not give up. Increasingly, this message is being documented in the literature as we move into an era where consumers are showing the way forward to an exciting new world where recovery is not just a word but a very real possibility.

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The International Journal of Psychosocial Rehabilitation
Volume 14, Number 1
July 2009– June 2010

The International Journal of Psychosocial Rehabilitation

The effects of a cognitive training program on trained and untrained cognitive functions of non demented elderly and Alzheimer's patients.

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Citation:
Tsantali E, Tsolaki M, & Economides D. (2009). The effects of a cognitive training program on trained and untrained cognitive functions of non demented elderly and Alzheimer's patients. **International Journal of Psychosocial Rehabilitation. 14 (1), 77-98**

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Acknowledgement to Professor A. Efklides and Professor G. Kiosseoglou (Cognitive and Ex-perimental Section of School of Psychology, Aristotle University of Thessaloniki, Greece) for their useful suggestion and remarks for the design and the procedure of the study.

Abstract

Cognitive training (CT) prevents or slows the progression of dementia though there are many cases that CT improves cognitive functions especially in the early first stages of the disease through practicing tasks. The aim of our study was to improve naming deficits of Alzheimer's disease (AD) patients and to maintain this improvement for a long period through a training program based on dual cognitive support and deep learning. Our final sample comprised of 4 groups; eleven mild AD patients and 10 non demented elderly as experimental groups and 11 AD patients and 10 non demented elderly as control groups. The training program lasted about 4 months with 3 hours individual sessions per week and home exercises for the rest of the weekdays. Our results indicate that mild AD patients improve their naming abilities applying trained memory strategies, they maintain this improvement for a long period (at least 11 months) and transfer it to other indirectly trained cognitive functions and abilities, such as episodic memory, attention, verbal fluency and semantic association.
Key words: Alzheimer Disease, Cognitive Intervention, cognitive training, aging, naming disorders.

Introduction

Dementia of Alzheimer's type (AD) has been known to cause cognitive and especially episodic and working memory deficits since the first stages of the disease (Brandt & Rich, 1998). Memory difficulties are also present in cognitively non demented elderly people but they are not so serious as the elder people are still functional and communicative (Welsh, Butters, Hughes, Mohs, & Heyman, 1992). There are also naming deficits in AD patients indicated a semantic memory disorganization and/or an inability to access the lexical labels of the items (Hodges, Salmon, & Butters, 1992; Whatmough, Chertkow, Murtha, Templeman, Babins, & Kelner, 2003). The above deficits are accompanied progressively by functional disabilities (Morris, 1996).

As AD is a degenerative type of dementia there is a debate about the usefulness of cognitive support for the disease management . Most of the early rehabilitation studies used cognitive support achieved short-term effects after the training program (Abrahams & Camp, 1993; Bäckman & Herlitz, 1990). For this reason many researchers talked about the inefficiency of cognitive support (Small, Rabins, Barry, Buckholtz, DeKosky, Ferris, Finkel, et al., 1997), as there were mainly methodological problems. Specifically, the first studies did not include mild AD patients (Bäckman et al., 1990), they used various kinds of techniques to enhance memory performance such as organizational instructions, verbal mediators, more time for recall, or rich stimuli inputs. Among them there were tasks with internal organization and cohesion, self-generation activity or cognitive support only for encoding or for recall processing (Morris, 1996). Their impacts were insufficient, as their main goal was not the real problem in AD which is the encoding and learning of new information. For all the previous reasons the results were short lived and restricted to the training tasks (Morris, 1996).

However, in recent years there have been many studies that achieved satisfactory or life long results using cognitive support (Abrahams et al.,1993; Bäckman, 1992, 1996; Bourgeois, 1990, 1992; Camp, Foss, O' Hanlon, & Stevens, 1996; Camp, Judge, Bye, Fox, Bowden, Bell, Valencic, & Mattern, 1997; Camp, & Stevens, 1990; Clare, 1999; Clare, Wilson, Carter, Gosses, Breen & Hodges, 2000; Loewenstein, Acevedo, Czaja & Duara, 2004; Quayhagen, Quayhagen, Corbeil, Roth, & Rodgers, 1995; Screiber, Schweizer, Lutz, Kalveram, & Jancke,1999; Talassi, Guerreschi, Feriani, Fedi, Bianchetti, & Trabucchi, 2007; Tarraga, Boada, Modinos, Espinosa, Diego, Morera, Guitart, et al., 2006; Tsantali, & Tsolaki, 2007; Woods, 1996a, 1996b). The enthusiasm was so great that there were studies suggested that cognitive intervention (CI) could even reverse the progress of AD. The general conclusion from the recent studies was that mild AD patients could learn new information and maintain it for a considerable time and that CI should be designed for specific type of memory problems, should not produce memory load to the patients, and provide the appropriate cues for both encoding and recall processes (Bäckman, 1992; Woods,1996).

A meta analysis study of cognitive training programs in Alzheimer's disease indicates medium effect sizes for learning, memory, executive functioning, activities of daily living, general cognitive problems, though small effects in visual learning and motor speed (Sitzer, Twamley, & Jeste, 2006). However, there is still the problem that patients do not transfer strategies and skills they learn to everyday life which is among the criteria for the success of the cognitive intervention programs.

The aims of the study

The aim of our study was to use a dual cognitive support training program to mild AD patients in order 1) to reduce naming disorders in the first stages of the disease for a considerable time, 2) to study the generalization of the training effects on untrained lexical items of the trained categories and 3) to investigate the transfer effects on non trained abilities. Dual cognitive support involves the provision of cues and the enhancement of the organization of the to-be-remembered information at both encoding and retrieval of the information (Mimura & Komatsu, 2007).

Method

Assessment of AD

The diagnosis of AD was based on clinical criteria, medical history, biological, physical, neuropsy-chological and neuroimaging assessment. The clinical assessment was ascertained by the NINCDS-ADRDA (McKhann, Drachman, Folstein, Katzman, Price, & Stadlan, 1984) and DSM- IV (American Psychiatric Association,1994) criteria. We also administered the Greek edition of Mini Mental State Examination (Folstein, Folstein, & McHugh, 1975; Fountoulakis, Tsolaki, Chantzi, & Kazis, 2000), CAMDEX (Roth, Huppert, Tym, & Mountjoy, 1988) and the Clinical Dementia Rating (CDR) (Hughes, Berg, Danziger, Cohen, & Martin, 1982) scales in order to estimate the general level of cognitive state and the severity of AD. The Hachinski Scale (Hachinski, Iliff, Zihkla, duBoulay, McAllister, Marshall, Russell, & Symon, 1975) and the Geriatric Depression Scale (GDS) (Sheikh & Yesavage, 1986; Fountoulakis, Tsolaki, Iacovides, Yesavage , O' Hara, Kazis, & Ierodiaconou, 1999) were administered for the assessment of vascular dementia and depression respectively. The diagnosis was posed by a disciplinary scientific team. Memory and attention disorders were assessed through an extended neuropsychological battery included the Pyramids & Palm Trees (Howard & Patterson, 1992), the Rivermead Behavioural Memory Test (Wilson, Clare, Baddeley, Cockburn, Watson, & Tate, 1998) and the Wisconsin Card Sorting Test (Heaton, Chelune, Talley, Kay, & Curtis,1981). Language deficits were measured by the Greek edition of the Boston Naming Test (Kaplan, Goodlass, Weintraub, & Segal, 1983; Tsantali, Lekka, Tsolaki, Kazi, & Kazis, 2003), subtests of the Psycholinguistic Assessment of Language Processing in Aphasia – PALPA (50, 51, 56, 58, 59) (Kay, Lesser, & Coltheart, 1992; Tsantali, Tsolaki, & Pita, 2003) and subtests of the Greek edition of the Boston Diagnostic Aphasia Examination (BDAE) (Narrative Writing, Reading Comprehension of sentences and paragraphs, Comprehension of Comprehension of Oral spelling, Verbal Fluency-Animals) (Goodglass & Kaplan, 1983;Tsantali, Tsolaki, Efklides, Kiosseoglou, & Pita, 2001).

Participants

The final sample of 42 participants arose from a bigger sample of 90 outpatients and elderly volunteers through the rigorous application of the following criteria: 1) the stage of Alzheimer's disease (mild, CDR=1), 2) the similar age and educational level, 3) the similar cognitive and naming profile, 4) the willingness and the consensus of engaging in a rehabilitation program, 5) the duration and the type of pharmacological intervention (inhibitors of cholinesterase). Then the 42 recruited participants randomized in four groups according to their cognitive state (demented-non demented). There were 2 control and 2 experimental groups. Specifically, the experimental groups consisted of 11 mild AD patients and 10 non demented elderly participated in the training program. The control groups included 11 and 10 participants respectively. The research was single-blind and the final sample was matched in age and education $F(1,41) = 2.27$, $p > .05$, $F(1, 41) = 1.0$, $p > .05$, respectively.

All participants came from the city of Thessaloniki in Greece and from the nearby rural areas. The patients recruited from the 3rd University Department of Neurology of 'G. Papanikolaou' hospital in Thessaloniki in Greece. Though the non demented elderly recruited from the Centers of Open Support of Elderly in Thessaloniki and the Geriatric Unit of Hippokration hospital in Thessaloniki. All participants were native Greek speakers, with no auditory or visual self-reported problems. They could read and recognize the visual items of the tasks and none of them was institutionalized or had alcoholic or drug abuse history. The patients also took inhibitors of cholinesterase for about 4-6 months according to their medical history before the beginning of the program. The demographic characteristics of the participants are shown in Table 1. The participants and their caregivers were informed about the details of the procedure and gave their oral consensus for the testing and intervention program without earning money.

Table 1. Demographic characteristics of the sample

DISORDER	CONDITION	N	AGE		EDUCATION		MMSE	
			MEAN	SD	MEAN	SD	MEAN	SD
ALZHEIMER	EXPERIMENTAL	11	72.0	6.8	10	4.1	22.4	1.8
	CONTROL	11	75.7	5.4	8.3	4.5	23.5	1.5
NON DEMENTED	EXPERIMENTAL	10	72.4	5.1	7.4	3.9	27.2	1.6
	CONTROL	10	70.2	4.2	8.4	4.0	27.6	1.3
TOTAL		42	72.6	5.3	8.5	4.1	25.2	1.6

The stages of the study

The first stage of our study included the baseline clinical, neuropsychological (table 2 and table 3), laboratory and neuroimaging assessment. It lasted 4 sessions and conducted by an expert team ignored the purpose of the study. During the second stage the participants were given a naming task with colorful real objects pictures of five categories (food, tool, fruit, vegetable, animal)(200 items). The items ranged in familiarity from very familiar, moderately familiar to less familiar and according to their accessibility, easy, moderately difficult and difficult considering the Greek reality. The third stage included the application of the 4 month cognitive training program, the fourth stage included the 3 month follow up naming assessment and finally, the fifth stage the 6 month follow up cognitive, language and naming assessment.

Design-Procedure of the cognitive training program.

During the first phase of the training program the examiner recorded the non named items by the participant without giving any cues. In the second phase, the experimental groups (AD and non demented) were practiced individually on memory strategies of remembering the faded or the ‘don’t know’ lexical labels emphasizing in the semantic coding and recall of the specific characteristics of the objects. The aim was to help the participants to learn how to activate and reorganize the intact memory information that pertained to objects of the pictures or to learn new information about the failed naming items in order to differentiate them from similar ones. According to the literature teaching of memory strategies on how to keep in memory the association between the meaning and the lexical labels of the items to be named would support the naming procedure. Memory strategies facilitated the reorganiza-tion of the semantic categories or the relearning of the meaning, the function and the lexical label of the fading items would help patients to associate the relearned information with their lexical labels of the items (Bushke,1984; Diesfeldt,1984; Martin, Brouwers, Cox, & Fedio, 1985a; Martin, & Fedio, 1983). Each naming confrontation picture depicted 4 items from the same superordinate category. During the third phase the participant was practiced until errorless learning was achieved (i.e., naming correctly about 90% of the session’s objects). This practice phase involved retrieval of information about the function, semantic relations, semantic associations, visual characteristics of the objects, as well as finding links between the items of the same superordinate category. Participants were also asked to associate all of the objects with their lexical labels. In this way the connections between semantic and phonological information were strengthened (Bushke,1984; Diesfeldt,1984; Martin et al.,1985a).

Each session was individualized and lasted 60 minutes. The duration of the training program lasted four months with three hour/ week sessions and home exercises for the rest of the week days. This timing was arisen by the pilot study and was in congruence with the most of the recent cognitive training programs of the literature for Alzheimer's patients. The examiner tested the effectiveness of the above memory strategies during the immediate and delayed recall of information and the processing of deep learning by hiding and recall four items per four successive pictures, e.g., one item for each picture (there were 4 items per picture). Then she was asking the participant to recall and name the hidden items bringing in mind the trained information about them and the associations with the non hidden items (for more details see Appendix). If the participant could not recall the object, the examiner gave semantic cues that were used in the encoding phase and the participant was trying again. If the participant was failed again, a phonological cue was given in order to facilitate the phonological access of the hidden item. After achieving errorless learning per 4 pictures, the examiner was increasing the level of difficulty and she was hiding 8 instead of four items in 4 sequencing pictures. She was asking the patient to recall and name them using the previously learned semantic associations and information (delay recall). This procedure was continued until achieved about 90% of correct naming. Home exercises were aimed to rehearse the learned or the reorganized information about the training items and to deep learning through recall objects of similar superordinate categories usually non trained objects during the intervention (Appendix).

A follow up after three and six months of the completion of the training program was also implemented. At the three months follow up we retested the naming of the baseline 200 items. Though, after a period of six months we also retested the participants to all the neuropsychological and psycholinguistic tests of the baseline condition.

Table 2 Baseline neuropsychological assessment						
	AD		TOTAL	NON DEMENTED		TOTAL
NEURO-PSYCHOLOGICAL TESTS	CONTR.	EXPERIM.	AD	CONTROL	EXPER.	NON DEM
	MEANSD	MEAN SD	MEAN SD	MEAN SD	MEAN SD	MEAN SD
MMSE	23.5 1.5	22.4 1.8	23.0 1.6	27.6 1.3	27.2 1.6	27.4 1.5
CAMCOG	75.8 8.5	76.8 6.7	76.3 7.6	91.2 9.1	85.0 9.3	88.1 9.6
CAMCOG- time	42.6 7.6	49.6 5.4	46.0 7.4	35.0 6.0	40.0 6.0	38.0 6.0
BNT no cue	32.7 6.6	35.0 5.9	33.9 6.2	42.9 7.3	41.5 6.2	42.0 6.6
BNT semantic cue	36.2 7.0	37.2 3.7	36.7 5.5	44.9 6.8	44.9 5.4	44.9 6.1
BNT phonological cue	41.8 8.3	43.4 3.5	42.6 6.3	49.5 7.1	50.9 7.1	50.3 5.5
BNT- time	18.0 4.5	17.8 5.5	17.9 4.9	13.9 5.7	14.5 6.6	14.3 6.1
PPT	45.3 3.0	44.7 3.0	45.0 3.0	48.9 1.5	48.4 2.5	48.6 2.0
PPT-time	14.2 1.6	12.2 2.4	13.2 2.2	10.6 4.0	11.4 5.2	11.0 4.6

Direct Story (RBMT)	8.8 2.2	7.3 3.1	8.0 2.7	14.5 2.3	15.2 2.6	14.9 2.5
Indirect Story (RBMT)	8.0 2.2	7.5 3.0	7.8 2.6	14.0 2.2	14.2 3.0	14.1 2.6
Direct Route (RBMT)	3.7 0.6	3.9 0.9	3.8 0.7	4.8 0.2	4.7 0.6	4.7 0.4
Indirect Route (RBMT)	3.5 0.5	3.8 0.4	3.7 0.5	4.7 0.5	4.7 0.6	4.7 0.6
Face Recognition (RBMT)	3.5 0.8	3.7 1.3	3.6 1.0	4.9 0.3	4.9 0.3	4.9 0.3
Object (RBMT)	1.1 1.0	1.4 0.9	1.2 0.9	1.2 0.5	1.2 0.4	1.2 0.4
Name- Face (RBMT)	0.3 0.2	0.3 0.3	0.3 0.2	0.9 0.2	1.0 0.3	1.0 0.3
Message (RBMT)	1.1 0.3	0.9 0.3	1.0 0.3	1.0 0.0	1.0 0.0	1.0 0.0
Indirect Message (RBMT)	0.4 0.8	0.0 0.0	0.2 0.6	0.9 0.2	1.0 0.0	0.9 0.2
Wisconcin	1.7 1.1	2.0 1.4	1.9 1.3	4.1 1.4	3.0 2.5	3.6 2.0
Wisconcin-time	20.4 3.7	22 6.5	21.2 5.2	11.2 2.5	11.4 6.6	11.3 4.6
GDS	4.3 2.7	4.3 1.2	4.3 2.0	2.6 0.7	3.3 1.1	3.0 1.0

Table 3. Baseline psycholinguistic assessment

Psycholinguistic Tests	AD		TOTAL	NON DEMENTED		TOTAL
	CONTROL	EXPERIM.	AD	CONTROL	EXPERIM.	NON DEM
	MEAN SD	MEAN SD	MEAN SD	MEAN SD	MEAN SD	MEAN SD
MATCHING PICTURES-SENTENCE	48.7 5.9	47.0 1.9	47.9 4.4	53.4 1.4	52.0 3.7	52.5 3.0
TIME1	28.6 13.4	24.4 6.3	26.6 10.5	19.4 9.9	17.8 7.2	18.5 8.2
MATCHING PICTURE-PREPOSITIONS	17.4 2.5	17.6 1.4	17.5 1.9	19.9 1.9	19.3 2.9	19.5 2.5
TIME2	8.0 3.0	8.6 1.8	8.4 2.5	6.9 2.9	7.7 3.7	7.4 3.3
SYNONYMS CONCRETE	12.0 1.6	13.4 1.1	12.7 1.5	14.0 0.9	13.4 1.0	13.7 1.0
ABSTRACT	11.5 2.7	13 2.2	12.2 2.6	13.5 1.8	15.0 2.6	14.4 2.4

TIME3	9.2 2.9	8.0 1.9	8.5 2.5	6.6 2.9	7.9 3.6	7.4 3.3
SYNONYM JUDGMENT	54.0 3.9	55.3 1.6	54.6 3.0	57.8 2.7	56.3 1.8	56.9 2.2
TIME 4	10.0 4.2	6.6 2.0	8.4 3.7	6.1 3.4	5.9 2.7	6.0 2.9
NARRATIVE (BDAE)	3.8 0.7	4.2 0.3	3.9 0.6	4.8 0.3	4.9 0.3	4.9 0.3
ORAL SPELLING (BDAE)	3.8 0.6	3.9 0.8	3.9 0.7	6.5 1.6	6.0 1.3	6.3 1.4
READING COMPR. (BDAE)	6.3 0.9	3.9 0.8	6.5 0.8	8.9 0.8	8.0 0.9	8.3 1.0
VERBAL FLUENCY- (Animals)	12.3 1.8	12.7 2.5	12.5 2.1	19.4 3.2	19.3 1.6	19.3 2.4

Results

During the baseline condition the t-test for independent samples for the two AD groups indicated no statistically significant differences according to the age, the education, the cognitive state (MMSE) and the naming performance $t(20) = 1.4, p > .05$, $t(20) = .98, p > .05$, $t(20) = .13, p > .05$, $t(20)=.33, p > .05$ respectively. So did the 2 non demented aging groups $t(18) = 1.0, p > .05$, $t(18) = .56, p > .05$, $t(18) = -1.99, p > .05$, $t(18) = -2.0, p > .05$, respectively. Applying the one-way ANOVA in the baseline condition with independent variable the disease and dependent variable the neuropsychological and psycholinguistic performance for the two AD groups we observed no statistically significant difference $p > .000$ between subjects (table 4 and table 5). We also applied the one-way ANOVA three and six months after the baseline condition for the two AD groups, and we observed statistically significant differences in naming scores $F(1, 21) = 130.3$, $p=.000$ ($\eta2=.88$, $\eta2=.91$, respectively). We followed the same procedure for the two non demented groups, 3 and 6 months after the baseline condition and we found statistically significant difference in naming performance too, $F(1, 19)=802.7$, $p=.000$ ($\eta2=.41$, $\eta2=.38$ respectively).

Table 4. F values for the AD and Non demented aging groups in neuropsychological tests

Neuropsychological tests	AD		NON DEMENDED		Neuropsychological tests	AD	
	F	df*	F	df*		F	df*
MMSE	0.79	20	0.59	18	Indirect story recall (RBMT)	1.9	20
CAMCOG	0.92	20	0.49	18	Direct Route (RBMT)	0.18	20
CAMCOG- time	45	20	0.21	18	Indirect Route (RBMT)	1.7	20
BNT no cue	0.62	20	0.01	18	Face Recognition (RBMT)	0.15	20

BNT semantic cue	3.7	20	0.29	18	Object (RBMT)	2.6	20
BNT phonological cue	7.3	20	0.92	18	Face-Name (RBMT)	0	20
BNT time	0.52	20	1.9	18	Direct Message (RBMT)	0	20
PPT	0.02	20	2.7	18	Indirect Messsage (RBMT)	25	20
PPT-time	0.19	20	0.6	18	Wisconcin	0.01	20
Direct story recall (RBMT)	1	20	2.9	18	Wisconcin- time	1.2	20
df* AD : 2, 20; df* Non Demented: 2, 18; p >.000 for AD; p >.000 for Non Demented							

Table 5. F values for AD and Non Demented in psycholinguistics tests

Psycholinguistic tests	AD			NON DEMENTED	
	F	df	p	F	df p
Matching pictures-sentences	7.6	20	>.000	6.4	18 >.000
Time	3.8	20	>.000	0.24	18 >.000
Matching pictures-sentences-prepositions	2	20	>.000	0.28	18 >.000
Time	0.6	20	>.000	0.44	18 >.000
Synonyms- Concrete	0.1	20	>.000	1	18 >.000
Synonyms- Abstract	0.14	20	>.000	0.46	18 >.000
Time	3	20	>.000	1	18 >.000
Synonym Judgment	6.7	20	>.000	0.78	18 >.000
Time	7.7	20	>.000	0.27	18 >.000
Narrative writing (BDAE)	6.2	20	>.000	0.08	18 >.000
Auditory Syllabication	0.09	20	>.000	0.04	18 >.000

Reading Comprehension	0.1	20	>.000	0.12	18 >.000
Verbal Fluency (Animals)	0.7	20	>.000	2.2	18 >.000
df* AD : 2, 20; p >.000 for AD; p >.000 for AD; p >.000 for Non Demented					

Applying the ANOVA of repeated measures within the experimental AD group we observed main effects of the training program for the 3 time-phases F (1, 10) =167.0, p = .000. Specifically, 3 months after the intervention, the experimental AD group showed statistically significant improvement in naming performance p = .000 from the baseline condition, as well as 6 months after the end of the training program p = .000 (table, 6).

For the control AD group the ANOVA of repeated measures indicated statistically significant difference in naming performance for the 3 time phases F (1, 10) = 503.0, p = .000. Specifically, 3 months after the baseline condition we observed no statistically significant difference in naming performance p > .05, as well as between the third and sixth month p > .05. However, we observed statistically significant difference in naming performance after 6 months from the baseline condition p = .013 (table, 6).

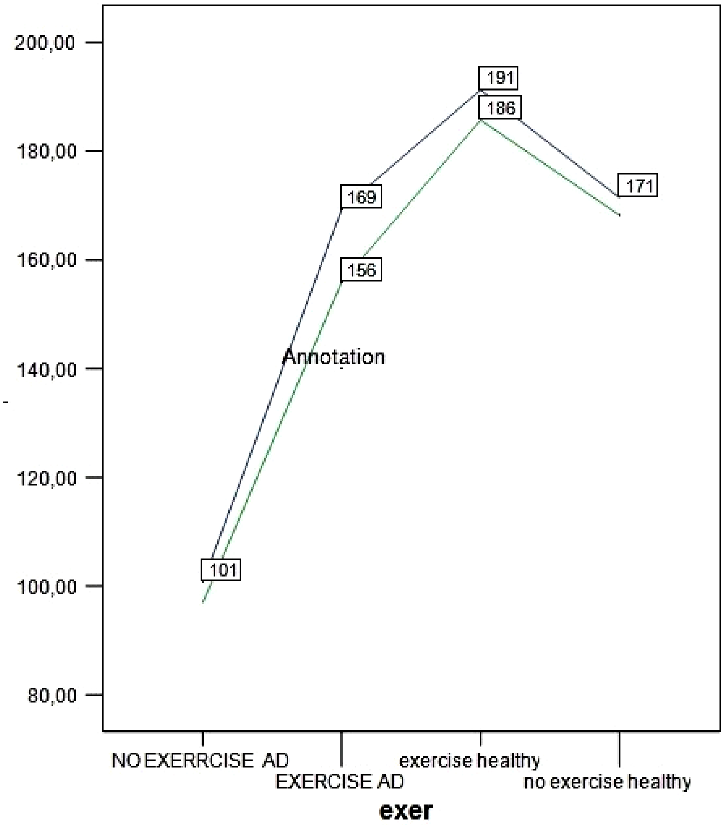
We also observed main effects of the training program for the experimental non demented aging F (1, 9) = 39.2, p = .000. There was statistically significant improvement 3 months after the training program p = .000 and statistically significant decline from the third to the sixth month p = .002. However, the naming performance continued to be better than the baseline condition 6 months after the end of the training program p = .001 (table, 6).

In contrast, the control non demented aging group indicated no statistically significant difference during the 3 temporal phases F (1, 9) = 3.88, p = .04 (table, 6). The diagram no 1 shows the naming performance during the baseline and follow up conditions.

Table 6. Mean and SD in naming performance in the 3 phases of performance.

GROUPS	Baseline		3 months Follow up		6 months Follow up	
	Mean	SD	Mean	SD	Mean	SD
AD CONTROL	103	11.8	101	12.9	97	9.7
AD EXPERIMENTAL	101	15.4	169	13.3	156	9.4
NON DEM. CONTROL	172	13.2	172	15.0	168	12.6
NON DEM. EXPERIMENTAL	157	22.5	191	9.0	185.7	10.8

Figure 1 Naming Performance of the 4 groups in baseline condition and after 6 months of the end of the intervention program



In order to investigate the generalization of the effects on untrained naming items (table, 7) after 6 months of the end of the program we tested the 4 groups on untrained items of the trained categories (60 items). Performing the analysis of Tukey we observed moderate statistically significant differences between the AD groups p= .026 with better results for the experimental AD group. We also observed statistically significant difference between the 2 experimental groups p = .000. The experimental non demented aging group achieved better performance than the experimental AD group p=.000.

Table 7. Naming Performance on untrained items

Subjects	Performance on Untrained Items	
	EXP. GROUP*	CONT.GROUP^
	MEAN S.D	MEAN S.D
AD	35.0 6.2	27.9 5.6
NON DEM#	57.2 4.6	55.2 6.3

*EXP. GROUP=EXPERIMENTAL GROUP ^CONT.GROUP=CONTROL GROUP #NON DEM=NON DEMENTED

Neuropsychological and psycholinguistic assessment 6 months after the baseline condition

Between groups

In order to test the hypothesis regarding the transfer of training effects on non trained cognitive abilities we applied the t-test for matched groups between the baseline and retest scores after 6 months of the end of the training program. We observed statistically significant differences between the 2 AD groups to the following neuropsychological tests: the MMSE F (1, 20) = 66.7, p = .000, the CAMCOG F (1, 20) = 45.5, p = .000, the time of responding in CAMCOG F (1, 20) = 5.15, p = .034; the BNT in no cue, semantic and phonological cue condition F (1, 20) = 14.2, p = .001, F (1, 20) = 19.3, p = .000, F (1, 20) = 15.8, p = .001 respectively and the responding time of BNT F (1, 20) = 16.2, p = .001; the Pyramids and Palm Trees and the time of responding in the PPT F (1, 20) = 36.6, p = .000, F (1, 20) = 14, p = .001 respectively; the Wisconsin and marginally the responding time of Wisconsin F (1, 20) = 45.2, p = .000, F (1, 20) = 4.5, p = .047, respectively.

According to the memory function assessed by the RBMT subtests we observed statistically significant differences between the AD groups in the subtests of the direct and indirect recall of the story F (1, 20) = 17.0, p = .001, F (1, 20) = 13.8, p = .001 respectively, and the direct and indirect recall of route F (1, 20) = 24.5, p = .000, F (1, 20) = 16.6, p = .001 respectively.
According to the psycholinguist tests the AD groups performed statistically significant differences to the following ones: the matching of picture-sentence PALPA 56 F (1, 20) = 14.8, p = .001 and the responding time of the PALPA 56 F (1, 20) = 23.0, p = .000; the matching of picture- sentences with propositions PALPA 59 F (1, 20) = 22.4, p = .000; the time of responding of the Synonyms PALPA 50 F (1, 20) = 13.5, p = .001; the subtest of PALPA 51a F (1, 20) = 5.4, p = .03; the Animals (BDAE) F (1, 20) = 130.8, p = .000; the Comprehension of Comprehension of Oral spelling (BDAE) F(1, 20) = 19.5, p = .000 and the Reading Comprehension of sentences and paragraphs (BDAE) F (1, 20) = 13.0, p = .002.

We didn’t observe statistically significant differences between the 2 non demented aging groups in neither neuropsychological nor psycholinguistic test (p>.05).

Within groups

The next step was to investigate the neuropsychological and psycholinguistic performance within subjects after 11 months from the baseline condition. The ANOVA of repeated measures indicated statistically significant differences for the experimental AD group in the following neuropsychological tests: the MMSE F (1, 10) = 74.1, p = .000, the CAMCOG F (1, 10) = 81.5, p = .000, the responding time of CAMCOG F (1, 10) = 30.3, p = .000; the BNT with no cue, semantic and phonological cue condition and the responding time of the BNT F (1, 10) = 30.8, p = .000, F (1, 10) = 43.0, p = .000, F (1, 10) = 42.8, p = .000 respectively; the PPT and the time responding of the PPT F (1, 10) = 72.4, p = .000, F (1, 10) = 11.0, p = .000 respectively, and the Wisconsin F (1, 10) = 190.0, p = .000.

According to memory function the experimental AD group performed statistically significant differences to the following subtests of the Rivermead: the direct recall F (1, 10) = 9.8, p = .012 and indirect recall of the story F (1, 10) = 702.0, p = .008, the direct recall F (1, 10) = 6.3, p = .000 and indirect recall of a certain route in the space F (1, 10) = 4.5, p = .031, the indirect recall of a message F (1, 10) = 1, p = .026 and the remind of recall of a personal object F (1, 10) = 0.3, p = .002 (table 8).
According to the psycholinguistic tests the experimental AD group indicated statistically significant differences to the following ones: the Matching of picture – sentence PALPA 56 F (1, 10) = 50.6, p = .000, the responding time of PALPA 56 F (1, 10) = 9.6, p = .011, the Matching of picture – sentence

preposition PALPA 59 F (1, 10) = 31.6, p = .000, the Written narrative of the BDAE F (1, 10) = 49.2, p = .000 and the Comprehension of Oral spelling of the BDAE F (1, 10) = 150.8, p = .000 (table, 9).

For the control AD group the ANOVA of repeated measures analysis (baseline vs 6 month follow up) indicated statistically significant differences to the following neuropsychological tests: the MMSE F (1,10) = 36.8, p = .000, the CAMCOG F (1,10) = 9.7, p = .011, the responding time of WISCONSIN F (1,10) = 5.9, p = .035. Though in the psycholinguistic tests the control AD group indicated statistically significant differences just in the subtest of the Matching picture – sentence PALPA 56 F (1,10) = 6.92, p = .025 (table 8 and 9).

Applying the same statistical procedure (ANOVA repeated measures 11 months from the baseline) for the experimental non demented aging group we observed statistically significant differences for the following neuropsychological tests: the MMSE F (1, 9) = 49.8, p = .000, the CAMCOG F (1, 9) = 50.8, p = .000, the responding time of the CAMCOG F (1, 9) = 28.5, p = .000; the BNT no cue, semantic and phonological cue condition F (1, 9) = 72.9, p = .000, F (1, 9) = 40.9, p = .000, F (1, 9) = 36.0, p = .000, the responding time of the BNT F (1, 9) = 13.9, p = .005,; the PPT F (1, 9) = 7.5, p = .023, the responding time of the PPT, F (1, 9) = 18.6, p = .002;, the Wisconsin F (1, 9) = 34.0, p = .000 and the responding time of the Wisconsin, F (1, 9) = 11.2, p = .009 (table 8 and 9). The experimental non demented group indicated also statistically significant differences to the direct and indirect recall of the story of the Rivermead F (1, 9) = 9.8, p = .012, F (1, 9) = 10.8, p = .009 respectively (table, 8). According to the psycholinguistic tests the experimental non demented group indicated statistically significant differences to the following subtests: the Matching of pictures-sentences PALPA 56 F (1, 9)= 8.4, p = .018, the Matching of pictures-sentences prepositions PALPA 59 F (1, 9) = .89, p = .005, the Judgment of Synonyms PALPA50 F (1, 9) = 10.5, p = .010 and the Comprehension of Oral spelling (BDAE) F (1, 9) = 11.1, p = .009. However, they performed no statistically significant difference to the subtests of the Synonyms (Concert-Abstract) (PALPA 51a & b), the Written narrative (BDAE), the Reading of sentences and paragraphs (BDAE), the Animals (p>.050) (table, 9).

The control non demented aging group indicated no statistically significant differences in any neuropsychological nor psycholinguistic tests (p>.05).

Table 8. Retests in Neuropsychological tests 6 months after the end of the program

NEURO PSYCHOLOGICAL TESTS	AD		NON DEMENTED	
	NO EXERCISE	EXERCISE	NO EXERCISE	EXERCISE
	MEAN SD	MEAN SD	MEAN SD	MEAN SD
MMSE	21.5 1.9	27.2 1.2	27.8 1.8	28.9 1.0
CAMCOG	72.3 7.9	90.0 3.6	90.4 7.9	93.8 6.7
CAMCOG- time	44.5 5.2	38.2 7.7	40.6 19.0	31.3 3.2
BNT no cue	33.0 6.2	43.9 7.3	43.3 6.0	47.9 6.5
BNT semantic cue	35.4 6.2	46.7 5.9	44.2 6.2	49.5 5.6
BNT-phonological cue	40.5 8.8	52.3 4.3	51.7 3.9	54.4 3.9
BNT time	19.5 6.0	10.4 4.6	12.0 3.3	9.1 2.6

PPT	45.5 1.8	49.7 1.5	49.6 1.3	50.6 1.7
PPTtime	14.0 3.4	8.8 3.0	13.2 13.2	6.5 3.6
Immediate Recall of Story (RMBT)	7.0 3.6	12.7 2.8	14.8 2.7	16.4 3.0
Indirect Recall of Story (RBMT)	6.3 3.7	11.6 3.0	14.4 2.7	16.2 3.0
Route (RBMT)	3.4 0.7	4.8 0.6	5.0 0.0	5.0 0.0
Indirect Route (RBMT)	3.4 0.7	4.5 0.7	5.0 0.0	5.0 0.0
Appointmet (RBMT)	1.0 1.0	1.4 0.7	1.0 0.0	1.3 0.5
Face Recognition (RBMT)	4.0 0.9	4.6 0.9	5.0 0.0	5.0 0.0
Object (RBMT)	1.2 1.0	1.5 0.5	1.2 0.4	1.1 0.3
Face-Name (RBMT)	0.4 0.4	0.6 0.4	1.0 0.0	0.95 0.1
Message (RBMT)	0.8 0.4	1.0 0.0	1.0 0.0	1.0 0.0
Indirect Message (RBMT)	0.4 0.7	0.7 0.5	1.0 0.0	1.0 0.0
Wisconcin	1.7 1.1	3.7 1.7	4.1 1.7	4.0 1.6
Wisconcin time	17 4.8	12.7 9.9	10.0 5.3	8.5 3.2

Table 9. Retest of the psycholinguistic assessment 6 months after the end of the program

PSYCHO LINGUISTIC TESTS	AD			
	EXPERIM.	CONTROL	EXPERIM.	CONTROL
	MEAN SD	MEAN SD	MEAN SD	MEAN SD
Matching picture-sentence PALPA	52.8 1.5	47.0 4.7	54.4 3.3	53.4 1.5
TIME 1	17.7 2.9	30.9 8.6	14.3 4.8	18.7 8.1
Matching picture- Prepositions PALPA	20.5 1.5	16.9 1.9	21.0 1.9	20.6 2.4
TIME2	7.3 2.5	10.0 5.5	6.7 2.7	7.4 3.3
Synonyms CONCRETE PALPA	13.6 2.9	11.0 2.3	14.3 1.3	13.4 2.0
Synonyms ABSTRACT	13.0 2.5	11.0 2.8	15.0 1.4	15.5 0.5
TIME3	6.8 2.8	10.0 4.5	4.4 2.4	6.0 3.0
Judgment of Synonyms PALPA	53.4 12.9	41.5 19.2	58.2 1.5	52.7 14.2
TIME 4	6.7 3.6	12.0 3.3	4.0 1.5	6.8 4.0
Narrative Written BDAE	4.9 0.2	4.5 1.9	5.0 0.0	4.9 0.3
Auditory Syllabication BDAE	6.5 1.0	4.3 1.3	7.2 0.8	6.3 1.4
Reading Comprehension BDAE	8.2 0.6	6.6 1.3	8.3 1.6	8.7 0.9
Verbal Fluency-Animals	20.7 2.0	11.5 1.7	18.9 3.4	19.8 3.0

Discussion

Recent literature indicates that there is a long debate regarding the effectiveness of cognitive training in AD patients. Our results are consistent with the findings of studies suggested that cognitive training can have long term and small generalization effects in the first stages of AD when examiners use systematically (3 times per week) an individual dual cognitive support program at least for 4 months.

Applying the repeated measures ANOVA, 3 and 6 months after the training program we observed that both the experimental groups (AD-Non Demented) improved their naming performance and maintained it at least for 11 months from the baseline condition comparing to the control groups. So we confirmed the first hypotheses that our cognitive training program reduced the naming deficits for a considerable time (at least 6 months after the end of the program) as in the study of Piccolini, Amadio, Spazzafumo, Moroni, & Freddi, 1992. Other studies suggest that there are some rehabilitative techniques with positive effects on the learning capacity for demented elderly (Yesavage, & Jacob, 1984; Hill, Sheikh, & Yesavage,1987; Yesavage, Sheikh, & Friedman,1990) lasted at least for 6 months (Sheikh, Hill, & Yesavage,1986) and retrograde the decline associated with old age. In our opinion the observed naming improvement in our study is due to the deep learning effects achieved during encoding and recall procedure as suggested from the literature too. Additionally, the techniques of the connecting of the new trained knowledge with the old intact one under the examiner's assistance and the errorless learning condition had significant role too. The training and relearning of the specific characteristics between the same category objects helped the reorganisation of the intact and faded information in semantic memory and the errorless learning condition strengthened its consolidation. We can't prove if the trained coding techniques were applied consciously or not to untrained matrix, e.g., the direct or indirect story/route recall of the RBMT, as the experimental AD group showed statistically significant improvement 11 months from the baseline condition, or if it was practise effect. This needs further investigation.

The control AD group indicated statistically significant decline in naming performance for the 3 time phases. Specifically, there was no statistically significant naming decline 3 months after the baseline condition though there was moderate statistically significant decline in naming performance 6 months from the baseline. This may means that the vocabulary is reducing slowly in mild dementia.

The experimental non demented aging group although performed better than the experimental AD one, their naming performance declined to the sixth month too. This slight deduction was concerned the less familiar everyday objects and indicates that the everyday living is an essential factor of advanced learning. In contrast, the control non demented aging group showed no statistically significant difference in naming performance during the 3 temporal phases. So our results are in congruence with the references that the vocabulary remains intact until the 7th decade (Obler & Albert,1984) independently of culture. Our study also found a small generalization effect to untrained objects of the trained categories, as the experimental groups showed significant naming improvement than the control ones. We suppose that the training program and the home exercises helped them to strengthen the relearned information and to reorganize their semantic memory.

Besides the improvement of naming ability, the training program improved other untrained cognitive functions and abilities six months after the end of it. The experimental AD group improved the functions of the semantic and episodic memory and the attention. They seemed to transfer the trained memory strategies from the visuosemantic matrix (pictures of everyday objects) to oral-semantic no trained matrix (direct- indirect story recall) which means that the modality of the stimuli is not so crucial factor as the trained strategies. We suppose that the errorless learning condition, the extended repetition of the stimuli and the deep learning improved the global cognitive state of the AD and specifically the performance of episodic and working memory (Comprehension of Oral spelling of the BDAE). This may happened as the participants have to find associations and links per 4 items in order to recall a hidden item after a few minutes delay and were practiced to use coding and restore strategies. The participants also took advantage of the phonological cues in the BNT and showed an improved shifting ability from one rule to another and from one category to another, as indicated by the Wisconsin. The training program additionally enhanced other language abilities of the experimental AD group as the psycholinguistic tests indicated. These included matching ability, synonym judgement, verbal fluency and reading comprehension ability. This improvement could be explained by the fact that deep learning is achieved by the application of these abilities (judgement and comprehension of differences of similar objects and extended rehearse).

According to the performance we observed no statistically significant differences between the 2 non demented groups in neither neuropsychological nor psycholinguistic test. This could be mean that there is no or not considerable cognitive or language decline during 11 months for non demented elderly.

According to the performance within groups we observed that the experimental AD group indicated statistically significant differences in cognitive functions and linguistic abilities 11 months from the baseline condition. They achieved a better performance in global cognitive state (MMSE), semantic memory (PPT), naming ability (BNT), attention (Wisconsin), store and recall ability (RBMT), the responding time and the digit span of working memory. This may means that the experimental AD group used trained memory strategies in a conscious or unconscious way in direct or indirect recall of information and the results of this training can be seen even in prospective memory (recall of personal object), an untrained function. They also improved other language abilities as matching, critical judgment and narrative writing. This improvement perhaps can be explained as a result of the deep learning too, as we practised them in the coding phase during the intervention program.

The control AD group indicated statistically significant cognitive decline, a slower speed of information processing, and a matching ability deficit 7 months from the baseline condition considering the performance in the MMSE, the CAMCOG, the Wisconsin responding time and the Matching picture-sentences (PALPA 56). Matching ability in a complex material task presupposes intact function of a couple of functions and processing, as keeping and processing information in the digit span of working memory, an intact buffer of working memory; good reading comprehension ability; intact mechanism of coding and decoding of information; good organization of semantic memory; good working of the mechanisms of searching and finding information in mental lexicon; intact judgment ability in order to find the differences between similar pictures. Summarizing, the experimental AD group was improved in general cognitive performance and episodic memory as they used better strategies of encoding and recalling information reducing their omissions or mistakes six months after the end of the training program.

The experimental non demented aging group indicated statistically significant improvements in many neuropsychological tests too. This means that the same training program had about similar impacts to the experimental groups. Besides the naming ability this group improved the semantic memory (PPT), the attention (WISCONSIN), the speed of information processing (time) and the episodic memory (direct and indirect recall of the Rivermed story). The training program produced no improvement to other language abilities which means that the same program activated different cognitive and language abilities in a non demented brain. So we suggest that the non demented people need a more high level and demanded memory training program in order to be improved to the same abilities, as the experimental AD group did.

The control non demented group didn’t show statistically significant differences in neither neuropsychological nor psycholinguistic tests. This could be mean that during 7 months there is no obvious cognitive and/or language decline for non demented elderly people.

Our conclusions are that mild AD patients can achieve reorganization of intact and relearned faded information using trained memory strategies based on deep learning. Memory strategies helped the interconnection of faded semantic information and the association between the meaning, the function, the characteristics and the lexical labels of the items. They maintained the relearned information at least for 11 months from the baseline condition without feedback or notable decline in naming ability. They also transferred these strategies to other cognitive and language abilities (e.g., general cognitive state, attention). So our results agree with the conclusion of the meta analysis study of Sitzer, et al., 2006 that cognitive training programs in mild Alzheimer's disease achieves medium effect sizes for learning, memory, executive functioning and general cognitive state. However, there is still the problem if the patients transfer the learned strategies and skills to everyday life which is among the criteria for cognitive intervention success. The intact semantic memory seems to be presupposition in order to achieve naming and general cognitive improvement as other researchers suggested in the past (Ellis & Young, 1988). However, among the factors which ensure a successful intervention are the motivations of the patients, the willingness of improvement and the using of everyday stimuli. In this way we can encourage the patient to transfer the trained information to actual life conditions. A friendly and supportive environment is also needed so that the patient feels comfortable and maintains effort through all the phases of the training program.

According to the question if every non constructed training program or with psychotherapeutic role could have a similar effect, there are many studies that they indicated no improvement (Goldstein et al., 1982; Goldwasser, Averbach, & Harkins, 1987; Wallis, Boldwin, & Higginbotham, 1983). The answer is similar for the claim that the experimental groups may be helped because of the psychologist's presentation. Tarraga, et al., 2006 showed that the Alzheimer's group participated to a psychotherapeutic program of social skills or the control AD group showed no improvement. Some of psychosocial methods are more appropriate or with insufficient indications for the reduction of depression, aggression or apathy in Alzheimer disease under specific circumstances (Verkaik, van Weert, & Francke, 2005). Similarly, Talassi, et al., , 2007 suggest that only a rehabilitation cognitive program which provides a punctual cognitive stimulation has significant effects. According to the pharmacological treatment, our results are in congruence with that of Bottino, Carvalho, Alvarez, Avilia, Zukauskas, Bustamente et al., 2005 and Cipriani, Bianchetti, & Trabucchi et al., 2006 for the cognitive improvement of mild AD patients associated with inhibitors of acetylocholinesterase and a cognitive training program. However, it would be helpful to have an additional control and experimental group without pharmacological treatment. We also conclude that there are flexible boarders between cognitive functions as while the clinicians are trying to train a cognitive deficit, they improve others indirectly interconnected abilities.

Furthermore, the question remains if the patients and their relatives are aware of this cognitive improvement and if the training has effects on the activities of daily living and social skills. These are questions to be pursued in future research. Even though, we agree with the opinion of Piccolini, et al., 1992 that it is an illusion to think that patients with irreversible cognitive deficits can recuperate, performing any kind of rehabilitative therapy. Though, we could train their caregivers on individualized cognitive training programs fitted to their patients' cognitive deficits in order to retrograde the progression of AD and minimize the cost of a cognitive training program.

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APPENDIX

For example: Look at the picture with the furniture:
Find and tell the differences between the 4 furniture (e.g., use, function, visual characteristics, place for setting). We do the same procedure too for the next tree pictures and then we hinted a moderate difficult for Greek reality item (e.g., armchair, pepper, steak, tea-pot) from each picture. Then we asked the participant to recall the hinted item having in front of him the rest of the each picture. If he/she could not recall it we gave semantic information used during the encode phase and if the participant couldn't find it again we gave the first syllable of this furniture.

Example of home exercises:

1. Find other 5 at least not trained furniture
2. Find other 5 at least not trained green vegetables
3. Find other 5 at least non trained foods with meat
4. Find other 5 at least not trained cookware.

The International Journal of Psychosocial Rehabilitation
Volume 14, Number 1
July 2009– June 2010

Integration of Peer Support Workers into Community Mental Health Teams

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Citation:
Richard AL, Jongbloed LE & MacFarlane A. (2009). 'Integration of Peer Support Workers into Community Mental Health Teams. **International Journal of Psychosocial Rehabilitation. 14 (1), 99-110**

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Abstract

Introduction: Although benefits of peer support are known, concerns also exist. Little is known regarding the experiences of occupational engagement as a Peer Support Worker (PSW) within Community Mental Health (CMH) teams.
Objectives: The purpose of this phenomenological study is to improve understanding of PSWs' experiences of perceived value and inclusion as CMH team members.
Method: Five PSWs were interviewed; interview questions related to: role, job security, career development, disclosure, policy, procedures, social inclusion, decision-making, perceived value, and the influence of recovery-models.
Results: Five themes were identified: role and power, institutional organization, access to resources, inter- and intrapersonal factors, and differences over time.
Discussion: Concepts found were compared to previous literature and may exist in additional settings. Considerations are made for practice and research.

Key words: Peer support work, community mental health, team integration

Introduction

There is an increasing movement in mental health care towards hiring individuals with personal experience with mental illness as Peer Support Workers (PSW) to support and assist current mental health clients in their recovery process. The involvement of PSWs in the system is one of the most visible examples to other service users, their families, and professional services providers that the respective mental health system is committed to inclusion, partnerships with clients, and the adoption of a recovery-oriented mental health system. Out of the Shadows at Last (Kirby & Keon, 2006), the Final Report of The Standing Senate Committee on Social Affairs, Science and Technology, states that "recovery provides a focus for re-orienting the design and delivery of mental health programs, services, and supports" (p. 45), that recovery is "the primary goal around which the mental health delivery system should be organized" (p. 43), and that "recovery must be placed at the centre of mental health reform" (p. 42).

A commitment to a recovery-oriented system is evident in an organization's involvement, in both service provision and program development, of consumers and family members. Anthony (2000) states that, in the establishment of standards for a recovery-oriented system, "consumers are actively sought for employment at all levels of organization" (p. 165). The simultaneous implicit recognition by clients and their families of working with, or alongside, a peer is that, regardless of their current symptomology, clients can, and do, lead fulfilling and rewarding lives, build relationships and partnerships, and find employment both within the service system and in other areas of competitive employment. In addition to supportive relationships with family members/friends and mental health professionals, mental health consumers identify supportive relationships with peers as a crucial factor for recovery and, in particular, peers as sources of inspiration, education, and support (Mancini, Hardiman, & Lawson, 2005).

Literature on the outcomes of employing PSWs on mental health teams has identified numerous benefits of occupational engagement in such a profession. Benefits for the health system include increasing resources, helping clients, decreasing stigma, and promoting PSW (Mowbray, Moxley, & Collins, 1998). Some of the personal benefits identified by PSWs include facilitating recovery, social approval, professional growth, skill development, mutual support, receiving money and work, job security, career direction, and positive feedback (Mowbray, et al., 1998; Salzer & Shear, 2002).

Related to client benefits, randomized controlled trials have shown earlier development of positive relationships with clients, increased contact with clients, and the promotion of empowerment and recovery with the use of peer staff compared to nonpeer staff (Corrigan, 2006; Sells, Davidson, Jewell, Falzer, & Rowe, 2006). However, PSWs may have more time available for client contact, which could have been a confounding variable. Lower rates of re-hospitalization over a three-year period have also been linked to peer-services for people living with both mental illness and addictions (Min, Whitecraft, Rothbard, & Salzer, 2007).

Furthermore, a systematic review showed that peer staff, compared to non-peer staff, had more client contact, fewer professional boundaries, and more outreach opportunities (Simpson & House, 2008). Clients receiving peer services were shown to also have improved quality of life and social functioning, fewer life issues, less family burden, longer durations before hospitalization, fewer hospitalizations, and shorter hospital stays, although nonpeer staff had lower employment turnover rates (Simpson & House, 2008). In a separate study, the majority of clients receiving peer counseling were positive about the experience and would recommend the service; however, no non-peer counselor comparison was made and only one peer counselor was involved in this study (Rummel-Kluge, Steigler-Kotzor, Schwarz, Hansen, & Kissling, 2008).

While many benefits of peer support have been described, concerns also exist. One major concern with PSW is research demonstrating that stigma exists even within the mental health system (Chin & Balon, 2006; Nordt, Rossler, & Lauber, 2006). Research studies have suggested that there are few differences between the attitudes of mental health professionals and the general public regarding the predicted outcomes of individuals with mental illness (Hugo, 2001; Lauber, Anthony, Ajdacic-Gross, & Rössler, 2004). In some instances, mental health professionals reported even less positive expectations than community samples (Hugo, 2001; Lauber, et al., 2004).

PSWs have also reported negative experiences of their work. These experiences related to job stress, lack of direction in job skills, lack of support from supervisors or administrators, concerns regarding responsibilities, and boundary issues (Mowbray, et al., 1998). Workers also experienced feelings that they were part of the health care team but always of lower status than other professionals (Mowbray, et al., 1998).

The present literature review demonstrates the importance of investigating the integration of PSW into mental health teams, looking specifically at their perceptions of inclusion and value as a team member to acknowledge areas for improvement. Unfortunately, little research exists on the topic, especially within a Canadian health care system. In the literature, PSWs have recommended increased hours and pay, more contact with peers, more employment opportunities, more opportunities to demonstrate skills, and more social activities as methods to improve the current experience as a PSW (Mowbray, et al., 1998). However, these results are not limited to community services, are based in an American system, and were not based on one-to-one interviews with PSWs which would allow a deeper understanding of their experiences.

In another qualitative American study with PSWs and other staff, a number of difficulties were identified including: variable staff attitudes towards PSW, role conflict and confusion, pre-existing relationships with professionals, alienating policies, inadequate training, lack of communication, disclosure of peer status, peer access to client records, job structure related perceived value, and a lack of social support in the workplace (Gates & Akabas, 2007). The results of the previous study highlight a number of areas that require further investigation. In addition, participants in the study were selected from a wide array of mental health services and facilities, with varying roles, training, policies, and procedures; significant contextual differences between agencies may have caused variations in the experiences of PSWs and these potential differences were not acknowledged. Furthermore, differences in sample sizes existed between groups and one-to-one interviews were conducted only with the nonpeer staff which may have influenced the information obtained from each group. Finally, the study did not focus specifically on CMH treatment.

The present study will provide clinically important information and contribute to this growing body of evidence in Peer Support research, specific to Vancouver CMH practice, which will assist in promoting the integration of PSWs. The present study asked the research question: what are the experiences of PSWs, in terms of their perceived value and inclusion as a team member, in selected Vancouver CMH teams? The purpose of this study is to gain an understanding of PSWs' perceptions of their value and inclusion in a sample of CMH teams as to provide direction for further research and initial considerations for CMH practice in British Columbia's lower mainland.

Method

Ethics approval was obtained through the Behavioural Research Ethics Board at the University of British Columbia and Vancouver Coastal Health Research Institute (Vancouver Community). No financial support was provided.

Participants

Using purposeful sampling, PSWs from three CMH teams were invited to participate in the study. Specific teams were selected to obtain samples from people working in different areas of the city (west side, east side, and downtown). Also, these teams had been identified by VCHA's Peer Support Coordinators as currently having a high number of PSW's employed, compared to other teams in the city. As well, the third author of this study is the Team Leader for one of the selected CMH teams and was therefore interested in the experiences of PSWs from his particular facility.

Posters with a brief summary of the project and contact information for the study authors were displayed at each team site. PSWs were also reminded of the opportunity to participate in the project by Team Leaders of their facilities. The first author also visited two of the teams to describe the project to participants and encourage increased participation, as recruitment was low at these facilities. No reimbursements were provided to participants.

Participants were included in the study if they spoke English, completed Vancouver Peer Support Training or the equivalent, had experience as a mental health consumer, and had been employed as a PSW at one of three selected Vancouver CMH teams for at least one year. One year was chosen because the PSWs would have had adequate exposure to the team and could comment on their experiences.

Five PSWs participated in the study (three males and two females). Two participants identified themselves in the 30-39 years of age category while the remaining three participants identified themselves in the 50-59 age category. The range of years that the participants reported that they have been working as PSWs was from 3.5 years to 11 years, with a mean of six years. The number of contracts that each participant was currently working ranged from one to six contracts at 20 hours per month for each contract (mean of 2.8 contracts). There was a range from one to four employed community facilities, with a mean of two community facilities per participant. Finally, all participants were recruited from two of the three selected CMH Teams.

Design/Procedure

Using a phenomenological approach, semi-structured open-ended audio-taped interviews were conducted off-site by the first author, as to ensure confidentiality to participants. Guiding questions were related to the experiences of participants' PSW role, job security, career development, disclosure of own mental illness, general and social inclusion within the team, decision making and treatment planning involvement, perceived value from team members, policies and procedures, and the influence of a recovery-oriented system. Interviews took place at a location chosen by participants, including busy coffee shops and a private room in a public library.

Participants were reassured that access to raw data would only be granted to the first and second authors, and not to the third author. This decision was to ensure that the third author (and team director for one of the VCHA CMH Teams) would not be able to identify participants, thereby increasing the validity of participants' responses.

Data Analysis

Qualitative data analysis occurred in a systematic approach which was adapted from that used in Backman, Del Fabro Smith, Smith, Montie, and Suto (2007) to fit with the present study and a phenomenological design. The first step in the data analysis process was the transcription of interviews. Second, interviews were each reviewed separately by the student researcher to further understanding of participants' individual experiences. Third, coding of individual transcripts occurred; sentences and paragraphs were coded for each of the five interviews to capture the primary meaning described by each participant. Fourth, grouping of codes occurred to form clusters of data; codes within and across participants that had similarity in meaning were combined. Since data analysis occurred with only one researcher, consultation with the second author also occurred at this stage to obtain feedback on the coding process and incorporate suggestions for grouping. Fifth, clusters were then combined into broader themes and a description of their meaning was given to each theme. In the description process, the researcher focused on the frequency of clusters across participants primarily, as well as the existence of information that was expressed as important to single participants. This process allowed for general experiences to be shared as well as multiple view points to be acknowledged, given the small sample size. Experiences that were solely related to issues of PSW and not related to membership, value, or inclusion within the team (e.g., the clinical importance of disclosing personal experiences of mental illness with clients and experiences of feeling valued by clients rather than staff) were excluded from the data. Sixth, member checking was utilized to improve reliability of findings; all participants were emailed the results of thematic analysis and opportunity was provided to participants to provide feedback on the accuracy of the main themes reflecting their experiences. Input from three participants was received, followed by incorporation of feedback into the findings. Finally, the final development and summary of themes occurred following a second consultation with the second author regarding the analysis process.

Results

Five main themes emerged in the data analysis process.

1. PSWs' Role and Power

Participants talked about their role at the CMH team as PSWs, with all participants reporting that much of their work takes place within the community and involves providing clients with basic support and helping clients participate in rehabilitation goals and leisure-based activities. One participant talked about new roles that have been provided to them which have contributed to feeling more included in the team, including involvement in program development, promoting the rehabilitation program, interviewing new PSWs, and involvement with accreditation: "I mean that's something, that you're being asked to participate in [accreditation], that's pretty important". The participant also discussed the importance of having their ideas acknowledged within their roles: "It just really felt demeaning to be told that you're part of this [project] and then the person went ahead and did whatever they wanted. Don't ask for my opinion if you don't care".

Participants discussed involvement with treatment planning, reporting that they are not involved in the initial process, but most participants were positive about this involvement. One aspect of their involvement in treatment planning which was discussed by four participants was goal setting. The importance of supervisors allowing flexibility and incorporating client and PSW feedback into the goal planning process was important for participants. Half the participants described feeling, at times, that their supervisors had too much goal planning power.

I really like [the flexibility in goal planning] because there are set goals and agreements, but also there is a little bit of freedom to find something that [the client] really likes. So helping be part of that process, I think that's really useful.

Participants talked about the decision to disclose their experiences of mental illness to clients, with all participants reporting that disclosure is generally left to their discretion and that they feel positive about this decision-making power. Participants also talked about broader decision making within the team, including the importance of PSW representation in committees: “I think having as many intelligent consumer voices on committees, or peer support [voices], are really valuable, especially if it is considered valuable”. One participant was positive of their committee involvement while two participants felt that PSWs are not adequately represented: “I can’t think of any actual committees or programs that [PSWs are] actually participating which [they] aren’t [participating] strictly as consumer contractors”.

2. Institutional Organization

Participants discussed numerous factors related to institutional organization of PSW that have influenced their value and inclusion as a team member, including a lack of union membership to manage institutional issues and promote PSWs as staff members: “In some ways we’re not technically employees, we’re not union. Some people consider [PSW] more of an honorarium”. Increased pay scales, opportunities for raises, and the provision of benefits (such as life and dental insurance) were suggested by three participants. A fourth participant discussed issues surrounding delayed monthly payments affecting their perceived value as a PSW. Disability pay was discussed by one participant who experienced difficulties with PSW pay not being automatically exempt from their disability. One participant, however, had a different outlook on unionization and changes in pay, reporting that higher wages could influence their abilities to relate to clients.

I know what time of the month it is because of how tight people’s finances are or whatever. I haven’t lost touch with those types of things and I think we might lose some of that connection [with higher wages].

Participants also discussed the contract system; three participants felt that removing the contract system and providing opportunity for full-time hours could increase team participation and PSW value. However, the majority of participants also stressed the importance of having options to work less than full-time hours for those satisfied with part-time work, and one participant felt that full-time hours would affect PSWs ability to be flexible in adapting to client schedules.

I wouldn’t want to see only bigger contracts because then that would exclude people that want to work smaller contracts. I would be afraid that they’d built it into one way that wouldn’t work for everyone.

Participants reported overall positive experiences related to job security. Four participants stating that they feel secure with their peer support positions: “I’d say of all the places I’ve ever worked, I feel the safest here, as far as turnover goes”. However, experiences related to career development were lacking for most participants: “[There is] nothing, nothing, nothing. Once a PSW, always a PSW”. Although most participants reported some educational opportunities, all but one participant reported that inclusion in this area could be improved. Issues were related to lack of paid education time, eligibility for courses, advertising of courses to PSWs, acknowledgement for attending workshops, and education aimed towards team members working outside of the field of medicine: “We’re not involved as much [as other team members]. We’re not eligible for a lot of the education opportunities”.

3. PSW Access to Organizational Resources

All participants discussed experiences related to access to resources and client information within the team. Most participants discussed a lack of working spaces at the team: “I wish we actually had a physical place in the mental health teams to call our own to help us ground ourselves there better, it would make it easier to just be there and communicate our needs”. However, one participant reported that lack of space is a universal issue and that PSWs are less likely than others to be working inside of the facility. All PSWs reported that they had access to computers; however, four reported that this access is primarily to use client computers which have created issues with availability and PSWs feeling excluded as staff members: “[I would like] having a computer that we could definitely use. Sometimes when I've used [a computer], I've used the client computers but again you kind of feel like a client". Other examples of feeling excluded for participants were a lack of access to administrative materials and being required to wait in the teams' waiting area prior to meetings. In general, PSWs expressed mostly positive experiences related to staff room access, stating that all participants were allowed to use this resource. Other positive experiences by some participants involved being assisted by staff with accessing community resources.

Access to client information was discussed by participants; all participants reported that they have little access to client information and no access to client files at the team. Two participants felt that this did not usually affect their experiences as a team member, "[I am not told client information if] it's not my business so it's not that important, just what I need to know to help them", with the exception of being unaware when clients have been hospitalized or placed into a shelter. The remaining participants felt that this level of access to client information was limiting in their role: "I guess it's like shadow boxing. Where you're just left really in the dark about what's happening [with a client] and you kind of have to feel your way around".

4. Inter- and Intrapersonal Factors

A number of interpersonal and intrapersonal factors related to PSW experiences as team members were discussed during interviews. Some participant discussed individual characteristics of PSWs which they related to their experiences in the team. These included the attitude, level of assertiveness, and age of the PSW.

In regards to social opportunities, all PSWs reported a lack of opportunity to socialize with the team, partially attributed to PSW often working away from the facility. Two participants noted that they feel disconnected from staff at times when they do spend breaks at the team:

"When I'm at the team and there's staff and PSWs, the PSWs tend to be together and the staff will to be together. There's definite walls". Some participants noted a social division between different staff members at the team, including separation of PSWs, the rehabilitation team, receptionists, and case managers. Furthermore, annual events were important as all participants stated that they have had experiences related to feeling excluded and included as a team member based on invitations to events such as team retreats and Christmas parties: "[We're included in social events] but they need to ask if we can go, if we can attend a party, like a Christmas party for the staff. I just find it ridiculous".

When there are team retreats and sort of functions designed to bring the team closer together the PSWs are usually excluded. We're not permitted to go to [the yearly retreats]. I think we should have the option of being invited, because there is talk that we're just like staff but it doesn't seem like it in most cases.

Participants discussed generally positive interpersonal experiences with staff and perceived attitudes of staff related to PSWs. The individual characteristics of the staff members that participants attributed to these positive experiences included staff members who were outspoken about recovery, welcoming to peer support staff, able to recognize the PSWs at the team, and being aware of the skills of PSWs. Positive feedback from team members was mentioned by three PSWs as a contributor to feeling valued: "The [staff] that do [respect you], they give you feedback that you're able to do things or you found out things that they didn't know. They just consider you another hand to help out". Two participants referred to the importance of being trusted by colleagues, and were both generally positive about the level of trust at their team: "[The team] gives us a lot of trust." All participants were generally positive regarding their experiences with direct supervisors, reporting having supervisors who advocate for PSWs, demonstrate trust in the PSWs, and are approachable, social, flexible, and receptive to feedback and opinions of the PSWs.

However, most participants talked about occasional negative experiences with staff members such as feeling that staff members are not always trusting of PSWs around client documentation, not feeling valued by the majority of team members, witnessing staff ignorance related to PSW level of recovery, being greeted differently by staff when introduced as PSW, and feeling viewed as a client. Most participants also talked about staff having varying levels of comfort working with PSWs: "Some mental health professionals are still not comfortable with feeling fully professionally aligned with people coming from our perspective. Others are very progressive, very relaxed about it".

Participants talked about generally positive experiences with communication, with two discussing the importance of direct communication between PSWs and staff members. All participants discussed communicating through monthly peer support meetings and one participant reported that they feel especially valued when managers also attend these meetings: "Some of the managers of the teams sit in on our conversations, on our peer support meetings, and that's really good. A lot of them don't". In addition, all participants attended monthly meetings with team members and there were differences in opinions regarding increased participation in these meetings; one participant felt excluded by being limited to only one meeting per month while another felt more attendance would be difficult: "A lot of the staff meetings, we're not allowed to attend. I find that you don't get to know a lot about what's going on [at the team]"; "[More involvement in team meetings] could be a mixed blessing because doing contract work is no picnic when you're juggling [contracts] and [taking] public transit, without a cell phone." Furthermore, one participant reported that although PSWs are attending team meetings, they are not actively included in the conversations.

Participants talked about the importance of building working relationships and mutual respect: "As [team members] work with us more closely they get a sense of our style of work and I think in many cases they begin to develop some very well earned respect for us". However, some participants reported that they have previously experienced issues with a lack of familiarity between staff and PSWs and would like to continue to improve this area: "One thing that frequently used to come up was I'd be sitting either in the staff room or in the photocopy room and people would have no idea of who you are". Participants reported that being employed for a significant length of time, spending time at the team, being involved with educational opportunities and social events, and being offered to participate in educational opportunities were factors related to familiarity with staff. Two participants differentiated between disciplines regarding relationship building opportunities: "I think our greatest allies are the Occupational Therapists and the way they're trained. First of all, most often, they're our supervisors so they know PSWs. They're also trained about taking risks and growing, and recovery is possible". One participant discussed "strange roles" that have occurred due to being co-workers with someone who had previously been involved with their mental health treatment.

5. Differences over time

Positive changes over time related to feelings of value and inclusion within the team was referred to by all participants, although most referred to these changes as a "slow process": "I feel that as PSWs, we are becoming part of the team. It is a very slow process of integration because a lot of boundaries are being kind of redrawn involving us". Examples of changes that PSWs reported noticing over time included: more inclusion to social events, more inclusion in committee, greater direct communication between PSWs and other team members, greater access to space within the team facility, greater inclusion in team meetings, and more clinical involvement. Three of the participants referred to the importance of changes in the integration of PSWs occurring in a partnership between PSWs and other staff members: "No one claims to have all the answers here, so we're kind of growing our way forward together"; "It all seems very positive right now. I guess were kind of growing together".

Discussion

The present study aimed to improve the understanding of PSWs' experiences as team members working within Vancouver CMH teams, focusing specifically on their perceived value and inclusion. Primary themes which emerged from participant interviews were: role and power as a PSW, institutional factors influencing their work, access to resources available to the team, interpersonal and intrapersonal factors which have influenced their experiences, and differences over time related to their integration into the team.

Similarities exist between the experiences of PSWs in the present study to those found in American studies, as many participants suggested that more inclusion in social activities, increased hours and pay, good communication, access to client information, and social support within the team are helpful in improving their experiences (Mowbray, et. al, 1998; Gates & Akabas, 2007). Participants also reported that differences among staff, in their comfort level of working with PSWs, exist and influence their experiences within the team, results similar to the findings of Gates and Akabas (2007).

Clinical Implications

Overall, the experiences of the PSWs were generally positive in regards to their role and power within the team, noting the importance of some flexibility in their work. Occupational Therapists and other clinicians working with PSWs in CMH health teams may want to promote open dialogue, acknowledge differing ideas, and provide positive feedback to PSWs to potentially encourage feelings of value and inclusion. PSWs also generally reported positive changes in their integration over time, noting that these changes are slow but moving in a positive direction. This finding provides some preliminary evidence that Vancouver Coastal Health Authority's (VCHA) CMH teams should continue in their current efforts to improve PSW integration.

Although variation did exist within the sample, most participants felt that there is room for improvement in Vancouver's CMH teams and that the current contract systems, low pay, and lack of benefits are negatively impacting their experience as an integrated team members. PSWs working in Vancouver CMH Teams are employed only within a contract system, working approximately 20 hours per month for each individual contract (D. Sesula, personal communication, November, 2008). In part, these contract systems were originally developed to allow PSWs to be employed while continuing to earn Disability Benefits, under the British Columbia Employment and Assistance for Persons with Disabilities, without exceeding the exemption limit of 500 dollars per month (D. Sesula, personal communication, August, 2009). However, this government policy has since changed and currently PSW earnings are exempt from those counted towards Disability Pay (British Columbia Government, 2005, May 1). This policy change allows VCHA more flexibility in reconsidering the current contract system. However, based on the interviews with the PSWs in the present study, changes in this system could potentially be negative if options for part-time hours were not ensured.

The importance of trust was discussed by participants, and research in hospital settings has also demonstrated statistically significant relationships between an organizations' social capital, including trust and value, and worker job satisfaction (Ommen, et al., 2009). Thus, initiations aimed at understanding and developing trust between PSWs and team members may be one method of improving teamwork and cohesion with PSWs in Vancouver CMH teams.

Results from the present study also suggest that some PSWs perceived inclusion may increase if they are less restricted in resource access, such as education, client information, computers, and physical space within the team. Improvement in social involvement within the team and addressing negative attitudes of staff members were suggested, although most interpersonal experiences within the team were positive for participants. PSWs also acknowledged the importance of good communication and relationship building, including ensuring familiarity with staff and including PSWs in staff meetings. Ensuring invitation of PSWs to annual staff events is one change that could be utilized to potentially increase some PSWs' inclusion and working relationships.

Limitations and Suggestions for Future Research

The results of the present study add to the current body of evidence related to PSWs' integration into CMH teams and provide initial practice considerations for VCHA. However, there are a number of limitations to the present study. The experiences of the PSWs varied greatly across teams and participants and the results of this qualitative study are not generalizable to all PSWs. Variable venues for data collection, with some of the coffee shops being loud and crowded, may have contributed to more difficulty with interview conversation. In addition, the limited experience of the student researcher in qualitative data collection and analysis may have influenced the results of the study. One must also be cautious of overgeneralizing the results as the present study had a small sample size and only had participants from two of the Vancouver CMH teams. More research is necessary to improve the amount of evidence in the area of PSWs' team integration and to also acknowledge the experiences of a larger proportion of the PSWs working in CMH teams. Quantitative research, looking at specific issues that have been noted in the present study and previous literature, such as institutional factors and access to resources, is one consideration for obtaining the opinions and concerns of larger sample sizes of PSWs.

In addition, the present study had only one researcher to code interviews. However, member checking and consultation with second author were utilized to increase the reliability of the findings. Future studies could further increase reliability by ensuring that multiple researchers are available to participate in thematic analysis.

The PSWs in this study may have been further along in team integration due to their length of employment at the teams being on average six years, and they may not recall many experiences as a newly employed PSWs. In addition, the present study noted multiple changes over time in the integration of PSW into CMH teams. Thus, PSWs who are being newly integrated into practice may also have differing experiences in their initial experiences. Future research should include PSWs who are in the earlier stages of team integration, to investigate if there are any differences in experiences.

Finally, the results of this study incorporate only the experiences and concerns of PSWs. Obtaining information from policy makers, other team members, and clients may be beneficial in fully understanding the issues affecting PSWs in practice. With a better understanding of these issues, changes in practice would be more feasible and effective.

Reflexivity

The first author is at least a decade younger than all participants. She is also being educated in Occupational Therapy, during a timeframe in which recovery model and psychosocial rehabilitation are large influences in Occupational Therapy practice. She also spent time with PSWs during fieldwork placements and have attended multiple workshops on recovery, stigma, and peer support, one of which was introduced to one of the participants in an educational role. These experiences may have influenced her interview questions and analysis of results differently as she began this project in support of the theoretical foundations behind PSW.

She also has limited experience in practice and health policy settings, outside of OT program, and therefore is not familiar with all of the practices and policies that have been in practice since PSW began in Vancouver CMH. Finally, having a Team Director for a CMH team as a third author for the study may have influenced participant responses. The present study tried to limit this by ensuring that the Team Director was not provided with any raw data. However, some participants may have provided different responses than they may have otherwise.

Conclusion

Overall, five PSWs from VCHA's CMH teams were interviewed for the present study and many positive experiences were reported as they related to their perceived value and inclusion; however, negative experiences were also noted. Five themes which impacted participants' experiences were found among participants. Participants discussed the importance of their role and power within the team, such as having ideas acknowledged, being actively involved in goal planning, and ensuring their voices are part of the mental health system. Institutional organization was discussed, including financial rewards for their work, the benefits and disadvantages of unionization, and the current contract system. PSWs' access to organizational resources, including physical space, computers, and documentation were important to many participants. The influence of inter- and intrapersonal factors on their perceived value and inclusion were shared, and the value of opportunities for socializing, for attending and actively participating in meetings, receiving positive feedback, and the development of trust among PSWs' as well as with other team members were all highlighted. Finally, slow but positive changes over time in the perceived value and inclusion of PSWs within the teams were noted by participants.

The results of the present study, combined with previous research, provide initial considerations and a number of directions for future researchers. With more information, VCHA, and other health authorities, can continue to improve the experiences of PSWs as mental health team members. As noted by one participant in this study, "[PSW] is kind of ground that we are all exploring together".

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Acknowledgment:We thank Regina Casey (Occupational Therapist), and Debbie Sesula and Renea Mohammed (Peer Support Coordinators for VCHA) for feedback on study design. We also sincerely thank the PSWs who participated in the study and the remainder of the Vancouver CMH teams who supported this project.

Author Contributions

Amy L. Richard, Occupational Therapy student researcher, was involved in all aspects of the project. Lyn Jongbloed, second author and faculty supervisor for this study, is credited for input on study design and data analysis, and timely review and critical scrutiny of manuscript. Andrew MacFarlane, third author and clinical supervisor for this study, is credited for conceptualization of the project, as well as some feedback on study design and critical scrutiny of manuscript.

The International Journal of Psychosocial Rehabilitation
Volume 14, Number 1
July 2009– June 2010

Recovery in Schizophrenia:
The Viability of Recovery and Can Psychoanalysis Play a Role?

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Citation:
Osborn, LA. (2009). Recovery in Schizophrenia: The Viability of Recovery and Can Psychoanalysis Play a Role? **International Journal of Psychosocial Rehabilitation. Vol 14(1).** 112-118

Acknowledgments: A special thanks to Kyung-Hee Kim, PhD for the opportunity to write this manuscript and for assisting in the submission of it for publication.

Abstract

This paper reviews the idea of schizophrenia as a chronic, progressive, incurable, genetic defect of the brain; this view being promoted by mainstream media, pharmaceutical companies, psychiatric professionals, and the government (Breeding, 2008). However, in examining the research it would appear that there is merit to the concept of recovery in schizophrenia. This paper addresses recovery rates of persons with schizophrenia, concluding that based on the research; recovery is possible and should be a goal of patients. Additionally, this paper looks at psychoanalysis and its role in treating persons with schizophrenia. The paper concludes with findings consistent with Gottdiener (2006) that there are inconsistencies in the literature. Because of these inconsistencies declaring a moratorium is premature and more empirical studies are required.

Key Words: schizophrenia, recovery, psychoanalysis, psychosis

Introduction

A prominent and accepted view of schizophrenia is that it is a chronic, progressive, incurable, genetic defect of the brain; this view being promoted by mainstream media, pharmaceutical companies, psychiatric professionals, and the government (Breeding, 2008). Fowler and Celenza (2008) indicate that schizophrenia is increasingly viewed as a chronic, biological illness. The American Psychiatric Association states that a return to full pre-morbid function is not common with schizophrenia (Karon, 2008). Shean (2008) states that since the diagnosis of schizophrenia was first introduced, schizophrenia has been thought of as a chronic debilitating disorder with a deteriorating course and little to no hope for sustained recovery. This pessimistic viewpoint arguably dates back to the time of Kraepelin, who was the first to classify symptoms with predicted outcomes, stating that in dementia praecox 75% of patients could be expected to deteriorate to end stage dementia (Whitaker, 2003). A review of the literature, however, would lend a different impression of schizophrenia's recoverability. Davidson (2008) concludes that a majority of people with schizophrenia are seen to improve. Moreover, recovery and wellness should be the goal of each patient (Smith & Bartholomew, 2006), as opposed to pathology, symptomology and illness. Recovery rates of persons suffering from major mental illness shed light on the seemingly incurability of schizophrenics. Harding, Zubin and Strauss (1987) find that between 60% and 70% of persons with schizophrenia were able to become self sufficient over time. This paper will review the concept of recovery as related to the mental health system and the literature related to recovery rates of persons with schizophrenia. Additionally, psychoanalytic approaches to treating schizophrenia will be reviewed and proposed.

Recovery in Schizophrenia

Beers (1908) stated that “Most sane people think that no insane person can reason logically. But that is not so” (p. 57). As early as the 18th and 19th centuries, recovery principles were promoted to patients in asylums or hospitals in the form of moral (psychological) treatment (see Pinel, 1806) leading to a discharge rate of 60% to 80% (Bockoven, 1972). When moral treatment was abandoned for medical based systems of care, discharge rates dropped helping to reinforce the idea of the chronicity of psychosis and other major mental illnesses. It was not until the 1990’s that the recovery movement began to gain momentum (Anthony, 1993). Smith and Bartholomew (2006) state that the recovery model promotes the idea that recovery is possible and should be the goal of all patients and it empowers patients to strive toward therapeutic goals and wellness. To contrast this, many hospitals and treatment centers operate under a medical model, which promotes the identification of symptoms, pathologies, and illness as well as a rigid control (Smith & Bartholomew). Furthermore, Smith and Bartholomew (2006) suggest that for recovery to be effective, hierarchies must be toppled and doctors must relinquish power so that they may empower the patient toward recovery. Anthony (1993) adds that recovery from mental illness involves more than recovery from the illness itself and may include dealing with the stigma patients have incorporated into their very being, side effects of unemployment, and crushed dreams.

The idea of recovery is the new trend in the mental health sector, being the subject at conferences, presentations, and of publications (Silverstein & Bellack, 2008). In the literature, however, there is no consensus about how to even define recovery (Liberman & Kopelowicz, 2005; Roe, Rudnick, & Gill, 2007). Furthermore, Davidson, O'Connell, Tondora, Staeheli, and Evans (2005) state that the word recovery has a variety of uses without having any meaningful implications. Such ambiguity and vagueness allow for ease of use by the clinician, consumer, and researcher but provide little merit for its use. Given the elusive nature of the concept of recovery it is difficult to assess the degree to which recovery principles are translated into actual practice and the extent to which this can even be assessed (Davidson et al., 2005). Nevertheless, recovery practices are being assessed and this occurrence is not new.

Given the exorbitant cost of their operation, asylums, from their construction were under careful scrutiny to illustrate the success of the institution at curing the insane. It was not, until the middle of the 20th century that this data was scrutinized and peer reviewed for efficacy. Bleuler (1972/1978) conducted a 23 year follow-up study with a sample (n=208) finding that 53% were recovered or significantly improved. Huber, Gross and Schuttler (1975) found that of their sample (n= 502) 55.9% of participants were socially recovered. Ciompi (1980) reported results from a 40 year follow study in Switzerland beginning in 1900 and concluded that the long term course of schizophrenia was favorable in 50% of the cases. Harding, Zubin and Strauss (1987) found that 30% of persons with schizophrenia fully recovered in the long run, and that 60% to 70% became self-sufficient. Ogawa et al. (1987) found that 56% significantly improved or recovered. Their sample (n=140) was followed-up between 21 to 27 years (= 23.6 years) post discharge (Harding & Keller, 1998). Lysaker and Buck (2008) summarized that most people with schizophrenia achieve long and meaningful periods of recovery, optimistic outlook on life and a sense of self worth. In a more recent study, Alem et al. (2009) concluded that 70% of patients achieved a complete remission in rural Ethiopia. The authors furthermore concluded that a third (30.8%) had continuous illness suffering, 5.7% had near-continuous remission, and less than a fifth (17.3%) experienced remission for about half of the follow-up period (Alem et al., 2009).

Lastly, Harrow, Grossman, Jobe, and Herbener's (2005) 15 year multi-follow-up research design found both promising and disappointing features associated with outcome and recovery in schizophrenia. Harrow et al. (2005) conclude that outcomes can be relatively positive but most people tend to have an episodic course. Davidson and McGlashan (2005) add that many longitudinal studies have a lack of clear criteria for diagnosis, unclear definitions of recovery, sampling bias, have no controls, and fail to address social and cultural contexts. Despite a clear definition of recovery (Silverstein & Bellack, 2008) and seemingly questionable research methods, at the National level there is a push to transform the mental health system to a consumer focused, recovery system (Harrow et al., 2005). Given the drive for recovery focused treatment, Katz and Gunderson (1990) assessed the overall treatment effects across psychoanalytic and supportive therapies, concluding that persons with schizophrenia can benefit from psychotherapy regardless of theoretical orientation and therapeutic technique. Persons with schizophrenia can improve and despite its seemingly unpopular approach, psychoanalysis may provide an effective medium to facility treatment and recovery of persons with schizophrenia.

Psychoanalytic Contributions to Schizophrenia

Psychoanalysis is now over one-hundred years old (Stone, 1999). The psychoanalytic treatment methods taught today are practically unchanged since the time of Freud and the other psychoanalytic founders (Alexander, 2004). It was not popular to be a reformer among the pioneers of psychoanalysis and those that tried were labeled dissenters and excommunicated creating an environment that did not support change from the beginning (Alexander). Early on, Freud did not believe in the possibility of treating schizophrenia patients with psychoanalysis and not wanting to be labeled separatists, only a few psychoanalysts attempted to treat persons with schizophrenia (Stone). Around 1907 to 1908, some of Freud's inner circle, Federn, Jung, and Abraham, began to express that psychoanalysis could be applied effectively to schizophrenia (Stone). After this time practitioners began applying psychoanalysis to persons with schizophrenia and published their results in the form of case studies. Ferenczi and Meyer in particular helped to popularize psychoanalysis as a viable treatment option (Stone).

Leffel (1999) stated that one of the arguments about psychoanalytic treatment and schizophrenia is centered on whether schizophrenia is a deficit or a defense. The deficit stance states that a schizophrenic person is qualitatively different from others, whereas the defense model places a schizophrenic on the same continuum with other people (Leffel). The latter model argues essentially that a person with schizophrenia is comparable, by using a continuum to a person without schizophrenia. In the deficit model, because of the deficits, a schizophrenic person is not comparable to one without the illness, which appears dehumanizing. Leffel further elaborated on the deficit model by adding that from childhood, a pre-schizophrenic person because of deficient perceptual abilities or learning ability does not normally internalize a sense of self and through stress what internalizations the persons does have disappear. This model does not exclude a biological or medical influence but does not require it.

Today, current perspectives recognize that early psychodynamic approaches to the treatment of schizophrenia were probably misguided and lacked rigorous study because of the heavy use of case reports (Rosenbaum & Harder, 2007). The case study approach makes replication difficult, if not impossible, as well as affecting the ability to generalize any results obtained. More recent research on the efficacy of individual psychodynamic psychotherapy for people with schizophrenia has produced contradictory findings (Gottdiener, 2006).

Karon and VandenBos (1981) randomly assigned schizophrenic patients to an average of 70 sessions of psychoanalytic psychotherapy, medication used effectively, or both. They found that psychotherapy alone, or with initial medication that was withdrawn as soon as the patients could tolerate being without it, led to earlier discharge from the hospital, low recidivism, and improved their thought disorders more than medication alone. Gottdiener and Haslam’s (2002) meta-analysis of 37 studies published between 1954 and 1999, found that individual psychodynamic psychotherapy was associated with significant improvement in persons with schizophrenia (r = .31). They also compared cognitive behavioral and non-psychodynamic therapies to psychodynamic approaches and found that all three produced similar results but they found significant improvements when medication was combined with psychodynamic therapy.

Using randomized controlled clinical trials, May (1968) concluded the contrary of Karon and VandeBos (1981). May found that patients treated only with medication and those treated with individual supportive psychodynamic psychotherapy and conjoint antipsychotic medication had significantly greater improvement rates than patients who received only supportive psychodynamic psychotherapy. This study illustrated that a psychodynamic approach alone was not enough to bring about recovery and decrease symptoms, as well as medication being able to produce the same results without analysis. Additionally, Drake and Sederer (1986) found detrimental effects of psychoanalytic treatment. They conclude that intensive treatment has negative effects, focuses on rapid changes, and fails to appreciate the importance of the treatment alliance. Further, they offer several suggestions some of which include focusing on long-term adjustment, establish a therapeutic alliance, and to let the patient have an active role in treatment.

When summarizing the available research from 1960-1970, Katz and Gunderson (1990) conclude that treatment by dynamically oriented therapist provides no assurance of additional improvement for schizophrenic patients. The authors also conclude that any improvements attributed to psychotherapy are rarely obvious or dramatic. Despite conflicting findings in the literature, Gottdiener (2006) argues that with a close examination of outcome data, a pessimistic viewpoint is unfounded in relation to psychodynamic psychotherapy and schizophrenia. This viewpoint is easily seen, however, if one looks at case studies when evaluating outcomes of psychoanalytic approaches. Given these findings, practitioners continue to apply psychoanalytic techniques today to persons with schizophrenia.

Additions to Psychoanalysis

Psychoanalytic practices continue today with new modifications and additions to the theory. Alexander (2004) comments about Sandor Rado who published several writings starting in 1948. Rado criticizes current psychoanalytic practices but not the underlying theory. Rado stresses to work with present life conditions as well as to build the self-confidence of the patient as opposed to illustrating the therapists power (Alexander, 2004). This idea relates highly to the ideas of promoting recovery in patients and by empowering the patient, the patient is more likely to succeed in treatment. Another addition to psychoanalytic practice comes from Richards (2007). Richards takes Sinason’s (1993) concept of internal cohabitation, or two minds or egos, one step further by applying psychoanalysis to it. In cohabitation there is a psychotic and a non-psychotic mind cohabitating in one body perhaps since birth; the psychotic mind is often experienced as an advice giver who expresses criticism and ridicule if the advice is not taken and often if it is (Richards, 2007). It is then necessary to conduct a dual-track analysis of both coexisting minds knowing that one mind can relate to the therapist while the other wishes to remain hidden (Richards).

Discussion & Conclusions

In reviewing the research it would appear that there are indeed conflicting reports of the efficacy of applying psychoanalytic theories to the treatment of schizophrenia. It is clear however, that whether one uses a psychoanalytic approach or cognitive behavioral approach, there is merit to talk therapy. Recovery of persons with schizophrenia is possible (Huber, Gross, & Schuttler, 1975; Harding, Zubin, & Strauss, 1987; Lysaker, & Buck, 2008) and should be the goal of each patient. Chadwick (2006) reported that one of the problems with biomedical approaches to schizophrenia is that patients feel that clinicians are not listening to their experiences and results in patients having little faith in psychiatrists to aid them in their recovery. This theme relates directly to the recovery model. If a patient has little faith in their clinician, he or she is less likely to feel empowered and be actively involved in their treatment, making recovery tenuous. Gray (2009) adds that people with mental health problems at the very least want their stories, narratives, and voices to be valued and taken into consideration. Katz and Gunderson (1990) indicated that careful selection of patients/participants, as opposed to random selection, specific use of technique and the alliance between the patient and therapist will all contribute to success in treatment of persons with schizophrenia. Shean (2008) adds that a comprehensive, well-integrated spectrum of psychosocial and rehabilitative services along with psychotropic medications, continued medication compliance, and access to comprehensive pharmacological management services can improve the efficacy of recovery. Mojtabai, Fochtmann, Chang, Kotov, Craig and Bromet (2009) add that recovery in this group of patients cannot be fully realized until ease of access to services and improvement of existing services is completed. Lastly, McWilliams (2008) concluded that there is hope for the continued practice of psychoanalysis and that for the theory and technique to survive it may be reinvented in an alternate form.

Implications

Because of the inconsistent findings when looking at psychoanalytic approaches to treating schizophrenia, declaring a moratorium (Meuser & Berenbaum, 1990; Dolnick, 1998) is premature. It is clear, however, the use of case studies must be abandoned as a means of illustrating psychoanalytic successes in treating schizophrenia. Furthermore, more current empirically based research studies are needed before a moratorium should be declared. Practitioners and researchers must work together to begin new original research studies to assess the efficacy. Fowler and Celenza (2008) write that unless outcome research identifies specific benefits of various modes of talk therapy in the treatment of schizophrenia, it is unlikely these treatments and especially psychoanalytic forms of treatment will be included in treatment guidelines and third-party-payer policies. Given the longer requirements of a psychoanalytic approach, this is a critical step if psychoanalysis is to continue to be used to treat schizophrenia. It must be able to work with the managed care system for it to survive. Furthermore, it must be ascertained through research how viable this approach is in the first place given these conflicting findings (May, 1968; Karon & VandenBos, 1981; Drake & Sederer, 1986; Gottdiener, & Haslam, 2002). Lastly, practitioners must utilize and not underestimate the effectiveness of the therapeutic relationship when working with persons with schizophrenia.

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The International Journal of Psychosocial Rehabilitation
Volume 14, Number 2
July 2009– June 2010

The Role of Work in Therapy: Results from a Survey of Licensed Clinicians in New Jersey

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Citation:
Gervey R & Cordeiro N. (2009). The EMILIA project: The Role of Work in Therapy: Results from a Survey of Licensed Clinicians in New Jersey. ***International Journal of Psychosocial Rehabilitation. Vol 14(2). 3-14***

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Acknowledgements:
This project was funded in part, through a Summer Research Internship grant received from the School of Health Related Professions at the University of Medicine and Dentistry of New Jersey.

Abstract

The purpose of this study is to explore the integration of work and therapy in the treatment of outpatients served by licensed clinicians. The relationship between clinicians' beliefs concerning the work capacity of persons with and without schizophrenia is explored. This study uses a mailed questionnaire survey to collect information from New Jersey licensed clinicians (psychiatrists, psychologists, social workers, counselors). More than 2,100 survey questionnaires were returned, yielding a return rate of about 19%. Most clinicians (84%)

indicate that they ‘usually to always’ inquire about work-related issues affecting their clients. Clinicians that expressed the belief that persons with schizophrenia were not capable of working were significantly more likely to recommend sheltered workshop placements whereas clinicians that expressed the belief that persons with schizophrenia were capable of work were significantly more likely to recommend competitive or supported employment placement. Implications for supported employment programs are discussed.

Terms: schizophrenia, supported employment, evidence-based practices, employment issues

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Introduction

Most supported employment services for persons with psychiatric disabilities fail to fully implement evidence-based practices (Bond et al., 2001; Campbell, Bond, Gervey, Pascaris, Tice & Revell, 2007; McHugo et al, 2007). Among the least adhered to evidence-based supported employment principle is the integration of clinical and vocational services (Campbell et al, 2007). The Individual Placement and Support (IPS) supported employment evidence-based fidelity scale has 3 items that operationally define mental health-vocational integration (Bond, Vogler, Resnick, 2001). Specifically, integration is measured on the IPS fidelity scale by: (1) the extent to which mental health and vocational treatment plans are contained in one record, (2) the degree to which vocational and mental health staff meet to discuss treatment plans and issues, and (3) the degree to which the mental health and vocational services are located within the same treatment facility. Implicit in these scale items is the notion that mental health clinicians need to ‘buy into’ the concept that competitive employment is a legitimate and vital part of mental health treatment for clients with severe mental illness.

The concerns and myths that clinicians harbor concerning the placement of persons with severe mental illness in competitive employment have been well articulated (Harding & Zaniser, 1994; Torrey, Bebout, Kline, 1998; Torrey, Becker, Drake, 1995). Dispelling these myths and concerns is one of a number of challenges faced by researchers and program administrators as well as consumer advocates in successfully disseminating and implementing evidence-based supported employment services.

The purpose of this study is to explore the role that work plays in the mental health treatment of clients served by licensed clinicians in the private and public sector. Four sets of questions guided the construction of the study questionnaire and subsequent data analyses. First, do the four licensed clinical disciplines (psychiatrists, psychologists, social workers, counselors) differ in their use of work issues during: the initial assessment phase of treatment, the treatment and goal planning phase of treatment, and the assessment of client progress in treatment? Second, does therapeutic setting (private vs. agency setting) play a role in the use of work as a treatment issue with clients? Third, do clinicians differ in their use of work issues in therapy as a function of client diagnosis (clients with schizophrenia vs. clients without schizophrenia)? And finally, does clinicians’ general assumptions about the work capacity of persons with schizophrenia impact the treatment recommendations that they prescribe for clients with schizophrenia?

Method

A mailed questionnaire survey was sent to all New Jersey licensed clinicians (psychiatrists, psychologists, social workers, counselors) asking about their beliefs and practices concerning the role of ‘work’ in their treatment of outpatient clients.

Sample

According to the New Jersey Division of Consumer Affairs (NJ DCA) and the New Jersey Chapter of the American Psychiatric Association at the time of the study there were approximately 11,200 licensed mental health clinicians in New Jersey: 6,240 licensed social workers, 2,387 licensed psychologists, 1,940 licensed counselors (i.e., licensed professional counselors, certified rehabilitation counselors), and 704 licensed psychiatrists. Survey questionnaires were mailed to all of these individuals.

Procedure

The mailing list for each group of licensed clinicians, with the exception of psychiatrists, was obtained from the New Jersey Division of Consumer Affairs (NJ DCA). The list of licensed psychiatrists was obtained from the New Jersey Chapter of the American Psychiatric Association. The survey instrument and the method used to collect the survey data was approved by the Institutional Review Board at the University of Medicine and Dentistry in New Jersey.

Measure

A self-report survey questionnaire was designed specifically for this study. The survey instrument consists of 12, closed-ended questions. The questionnaire was completed anonymously, however the questionnaire was color coded so that returns could be identified in terms of the respondent's profession. Question #1 determined whether the respondent was a practicing clinician as opposed to an administrator or teacher. Practicing clinicians are those providing direct clinical services to clients. Question #2 categorized the setting in which 'practicing clinicians' delivered therapy (i.e., private practice, agency setting, or both). Question #'s 3 through 7 asked about caseloads and practices, thus non-practicing clinicians were asked to skip these questions. For example, Question #3 asked respondents to estimate the percentage of persons with schizophrenia on their caseload. Question #'s 4 through 7 asked about the extent to which 'work issues' come up in the treatment of persons with and without schizophrenia (such as, the percentage of cases that have a work goal). All respondents were asked to complete Questions #'s 8 through 12. These last four questions asked respondents to provide information about their attitudes and beliefs about the work capacity of persons with schizophrenia. For example, Question #8 asked respondents to choose the most appropriate response to a person with schizophrenia that expresses an interest in work. Question # 11 asks about the perceived relationship between work behavior and psychiatric symptoms. Finally, a clinical vignette was presented describing a person who has just re-entered therapy after a brief psychiatric hospitalization and expresses a desire not to return to the day treatment program but instead wants to pursue employment. Respondents were asked to choose from a variety of options ranging from returning to the day treatment program, entering a sheltered workshop, being referred to the State VR system, a supported employment program or encouraged to find their own employment.

Data analyses

Data analyses include descriptive statistics of the study sample and frequency and percentages of item responses. Non-parametric statistics (Chi-Squares) are used to compare responses between the study's primary grouping variables: professional discipline (psychiatrists, psychologists, social workers, and counselors), clinical setting (private practice vs. agency), and client population (clients with and without schizophrenia). Post hoc analyses are performed when appropriate.

Results

Description of Sample

A total of 2,103 survey questionnaires were returned, yielding an overall return rate of nearly 19%. Return rates were similar across the four professional disciplines thus providing the study with a proportional representation of the licensed clinicians practicing within New Jersey. That is, of the survey respondents approximately 52% are licensed social workers, 24% are psychologists, 18% are counselors, and 6% are psychiatrists.

Eighty-seven percent of the respondents defined themselves as practicing clinicians. Nearly one-quarter (24.1%) reported working in agency/hospital setting, 43% reported working in private practice settings, and 19.8% reported working in both private and agency settings. Psychologists were more likely to be in private practice (67.7%) and rehabilitation counselors were more likely to be in agency settings (32.9%) or no clinical practice (20.7%) (x^2 (9, N = 2103) =258.33, p < .001).

Persons with Schizophrenia on Caseload

Individuals with schizophrenia comprise a very small percentage of the caseloads served by the licensed clinicians responding to the survey questionnaire. Ninety-two percent of the clinicians working in private practice reported that less than 5% of their caseloads are comprised of individuals with schizophrenia. Eighty-two percent of agency-based clinicians reported that individuals with schizophrenia represent less than 25% of their caseloads.

Among the four disciplines, psychiatrists are more likely to have the highest percentage of persons with schizophrenia on their caseloads both within the private practice setting (x^2(12, N = 1278) = 29.53, p < .01) and the agency setting (x^2(12, N = 901) = 52.37, p < .001).

Table 1

Frequency in which Employment Issues are Raised with Clients with Schizophrenia During Assessment Phase of Treatment: Comparisons Between Professional Disciplines

	Never to Sometimes		Usually to Always		
Professional Discipline	N	(%)	N	(%)	Total
Social Worker	212	31%	471	69%	683
Psychologist	82	24.9%	247	75.1%	329

Counselor	79	31.9%	169	68.1%	248
Psychiatrist	17	14.9%	97	85.1%	114
Total	390	28.4%	984	71.6%	1374

Note. Psychiatrists inquire about the work related issues of clients with schizophrenia more routinely (85%) than their clinical counterparts (x2(3, N = 1374) = 17.31, p < .001).

Employment Issues Raised in Treatment

Comparisons between professional disciplines and diagnostic groups. According to survey respondents, employment-related issues are raised quite frequently in therapy. Eighty-four percent of licensed clinicians indicated that they ‘usually to always’ inquire about work-related issues affecting their clients without schizophrenia. Table 1 reveals that 71.6% of licensed clinicians indicated that they ‘usually to always’ inquire about work-related issues within their clients with schizophrenia. Psychiatrists inquire about the work related issues of clients with schizophrenia more routinely (85%) than their clinical counterparts (x^2(3, N = 1374) = 17.31, p < .001).

Agency v. private practice settings. Licensed clinicians in private practice reported raising employment issues significantly more often (86.3% vs. 76.7%) than agency-based clinicians when working with clients without schizophrenia (x^2(1, N = 1296) = 17.59, p < .001); and with clients with schizophrenia (79.2% vs. 62.6%), (x^2(1, N = 1005) = 33.35, p < .001.

Table 2
Percentage of Clients with Schizophrenia with Explicit Employment-Related Treatment Goal: Comparisons Between Clinicians Working in Agency-Based v. Private Practice Settings

	Less than 50%		Greater than 50%		
Practice Setting	N	(%)	N	(%)	Total
Agency-Based	344	78.7%	93	21.3%	437
Private Practice	361	70.2%	153	29.8%	514
Total	705	74.1%	246	25.9%	951

Note. Clinicians in private practice reported significantly more clients with schizophrenia have a specific work-related treatment goal compared to clinicians working in agency *settings (x2(1, N = 951) = 8.43, p < .01).*

Explicit Employment-Related Treatment Goals

Comparisons between professional disciplines and diagnostic groups. The majority of clinicians reported that for most clients (with or without schizophrenia) employment-related treatment goals are not explicitly included in the treatment plan. Only one-quarter of the respondents reported that more than 50% of their clients with or without schizophrenia have a specific work-related treatment goal. Among the disciplines, social workers reported the lowest percentage of clients with work goals for clients with schizophrenia (x^2(12, N = 1305) = 30.34, p < .01).

Agency v. private practice settings. Private practice clinicians indicated that they include work-specific goals in the treatment plan of clients with schizophrenia significantly more frequently than clinicians working in agency settings. Table 2 shows that 29.8% of licensed practitioners in private practice reported that 50% or more of their clients with schizophrenia have a specific work-related treatment goal compared to 21.3% of clinicians working in agency settings (x^2(1, N = 951) = 8.43, p < .01).

Table 3

Frequency in which Treatment Progress of Clients with Schizophrenia is Evaluated Based on Employment Status and Work Adjustment: Comparisons Between Professional Disciplines

	Never to Sometimes		Usually to Always		
Professional Discipline	N	(%)	N	(%)	Total
Social Worker	188	27.6%	494	72.4%	682
Psychologist	60	18.4%	266	81.6%	326
Counselor	59	24%	187	76%	246
Psychiatrist	14	12.3%	100	87.7%	114
Total	321	23.5%	1047	76.5%	1368

Note. Psychiatrists reported using this criteria with their clients with schizophrenia significantly more frequently than other disciplines (x2(3, N = 1368) = 20.25, p< .001).

Evaluating Treatment Progress Based on Employment Status of Patient

Comparisons between professional disciplines and diagnostic groups. Most clinicians reported using the client's employment status and/or work adjustment in evaluating client progress in treatment. Eighty-eight percent of clinicians reported that they 'usually to always' use employment status and work adjustment in evaluating treatment progress with their clients without schizophrenia. Table 3 shows that 76.5% of clinicians reported that they 'usually to always' use employment status and work adjustment in evaluating treatment progress with their clients with schizophrenia. A significantly higher percentage of psychiatrists (87.7%) reported using this criteria with their clients with schizophrenia compared to the other disciplines ($x^2(3, N = 1368) = 20.25, p< .001$).

Agency v. private practice settings. Private practitioners compared to agency-based practitioners were significantly more likely to use employment status and work adjustment information in evaluating treatment success in clients without schizophrenia (91.9% v. 78.3%) ($x^2(1, N = 1304) = 47.14, p< .001$); and in clients with schizophrenia (87% v. 64.1%) ($x^2(1, N = 1002) = 71.80, p< .001$).

Table 4

High v. Low Expectations of Persons with Schizophrenia in Terms of Work Capacity: Comparison Between Professional Disciplines

	Low Expectation Less than 50%		High Expectation Greater than 50%		
Professional Discipline	N	(%)	N	(%)	Total
Social Worker	531	52.5%	480	47.5%	1011
Psychologist	202	44.4%	257	56%	459
Counselor	167	52%	167	48%	348
Psychiatrist	79	60.8%	51	39.2%	130
Total	993	51%	955	49%	1948

Note. Psychologists were more optimistic and psychiatrists were less optimistic than other licensed disciplines (x2(3, N = 1948) = 15.08, p< .01).

Capacity of Persons with Schizophrenia to Work

Survey respondents were sharply divided in terms of their beliefs concerning the work capacity of persons with schizophrenia. On average, nearly half (49%) of the respondents believed that persons with schizophrenia are capable of holding a job and indicated that the employment rate for persons with schizophrenia should be greater than 50%. The other half was less optimistic and indicated that the employment rate for persons with schizophrenia should be less than 50% (averaging closer to 15% to 25%). Table 4 reveals that psychologists (56%) were more optimistic and psychiatrists (39%) were less optimistic than other licensed disciplines ($x^2(3, N = 1948) = 15.08, p< .01$).

Subsequent analyses revealed that practicing clinicians with higher work capacity expectations of clients with schizophrenia: (1) raised employment issues more frequently with these clients ($x^2(1, N = 1322) = 26.15, p< .001$), (2) evaluated treatment success more frequently in terms of the employment status of these clients ($x^2(1, N = 1319) = 34.51, p < .001$), and (3) reported a higher percentage of explicit work-related treatment goals for these clients ($x^2(1, N = 1264) = 40.86, p< .001$).

Table 5

Treatment Recommendations of Clinicians with High and Low Work Capacity Expectations for Persons with Schizophrenia

Work Capacity Expectations	Treatment Recommendations: Client wishing to work following a brief hospitalization should be referred to a:												
	Day Treatment Program		Pre-Vocational Program		Sheltered Workshop		Supported Employment Program		DVRS office		Other *		Total
Low	265	60.9%	299	52.6%	155	60.5%	146	37.2%	49	43%	74	42.3%	988
High	170	39.1%	269	47.4%	101	39.5%	247	62.8%	65	57%	101	57.7%	953
Totals	435	22.4%	568	29.3%	256	13.2%	393	20.2%	114	06%	175	09%	1941

= Other category includes referral to seek competitive employment on their own, some combination of two or more categories, and other (write-in suggestions).

Note. Clinicians with high work capacity expectations are significantly more likely to refer clients to supported employment whereas clinicians with low work capacity expectations are more likely to refer the client back to their original day treatment program (x2(5, N = 1941) = 66.03, p< .001).

Clinicians' Recommendation to an Individual with Schizophrenia Recently Discharged from a Brief Hospital Stay Who Indicates an Interest in Pursuing Competitive Work Instead of Returning to Day Treatment Program: Clinical Vignette

Responses to the clinical vignette are presented in Table 5. The most frequent recommendation was to encourage the client to enroll in a pre-vocational program (29.3%). The next most common recommendation was for the client to return to their day treatment program for a period of symptom stabilization (22.4%), followed next by suggestions to enroll in a supported employment program (20.2%). Thirteen percent recommended that the client enroll in a sheltered workshop program, and 6% suggested that the person register with the state vocational rehabilitation agency. Only one-half of one-percent (10/1941) recommended the client to immediately pursue competitive employment. There were no significant differences between the disciplines in responding to this case vignette ($x^2(15, N = 2069) = 21.16, p < .13$) nor between clinicians working in different work settings (agency v. private practice) ($x^2(7, N = 1390) = 6.46, p < .48$) . However, clinicians with high expectations were twice as likely to recommend competitive and/or supported employment for the individual with schizophrenia as compared to clinicians that held low work capacity expectations ($x^2(1, N = 1941) = 7.66, p < .05$).

Discussion

Despite the relatively low response rate obtained on the questionnaire, and the small percentage of clients with schizophrenia served by the respondents, the findings of this study remain of high interest and value given that the respondents are proportionately representative of licensed clinicians in the State of New Jersey and represent a sample that is rarely recruited for studies related to vocational mental health issues. In fact, this is the only empirical study known to date that collects data from private practitioners concerning the role that work plays in the therapeutic relationship. One of the many refreshing findings that come out of this survey is the role that employment and work-related issues seem to play in the treatment of clients, including those with schizophrenia. Not only do the study sample consider employment relevant to their assessment of clients coming into treatment, but over 75% of these clinicians report that they 'usually to always' consider the client's employment status in assessing client progress in treatment. Nonetheless, only a quarter of clinicians report developing a specific work-related treatment goal for at least half of their client caseload. The good news however is that clients with schizophrenia are just as likely to be included in that group as persons without schizophrenia.

Given the lack of integration of vocational and clinical services in the public mental health sector (McHugo et al, 2007), the fact that this study finds clinicians integrating work issues into mental health treatment is extremely encouraging. Nonetheless, several familiar patterns emerge from the data. First, there is a general tendency for the licensed clinicians in this sample to assess employment status and work adjustment less routinely within their clients with schizophrenia than with clients without schizophrenia. Second, while psychiatrists in this sample consider work issues more frequently than their colleagues, they are, on the other hand less optimistic than their colleagues in terms of the work capacity of individuals with schizophrenia. Third, agency-based clinicians consistently consider work issues less frequently than private practitioners, regardless of client diagnosis. And fourth, the overwhelming experience of clinicians in both private and agency settings is that persons with schizophrenia in treatment are unemployed.

Seventy-five percent of all survey respondents report employment rates of less than 25% for their clients with schizophrenia with most indicating employment rates of less than 5%. This contrasts with more than 75% of clinicians reporting employment rates of at least 50% for their clients without schizophrenia. As expected, private practitioners report a significantly higher employment rate for persons with and without schizophrenia on their caseloads. While this might suggest a treatment setting effect in regards to how clinicians view the work capacity of persons with schizophrenia, the data suggests otherwise. After controlling for the employment rate of caseload clients with schizophrenia, both agency-based and private practice clinicians rate the work capacity of persons with schizophrenia similarly. That is, clinicians across therapeutic settings are just as likely have low work capacity expectations for persons with schizophrenia when caseload employment rates are under 25%. Conversely, clinicians across therapeutic settings report high work capacity expectations when caseload employment rates are over 50%. Consequently, there is a significant positive correlation between clinicians' work capacity expectations of persons with schizophrenia and clinicians' reported caseload employment rates of clients with schizophrenia. As the percentage of clients with schizophrenia on a clinician's caseload rises in terms of employment, there is a rise in the clinician's level of expectation of work capacity for this population. More importantly, there appears to be a tipping point in terms of reported confidence in the work capacity of persons with schizophrenia. When caseload employment rates approach 50%, the percentage of clinicians reporting confidence in the work capacity of persons with schizophrenia jumps from 38% to 61%.

In contrast, clinicians' work capacity expectations are significantly negatively correlated with the percentage of persons with schizophrenia on caseloads. That is, the larger the caseload of persons with schizophrenia, the lower the expectation of work capacity. Given that most individuals with schizophrenia receiving treatment are reported to be unemployed, it stands to reason that high caseloads of unemployed clients with schizophrenia reinforces the notion that this population is not work ready.

These findings suggest that clinicians' personal beliefs and attitudes about a client's work capacity may be influenced by direct observation of the client's working behavior at the time of treatment. These observations may also influence clinicians' inquiry of, and responsiveness to work-related issues in treatment. That is, clinicians that have a significant number of clients with schizophrenia employed may be more willing to regard the work capacity of clients with schizophrenia as 'reasonable'. Clinicians that have a low percentage of clients with schizophrenia employed may be more likely to hold a more negative belief about the work capacity of clients with schizophrenia and be less interested in, and more dismissive of the employment-directed goals of these clients. In fact, survey respondents that reported a low work capacity expectation of clients with schizophrenia also tended to assume a strong relationship between schizophrenic symptoms and work behavior. Therefore, these clinicians' may be reluctant to support the employment goals of clients with schizophrenia in the service of trying to help these clients stave off symptom exacerbation or relapse. Consistent with this assumption, clinicians in this study reporting low work capacity expectations for clients with schizophrenia were more likely to prescribe the more conservative, segregated and restrictive vocational treatment options available to them in the clinical vignette that had a client with schizophrenia requesting help in obtaining competitive employment after being discharged from a brief psychiatric hospitalization.

There are several practical, policy and research implications of the study findings. On a practical level, supported employment programs might be well served to target clinicians that have relatively high employment rates for persons with schizophrenia on their caseloads. This group may be more likely to believe in the work capacity of clients with schizophrenia and therefore more likely to refer clients to supported employment programs. Targeting clinicians with exceptionally large caseloads of unemployed clients with schizophrenia, while seemingly an efficient strategy for recruitment, might actually turn out to be counterproductive. This group of clinicians may in fact be among the least optimistic in terms of the work capacity of persons with schizophrenia.

On a policy level, supported employment programs might be more successful in helping to transform mental health clinicians' attitudes about the work capacity of persons with schizophrenia by making it a program goal to increase clinicians' caseload employment rates for persons with schizophrenia to at least 50%. This probably will require a change in recruitment strategy whereby programs would need to restrict the number of clinicians that they work with so that these clinicians might more readily experience the needed jump in employment associated with high work capacity expectations for persons with schizophrenia.

The hypotheses generated by this study suggest various lines of future research. For example, do clinicians who refer to supported employment programs have higher work capacity expectations of clients with schizophrenia than clinicians who do not refer to the program? Do clinicians who refer to supported employment programs and who witness a sizeable increase in their caseload employment rates demonstrate an increase in their work capacity expectations of clients with schizophrenia? Does mandating clinicians to inquire about work and setting work goals and monitoring clinicians' evaluation of their clients' progress in work behavior lead to increased work capacity expectations?

Finally, the limitations of this study must be acknowledged. While the response to the survey yield a proportional representation of professional licensed disciplines within New Jersey, over 80% of the target population did not participate in the survey. Thus, the study sample cannot be described as representative of licensed clinicians in New Jersey or elsewhere for that matter. It is quite possible that the sample consists of a disproportionate number of clinicians interested in the topic of work, thus making the study findings spurious. Furthermore, the fact that most respondents report serving small numbers of clients with schizophrenia puts into question the relevancy or validity of the data. In other words, should the reader accept the fact that clinicians who serve a small number of clients with schizophrenia provide a significant insight into supported employment and the issue of work capacity expectations for persons with severe mental illness? And lastly, the survey questionnaire itself is somewhat suspect in terms of reliability and validity since it was developed specifically for this study and did not undergone psychometric testing prior to administration.

Despite these obvious limitations, the authors believe that the findings offer the field a way to move a step closer toward understanding the mechanisms involved in helping to transform clinician attitudes toward work issues and setting work goals in the mental health treatment of persons with schizophrenia.

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The International Journal of Psychosocial Rehabilitation
Volume 14, Number 2
July 2009– June 2010

Reference Group Focused Therapy: A New Integrative Short-Term Social-Psychology Based Approach

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Citation:
Salganik I. & Soifer P. (2009). 'Reference Group Focused Therapy – a New Integrative Short-Term Social-Psychological Based Approach. **International Journal of Psychosocial Rehabilitation. 14 (2), 15-24.**

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Abstract

In this paper we present a new psychotherapeutic approach - Reference Group Focused Therapy (RGFT). The most striking feature of this approach is that it takes into consideration the entirety of person's social environment expressed through the corresponding reference groups and person's sub-cultural background as opposed to other psychotherapies. RGFT is based on a number of established social psychological theories as well as on social learning theory, object relation theory, attachment theory and other approaches.

RGFT addresses external person's reference groups (such as family, working place, etc.) along with his/her internalized groups. It belongs to short-term client-centered psycho-therapies and has already demonstrated its efficacy in different clinical entities such as phobias, OCD, eating disorders, adjustment disorder, somatization, anxiety disorder, panic attacks, and others. During the assessment phase of a treatment we use Trigger Event Analysis – a newly developed tool that enables understanding of person's individual vulnerability and allows both the prediction of the future conflicts as well as finding more effective ways of avoiding or minimizing them.

The treatment itself focuses on studying the conflicts of both internal (between the internalized groups) and external (between internalized and external groups) origin. One of the main goals of the treatment is to allow a patient to uncover the present (external groups) as well as historical (internalized groups) social influences thus promoting his/her individuation process along with amelioration of subjective distress. The article includes two case-reports illustrating the approach.

Key Words: Reference Group, social influence, social psychology, psychotherapy, conflict

> “ *Our mind is nothing but a bundle or collection of different perceptions, which succeed each other with an inconceivable rapidity, and are in a perpetual flux and movement."*
>
> *David Hume. A Treatise of Human Nature. Book I, Part 4, Section 6 (“Of Personal Identity”) 1739 (published anonymously)*

Introduction

Modern society is facing a dilemma.

On one hand statistics demonstrates a steady increase in stress-related disorders (Sutton. 2007), on another hand, though there is a common demand in quality of life improvement, society is not prepared to corresponding investments in both time and financial resources due to other prerogatives. Psychotherapy, which is one of the most effective tools in coping with stress (Brody & Stuart, 1994; Jones et al., 1999; Strain, 1995), has historically been transformed into an attribute associated with people who are well off financially, in some way not dissimilar to golf club or prestigious car (Austad, 1996). The wish to make psychotherapy more widespread, initiated development of short-term psychotherapies such as psychodynamic short-term treatments, cognitive-behavior therapy (CBT), interpersonal therapy (IPT), and others. All of these therapies share a dichotomistic view that distinguishes between an individual and his/her environment not seeing them as one undividable unity.

As a result, the problem that has been intrinsic with such therapies was an inevitable compromise in goal setting and a reductionist approach in their assessment of the human psyche. Social psychology with its emphasis on social influence has always accepted the view that a person should not be regarded outside the context of his/her social matrix (Myers, 2006). Yet, its subject was in general the explanation of normative social phenomena and not exploration of human psychopathology.

We introduce here a newly conceptualized psychotherapeutic approach based mostly on the elaborations of reference group theory and related concepts of social psychology along with other conceptions such as learning theory, attachment theory, object relation theory , and others. The approach is intended for treatment of a Social Influence Related Disturbance (SIRD).
SIRD is defined here as any mental or psychosomatic disorder that was originated or co-contributed by either external social influence mediated by individuals or groups and / or their intrapsychic internalizations.

It’s apparent that this category does not introduce any new nosological entity per se, its purpose is solely the shifting of point of view into the direction of the implied impact of social influence.

A patient, for that purpose, is regarded as a member of a social group or a number of groups. The disorder is seen in a context of functional and structural group changes, the patient’s interactions with the group, as well as interactions between the groups’ internal representations among themselves and/or external groups.

RGFT

As stated before, RGFT deals with a spectrum of disorders associated with social influence.

It may be implied, that these disorders (SIRD) originate from a psychological reaction to a stressor associated with influence caused by external or internalized groups. This view is congruent with Reference Group Theory (Hyman ,1942; Sherif, 1948; Merton & Kitt, 1950; Deutsch & Gerhard, 1955) which looks at psychosocial stressor and maladaptive response to it in context of person's reference groups (Hyman & Singer, 1968). We also adapt here the concept of the internalized group firstly introduced by Turner (Turner, 1987, 1991) which is analogous to the object relations' internal representation (Fairbairn, 1954; Guntrip, 1995). Additionally, we hypothesize that derivation of the RG's social influence is in the basic need for attachment similar to understanding of attachment theorists (Ainsworth et al., 1978; Bowlby, 1999) and that this influence is mostly mediated by modeling as stated by Bandura (Bandura et al., 1989, 1999). In our elaboration we were influenced also by the conception of multiple selves (James, 1950; Assagioli, 2000; Stone & Stone, 1983; Stone & Winkelman, 1993).

Before discussing the therapeutic approach, we introduce a number of theoretical elaborations.

The RGFT basic assumptions are as follows:

1. Person's behavior, emotions, and attitudes can be comprehended only within the context of his/her present and historical social matrix.

2. The reference groups differ in their impact on a person in accordance to the importance that he/she ascribes to those groups.

3. Person can be regarded as comprised of a "Primary Self" - a personality core that emerges prior to socialization (initiated by the begin of speech acquirement), his/her internal groups (Secondary Selves), and internalization of his/her subculture.

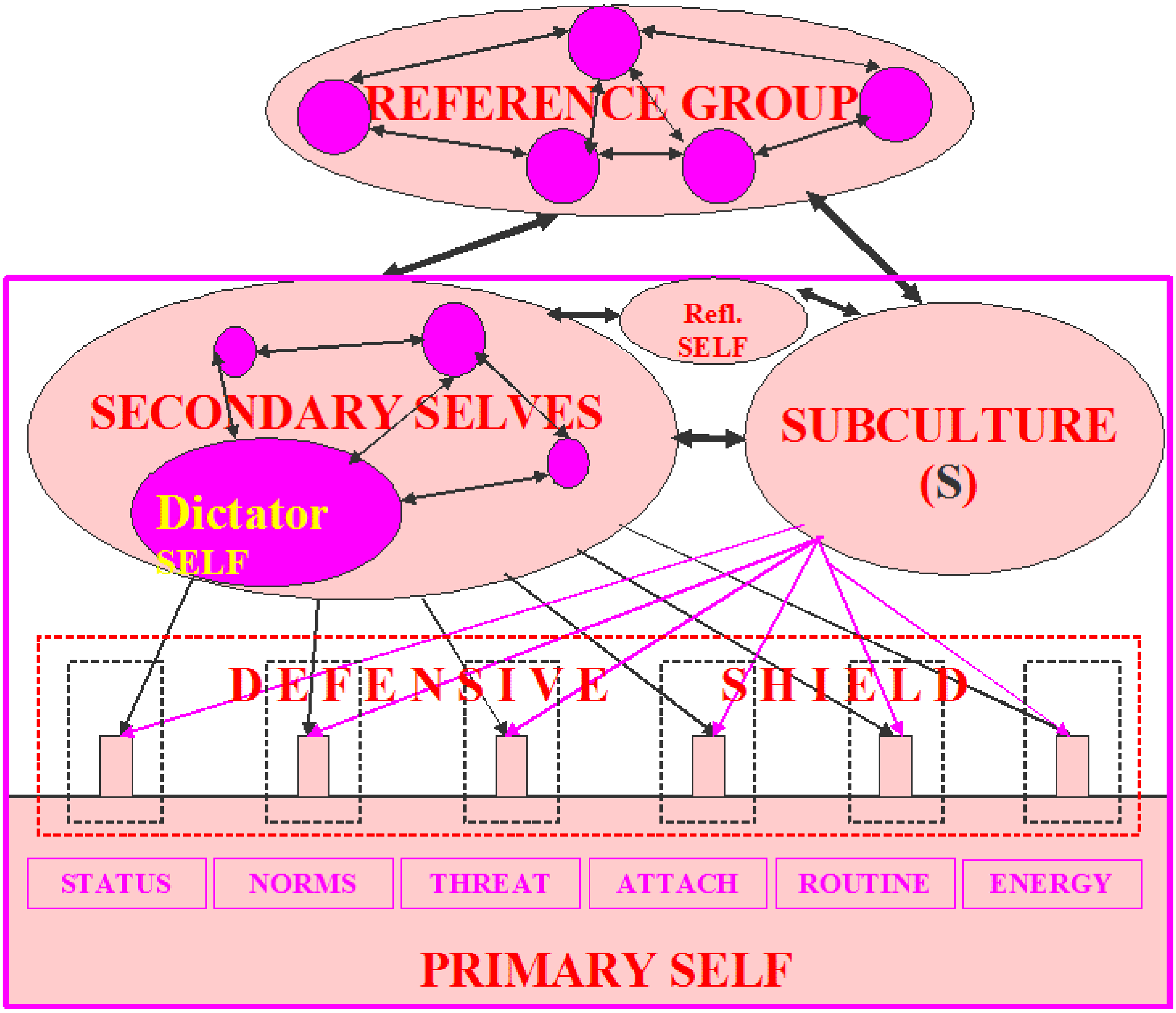
4. Social influence (mediated by the internal and external RGs) is partly conscious and partly unconscious.

5. Much of the psychopathology developed after the begin of person's socialization can be explained through the conflicts occurring among person's internal groups (Secondary Selves) as well as through conflicts between the person's internal (Secondary Selves) and external RGs and/or personality core (Primary Self)

Another important theoretical elaboration is Trigger Event Analysis (TEA) that has been described in details elsewhere (Salganik & Soifer, 2008). TEA divides all triggers leading to some kind of mental breakdown into 6 categories: Status, Norms, Attachment, Threat, Routine, Energy. These triggers have either explicit or implicit social characteristics, which means that they are associated with patients' RGs (either internal or external ones). The given context of mental deterioration leads to the conclusion that these triggers have to be regarded as negative triggers - events that precipitate deterioration in mental states.

TEA assumes that an individual reacts to all possible triggers in a for him/her unique and specific way. The same trigger that may have a profound impact upon one particular individual may leave another one totally unaffected. The personal sensitivity to specific triggers is categorized in exactly the same way as the triggers themselves. That means that each person will exhibit sensitivity (or lack of it) to such issues as changes in status, RG norms, attachments, threats, routine, and energy resources in a for him/her specific way. We call the corresponding personal sensitivities – Sensitivity Channels. For example, if a person is sensitive to changes in his /her status and the corresponding changes are imposed on him/her by the social environment, there will be a high probability for aversive mental response.

Figure I summarizes the described theoretical model:



Primary Self: is a psychical structure that develops prior to socialization. Socialization in the sense of RGFT overlaps greatly with the same term in social psychology and thus does not include the first two years of life prior to language acquisition and prior to the brain ability to internalize integrative aspects of the other object (or him/herself), including perception, cognition, emotion, and behavior.

Secondary Self: is a psychical structure that develops in a process of socialization. It represents the internal image and is a result of internalization of the corresponding RG (that could be a single person or a group of persons). Secondary Self comprises following characteristics (that in a way resemble a blue print of a corresponding person/group): perceptional, cognitional, emotional, and behavioral patterns.

Dictator Self: is a subtype of a Secondary Self which Reflective Self is tightly identified with. It is thus the most dominant among the Secondary Selves and influences greatly a person's perceptional, emotional, cognitive, and behavioral pattern.

Reflective Self: is a psychical structure that represents a person's autonomic ability to evaluate a given situation and to choose a corresponding adaptive response.

Subculture: is a source of a social influence upon a person that can not be inferred or deduced from any specific RG effect but is a result of an integrative impact of a certain social environment as a whole.

Defensive Shield: is a variety of mostly unconscious adaptive mechanisms that a person develops in order to diminish a negative impact on his/her Sensitivity Channels.

In addition, we summarize some novel aspects of our approach in comparison to other psychotherapies:

1. It takes into consideration an entirety of the patient's RGs and not just their selected subgroup

2. Secondary Selves are typically associated with real persons or RGs which are charged with certain personal significance

3. Secondary Selves are interrelated in a hierarchical order where the Dictator Self secures to itself the highest rank among the Secondary Selves.

4. Much of psychopathology is being interpreted through the conflicts among Secondary Selves themselves and between Secondary Selves and external RGs.

5. A new concept – Trigger Event Analysis reflects the individual sensitivity regarding the variety of possible psychosocial stresses.

RGFT (therapeutic aspects)

Assumptions about the therapy:

1. Psychotherapy's general goal is to facilitate patient's adaptation to his/her specific society

2. Individuation is an utmost goal of RGFT and can be achieved by exploring person's social influences and bringing them into consciousness

3. The treatment is client-centered, person is advised from the very beginning that he/she is the only one that actually knows and is in the position to cope with his/her problems and not the therapist. Any attempt on patient's side to invite social influence from the therapist is explored and patient's responsibility for resolving of his/her problem emphasized

4. The focus of the treatment is the investigation of "inversed" transference, e.g. the impact of patient's internal groups on his/her attitudes and behavior – ("acting on behalf of internal groups")

5. The treatment is "patient-driven", the working topics and the termination of treatment are determined by a patient

Treatment Guidelines

Patient Selection Criteria

1. An analysis of the patient's problem makes it feasible that there is a major issue associated with his external and/or internal RG's which comprises one or all of the following:

- Paucity of RG's number

- One or more of his/her RG's has a pathogenic quality (exerts a profound negative emotional impact -causes significant mental distress upon a person. We assume, in the context of TEA, that this negative impact will be upon one or more vulnerable Sensitivity Channels)

- One or more of his/her empathetic RG's has undergone recent functional or structural changes (empathetic group is the one that exerts a profound positive emotional impact upon a person. Again, this influence will be mediated through the one or more Sensitivity Channels involved)

- Existing conflict(s) between internalized groups themselves, and/or between internalized and external group(s), and/or any of the above with the primary self

2. A patient has to be cooperative with the therapy and to be able to comprehend its goals.

3. At assessment stage, an analysis of the internal and external RGs, that are relevant for a person should be performed.

It is crucial to evaluate whether the patient's RGs play an important role in initiation of the present mental crisis.

Trigger Event Analysis (TEA) is performed - typical triggers for a patient identified. The triggers are evaluated against the relevant RGs. If triggers are associated with only a limited number of specific external RGs, then the problem is likely to be with those external groups – RGFT for external groups (RGFT ext.) is advised. If triggers are more or less evenly distributed among different external RGs – there is probably a problem with the patient him/herself. In this case, RGFT for internalized groups (RGFT int) is advised.

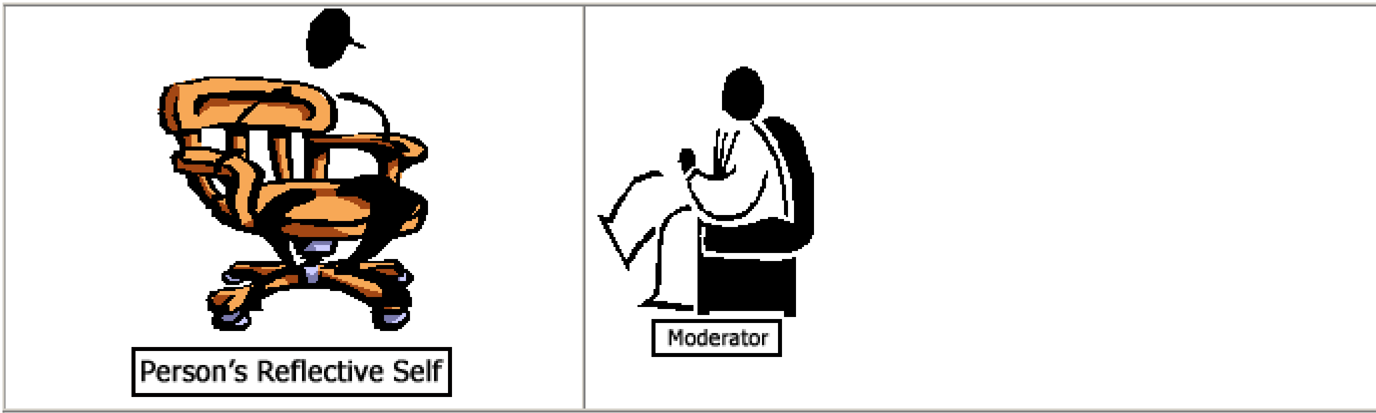
Therapeutic approach for the external RGs (RGFT ext) is handled elsewhere (Salganik & Soifer, 2008). It should be mentioned that though described in association with schizophrenic relapse, the paper conclusions may be as well generalized for other mental disorders associated with SIRD. In this paper we describe a therapeutic approach relevant for the internal RGs (RGFT int).

4. Treatment stage in RGFT int. is based on a proprietary theoretical model and aims at enhancement of patient's individuation and better awareness of social influences.

The RGFT int. Session:

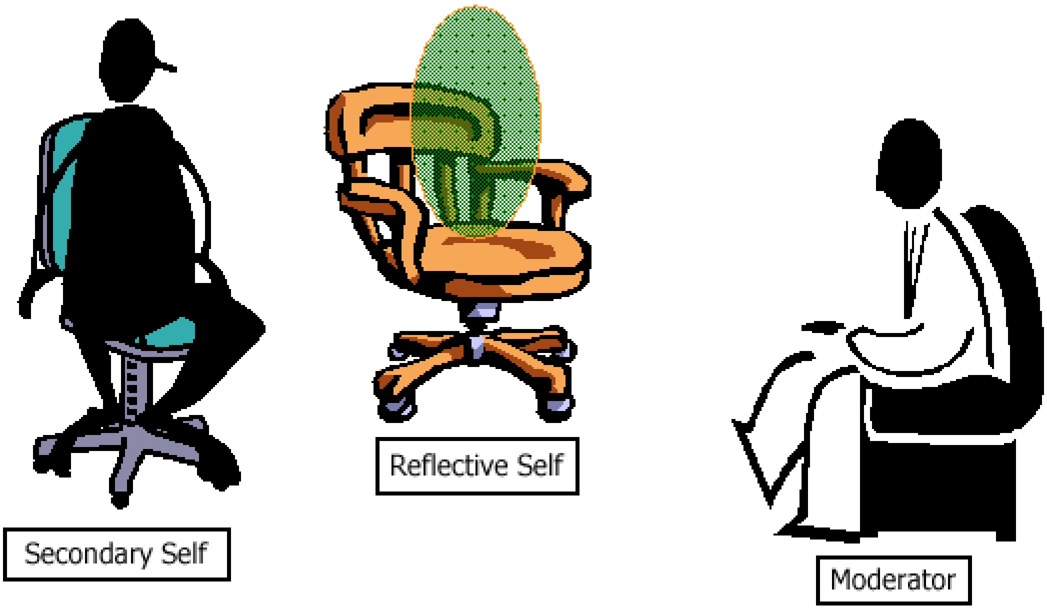
Step One: Deciding Which Secondary Self to Interview

- Identify the issue, distress, problem, or Secondary Self the patient wants to focus on.
- Moderator and person's Reflective Self can co-decide which Secondary Self to begin with.
- At the beginning of the treatment, the relevant Secondary Self is usually the Dictator Self.



Step Two: De-identification (similar to [Assagioli, 2000;, Stone & Winkelman, 1993) - interviewing the Secondary Self :

- Have the person physically move over from the Reflecting Self's chair into the chair or space of the self to be interviewed (usually the Secondary Self).
- Moderator asks the Secondary Self questions that bring forth who that SS is, its attitudes, scenarios, its reflection of a patient, etc. Extensive use of Socratic questioning.



Step Three: Harmonization

Evaluation of conflicts between the Secondary Selves and between certain Secondary Selves and Reflective Self that still persist following the process of de-identification. If detected the conflict is resolves by specially developed mediation techniques.

Case Report 1:

R. female, 21y. old, high school graduate, single. History of alternating bulimia and anorectic symptoms since the age of 12. Individual dynamic psychotherapy for a period of one and a half years, long standing family therapy and hospitalization on a specialized ward for the patients with eating disturbances for a period of 2 months. Despite the therapy, persistence of both bulimic and anorectic symptoms, recently appearance of depressive symptoms with high level of anxiety and sporadic suicidal ideation.

On the RGFT diagnostic interview where a patient was questioned about the most significant persons in her life she reported her father to be in the first place on the significance scale. It was obvious that the internalized image of the father served as a Dictator Self for the patient. During the interview of the internalized image on a “hot chair” her “father” turned out to be a rather dominant person with perfectionist character traits which was very persuasive and criticizing towards his family members including the patient herself.

As a result of a deidentification process R. realized already during the first session that many of her character traits originated in father’s influence on her. She understood that the father himself was trapped within his never ending striving for perfectionism which left him with a high level of anxiety and low self esteem despite his advanced social position.

In one of the following sessions R. asked by herself to initiate an interview with her own self representation as she was 7 – just before the birth of her smaller sister. Then, another self representation - just following the birth of her sister was interviewed. These representations, though in close time proximity were rather distinct. The R. “before” showed herself apprehensive about her future, felt that approaching birth of her sister signifies her mother’s disappointment in R. The R. “after” was a different story altogether. She was full of anger towards her parents that “left” her for the sake of her smaller sister and was out for revenge. “If they don’t want me as their daughter then I don’t need them as my mammy and Dad!”. Another internalized group of her peer friends at the age of 12 when R. showed her first anorectic symptoms demonstrated its eagerness to loose weight in order to line up with the most skinny models. Following seven treatment sessions R. was virtually free of her bulimic symptoms, she has rebuilt her relationships with all the members of her family and entered the University studies. During her 1.5y year follow-up she was still in remission.

Case report 2:

M., female, 22y old, high school graduate. Following the graduation party that lasted until the early morning hours fainted. Shortly after this episode she developed a severe agoraphobia that restricted her to not leaving her house for a period of four and a half years. Several treatment attempts with various antidepressant and anxiolytic medication did not result in any significant symptom relief. Her mother’s internalized image that served as the most dominant Dictator Self happened to demonstrate phobic attitudes in regard to fainting. As a result of the process of deidentification and harmonization, a patient could leave her house after two RGFT sessions and could reintegrate into the working process and restore her social life after 6 sessions. Her remission was still stable on a one year follow-up meeting.

Conclusions:

The described novel psychotherapeutic approach Reference Group Focused Therapy as opposed to other forms of psychotherapy addresses the entirety of the patient’s social matrix, including his/her sub-cultural background.

RGFT addresses not only external person's reference groups (such as family, working place, etc.) but his/her internalized groups as well. RGFT belongs to short-term client-centered psycho-therapies, it has already demonstrated its efficacy in different clinical entities such as phobias, OCD, eating disorder, adjustment disorder, somatization, anxiety disorder, panic attacks, and others. One of the crucial components of RGFT is Trigger Event Analysis – a newly developed tool that enables understanding of person's vulnerability and allows both the prediction of future conflicts as also searching for the effective ways of avoiding or minimizing them.

The treatment itself focuses on studying the conflicts of both internal (between the internalized groups) and external (between internalized and external groups) origin. One of the main goals of the treatment is to allow a patient to uncover the present (external groups) as well as historical (internalized groups) social influences thus promoting his/her individuation process. Studies are planned to compare RGFT with other established short-term therapies.

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The International Journal of Psychosocial Rehabilitation
Volume 14, Number 2
July 2009– June 2010

Optimizing Parent Coaches' Ability to Facilitate Mastery Experiences of Parents of Children with Autism

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Citation:
Raj A. & Kumar K.. (2009). Optimizing Parent Coaches' Ability to Facilitate Mastery Experiences of Parents of Children with Autism. ***International Journal of Psychosocial Rehabilitation. Vol 14(2). 51-63***

Acknowledgments:
This study was conducted as part of Archana Raj's doctoral thesis at University of Mysore, India. The authors wish to thank the parents, clients, staff, and management of Central West Autism Intervention services, ErinoakKids, Ontario, for the support and cooperation they extended to this study.

Abstract

Mastery experiences exert a significant influence on self-efficacy. A major component of mastery experience is positive appraisal of direct experiences with task-related behaviors. It is possible that parents of children with autism experience fewer opportunities for positive appraisal of parent-child interactions. This study proposes a sensitized model of parent coaching with in-built practices to support coaches to facilitate mastery experiences of this group of parents, in parent-child interactions. The relative capacities of this model and an existing model of parent coaching, as perceived by the coaches, in supporting them to facilitate mastery experiences of parents of children with autism, is the focus of this study. As perceived by the coaches, the sensitized model of coaching enhanced their ability to facilitate parental mastery experiences, compared to the existing model.

Keywords: self-efficacy, mastery experiences, sensitized parent-coaching model

Introduction

Autism is a neuro-developmental disorder characterized by severe qualitative impairments in reciprocal social interaction and communication, and restricted, repetitive behaviors, interests, and activities (American

Psychiatric Association, 2000). Lovaas et al., in 1973 first emphasized the importance of training parents as intervention providers for their children with autism. They noted that following intensive treatment, children whose parents received training to carry on the intervention continued to make gains compared to children who were returned to institutional settings. Since 1973, significant strides have been made in providing training/coaching to parents of children with autism, with a number of studies reporting parents gaining skills in facilitating functional social-communication and in managing challenging behaviors through parent coaching (e.g., Aldred, Green, & Adams, 2004; Wetherby & Woods, 2006; Rogers et al., 2006; Carr & Durand, 1985; Feldman & Werner, 2002).

In recent years, in developmental research, there has been increased appreciation of cognitive factors associated with parenting, with parental self-efficacy emerging as one of its most powerful predictors (Coleman and Karraker, 1997). Bandura (1977; 1986; and 1989) identifies self-efficacy in terms of one’s belief in one’s ability to successfully perform a particular behavior. In psychology and education, self-efficacy has proven to be a more consistent predictor of behavioral outcomes than have any other motivational constructs (Graham & Weiner, 1996). However, as identified by Coleman and Karraker (1997) and by Jones and Prinz (2005), information is sparse on interventions that target this construct centrally, for parents.

Families of children with autism report a greater number of stressors when compared with families of children with other disabilities (McGrath, 2006); further, it has been identified that the child’s state is the primary factor behind the high levels of stress experienced by this group of parents (Fleischmann, 2005). Sense of competence could be an area of particular vulnerability when child characteristics are chronic and result in special challenges to parenting (Kazak & Marvin, 1984). This information underlines the need for programs for children with autism to address the gap identified by Coleman and Karraker (1997) and Jones and Prinz (2005). The gamut of skill-deficits around social-communication and challenging behaviors that are associated with the diagnosis of autism often leave parents perplexed and feeling inadequate when interacting with their children. Most parents do not have a frame of reference of previous experiences and role models in interacting with children who are predominantly non-responsive in social contexts; therefore, there is often a tendency to become extremely reliant on the therapists as experts, and feeling that only trained therapists have the competence to address the child’s needs. The identifying feature of autism being a lack of social responsiveness, many parents fail to experience naturally occurring social-reinforcement contingencies experienced by parents of typically developing children and other developmental disabilities. Direct experience with parenting task behavior, in other words, would often have resulted in failure for them, in the form of a lack of, or inadequate social responsiveness from their children. Given the unique nature of parent-child interactions in autism, and the impact such interactions could have on parental cognitions, there is a need to develop parent-coaching models with the explicit purpose of influencing self-efficacy of parents of children with autism (Raj and Salagame, in press), with coaching practices geared to influence parental sense of competence. One way to achieve this end is for coaches to facilitate mastery experiences of the parents, through the process of coaching.

According to Bandura (1994), the most influential source on self-efficacy is through mastery experiences derived from an authentic experiential base. One’s personal history of accomplishment through direct task experience has been identified by Bandura (1989) as exerting the most powerful influence on mastery experiences. Every time a person has the opportunity to master a task, he/she will start to believe in his/her capability to perform the task. Therefore, it becomes paramount that a coaching model with the explicit purpose of affecting parental self-efficacy equips the coaches with techniques to provide experiences of mastery to the parents.

The question naturally arises as to the capacity of traditional parent-coaching models in existence for parents of children with autism to help coaches facilitate mastery experiences of the parents. Based on the primary means through which self-efficacy is believed to develop, i.e., through direct experience with task behavior, traditional parent coaching models with the three core practices of modeling, rehearsal, and feedback have the capacity to facilitate mastery experiences. However, most of these models were not designed with the purpose of influencing self-efficacy of parents of children with autism. Specific sensitivities have to be infused into the three core coaching practices of modeling, rehearsal, and feedback (Raj and Salagame, in press), to provide coaches with practices to efficiently facilitate mastery experiences of this group of parents. The goal of this study was to compare the relative efficacies of a traditional parent-coaching model and an enhanced model, to facilitate mastery experiences of parents, as perceived by the coaches.

In-order-to address this goal, an existing 'parent coaching model' was compared with an enhanced version of it, called hereafter as "sensitized coaching" developed by the authors, with specific sensitivities infused into the core coaching practices of modeling, rehearsal, and feedback. The current model of parent coaching at the participating agency in this study served as an example of an existing parent-coaching model. It was hypothesized that coaches would perceive the sensitized model of coaching to be more effective in facilitating mastery experiences of parents of children with autism, compared to the existing model. Coaching parents to conduct mand training for their child with autism was the vehicle used to answer the study question.

Method

Operational Definitions

Mand. Mand or request is a unique type of language that directly benefits the child by letting his/her care taker know what he/she wants or does not want at a particular moment. Mand is the first type of language to teach a child with language deficit, as in the case of most children with autism (Sundberg and Partington, 1998).

Mastery experience. The experience of completing an activity successfully, leading to increase in self-efficacy related to the activity (Jackson, 2002)

Dependent and independent variables

The dependent variable in this study was the coaches' perception of the relative capacity of the sensitized and existing models of parent coaching to facilitate mastery experiences of parents. The dependent variables were the two models of parent coaching.

Design of the study

A group of coaches were first trained on the existing model of parent coaching at the participating agency in this study and then on the sensitized model. They implemented the two models of coaching on two separate groups of parents, consecutively. Coaching was provided to parents in group 1, with the existing model of parent coaching at the participating agency. Following this phase, coaching was provided to parents in group 2 with the sensitized coaching model.

Participants

All parent coaches were Instructor Therapists (ITs) working for the participating agency. The twelve coaches who participated in this study were matched on specific variables as summarized in Table 1.
Fifteen mothers per group, matched on their pre-coaching self-efficacy scores received coaching. Table 2 summarizes characteristics of the parents. Their children were between the ages of four and eight years, had a diagnosis of autism, and were clients of the participating agency. These children exhibited low rates of mands (less than 10 times per hour in parent-child interactive situations). They did not exhibit aggression towards others and/or self-injurious behaviors (Raj and Salagame, in press).

Table 1
Characteristics of the 12 Coaches Who Participated in the Study

Variables	Specifics
Gender	Females
Education	Minimum of a college diploma in early childhood education or applied behavioral sciences
Average time/day spent in providing therapy	six hours
Average duration of employment with the agency	one year

Measures

A Coach Feedback Form was developed by the authors to measure coaches' perception of the capacity of the two models of parent coaching to equip them to influence mastery experiences of parents. In developing this form, the authors had discussions with a number of coaches at the participating agency to identify what they hoped to provide parents with, through coaching. Common themes that emerged included (a) enhance parent confidence; (b) create opportunities for productive parent-child interactions; (c) reduce parents' reliance on trained therapists; (d) help parents generalize skills across different environments; (e) have standards of performance for parents to work towards; and (e) keep parents motivated throughout the duration of the coaching period. In essence, what the coaches hoped for was to facilitate mastery experiences of the parents. The Feedback Form was developed based on the input from the coaches. The form has 22 statements. Coaches compared the existing and the sensitized models on each of the 22 statements. They used a 6-point scale with response options ranging from strongly agree to strongly disagree. Coaches' ratings were added up, resulting in separate scores for the sensitized and existing model. Based on the scores of 15 coaches, the Cronbach's alpha coefficient for this Form as it measures existing parent-coaching model is .96. Cronbach's alpha coefficient for this Form with-reference-to the sensitized parent-coaching model is .79.

Parents in group 1 and group 2 were matched on two measures of self-efficacy (a) The self-efficacy subscale of The Parenting Sense of Competence Scale (Mash and Johnston, 1983) and (b) The Task-Specific Self-Efficacy scale (Raj and Salagame, in press). The Parenting Sense of Competence Scale (PSOC) is in the public domain. Cronbach's alpha coefficient for the self-efficacy sub-scale is .76 (Johnston and Mash, 1989). The same for the Task-Specific Self-Efficacy Scale is .89 (Raj and Salagame, in press). The PSOC scale was used as a measure of domain-general self-efficacy of the participating parents and the Task-Specific Self-Efficacy scale was used as a measure of their sense of competence on facilitating mands for their children.

Procedures

Client Services Management Committee at the participating agency gave permission to conduct this study. Coaches who were employees of the agency were given information on the study, in face-to-face meetings with the first author. All coaches were supervised by their Senior Therapists (STs) and had received training on the existing parent coach model as part of their job. The same coaches received training on the sensitized model from the author, along with their STs, before implementing coaching for parents in group 2. The coaches were provided with the Feedback Form by the author once they concluded implementation of coaching with both the models. The coaches returned the completed Feedback Forms to the author in sealed envelopes, personally.

Parents who participated in the study were clients of the agency. Parent coaching is routinely offered to all parents of children in the autism program, at the participating agency, as part of the service delivery model. On behalf of the first author, Senior Therapists approached parents who had been identified to receive coaching on facilitating mands for their children, with information on the study. All parent participants gave informed consent. Parents were randomly assigned to group 1 and group 2. They reported on the two self-efficacy measures, before receiving the coaching interventions. These questionnaires were delivered to the parents by the STs working with the families. Completed questionnaires were collected in sealed envelopes by the STs and delivered to the first author.

The following provisions were in place to counter extraneous factors which could have potentially acted as confounds on the dependent variables (a) coaches received training on the sensitized model of coaching only after they finished implementing coaching with group; (b) both models of coaching were identified as parent coaching to limit any implications that one model might be inherently superior to the other; (c) coaches were not familiarized with the concepts of self-efficacy and mastery and; (d) all coaches had equal opportunities to establish rapport with the children and the parents before starting parent coaching.

Interventions

It is identified in literature that change in parental sense of competence depends on a change in ratio of successes to failures in parenting responding and on a change in the subsequent reappraisal of competencies (Bandura, 1981). Based on these directions and with the aim of providing coaches with specific tools to influence mastery experiences of parents, the following provisions were incorporated into the practices of modeling, rehearsal, and feedback in the existing model, resulting in a sensitized model of parent coaching. The provisions are as follows (a) operationally defining sub-skills of the task to pinpoint the behaviours to be modeled to the parent, and to make the task achievable; (b) creating opportunities for the parent to generalize sub-skills through rehearsal; (c) making quantitative data available to the parent, to engage in self-appraisal of competence, in addition to coach's feedback; and (d) systematically fading out coach's models to increase opportunities for the parent to perform the task independently (Raj and Salagame, in press).

Table 2
Characteristics of the 30 Parents Who Participated in the Study

Variables	Specifics
Gender	Females
Pre-intervention skill level	Less than five facilitations of child's mands observed during half-an-hour of mother-child interactions
Age range	30-40 years

Table 3 compares the existing model and the sensitized model of coaching and identifies how each feature of the sensitized model helps the coach to facilitate mastery experiences of the parents. Figure 1 and Figure 2 depict the salient features of the existing model and the sensitized model (Raj and Salagame, in press). Every parent who participated in this study received 1:1 coaching, in the presence of the child, for two hours on a specific day of the week. Parents in group 1 received three months of coaching according to the coaching practice at the agency. Duration of coaching for parents in group 2 was dependent on achieving performance criteria as outlined in Table 2.

Table 3
Comparison of the Two Models of Coaching and the Impact of the Sensitized Model on Coach's Capacity to Facilitate Mastery Experiences of the Parent

Existing Model	Sensitized Model	Impact on facilitating Mastery Experiences
Coaching addresses sub-skills of a targeted skill.	Sub-skills are further operationally defined, in a measurable, achievable way.	Target skill becomes objective, achievable, and measurable; supports goal setting and achievement.
Parents have	During rehearsal, the coach focuses on	Parent experiences success in

opportunities to rehearse sub-skills.	contriving a number of generalization opportunities on the sub-skills.	varied contexts of parent-child interactions.
Coach provides feedback to the parent.	In addition to feedback, coach maintains quantitative data on behalf on the parent and shares the progress towards achieving performance criteria.	Parent has a tangible and objective information system, for self-appraisal of performance.
Parent receives three months of coaching.	Coaching terminates only once parent achieves criterion on independent performance in (a) coaching sessions and (b) novel situations.	Parent has many opportunities for self-reflection, self-correction, and generalization of skills.
Arbitrary ratio of models from the coach and independent attempts by the parent.	Coach follows a prescribed ratio[a] of models and opportunities for independent attempts by parent, in-order-to fade out support, systematically.	Reduces parent's reliance on the coach.

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[a] The coach encourages the parent to try a sub-skill independently after the skill had been modeled to the parent, a maximum of two times. At the independent attempt, if the parent shows signs of not being able to follow through, the coach models the skill again two times and encourages the parent to try the skill independently.

Figure 1

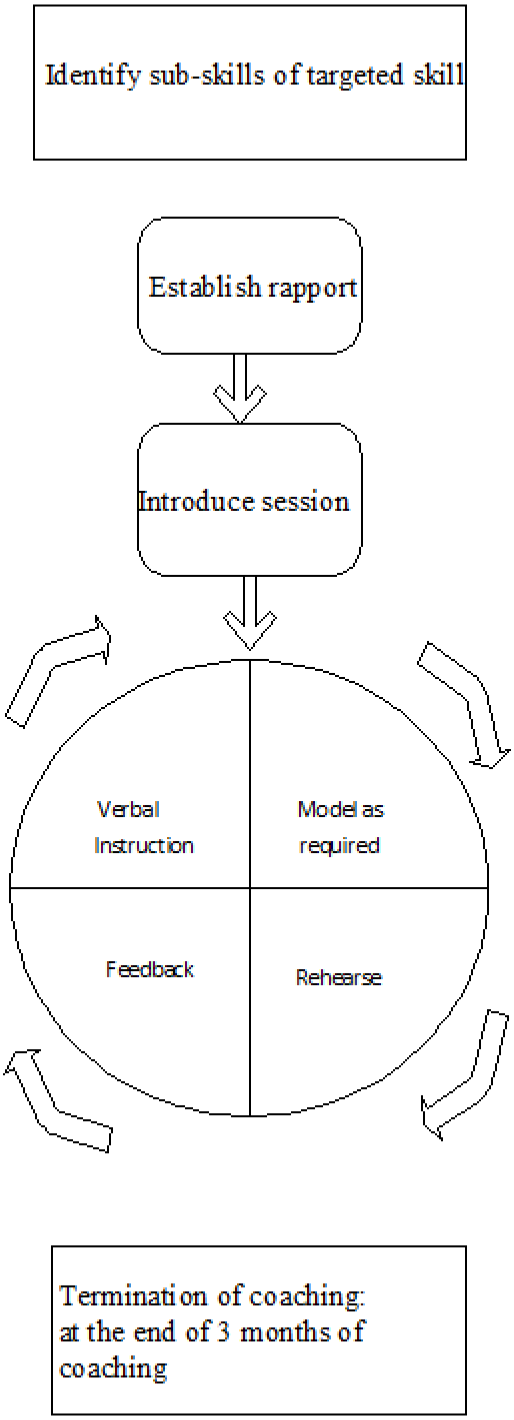
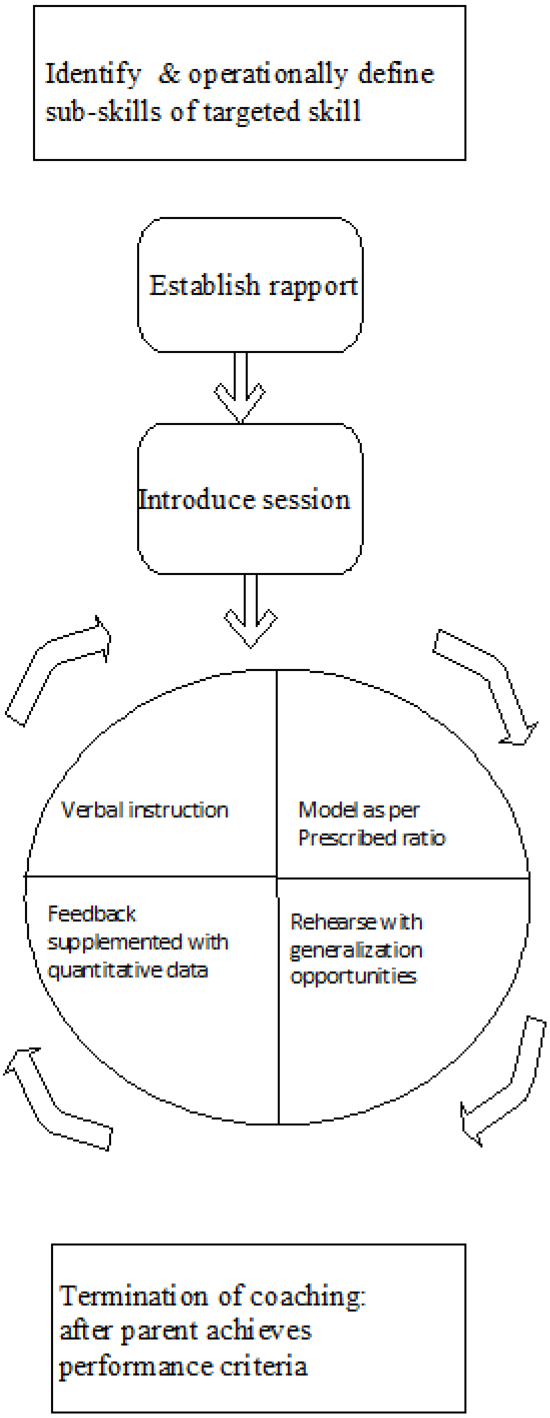

Identify sub-skills of targeted skill
Establish rapport
Introduce session
Verbal Instruction
Model as required
Feedback
Rehearse
Termination of coaching: at the end of 3 months of coaching

Figure 2


Identify & operationally define sub-skills of targeted skill
Establish rapport
Introduce session
Verbal instruction
Model as per Prescribed ratio
Feedback supplemented with quantitative data
Rehearse with generalization opportunities
Termination of coaching: after parent achieves performance criteria

Fidelity of implementation of coaching

STs observed and gave feedback to the coaches on both models of coaching, in-vivo or through videos on the coaching, on an average of two times per month. In addition, the supervising STs rated a random sample of coaches on procedural integrity for implementing the sensitized model of coaching on two separate occasions, during the course of the intervention. A rating scale of eight items, developed by the authors was used for this purpose. The results indicated that each of the coaches had 80% or above adherence to the prescribed procedures, across each of the two occasions (Raj & Salagame, in press).

Data analysis

The study involved repeated measurements on a single sample. Analysis of significance of difference between the coaches' ratings of the two models of coaching was conducted using the Wilcoxon Matched-Pairs Signed Ranks Test. In addition, a content analysis of the coaches' responses on the Feedback Form was also undertaken. The aim was to isolate features of the two models with reference to their relative capacities to influence mastery experiences.

Results

Wilcoxon Matched-Pairs Signed Ranks Test was used to test significance of difference of coaches' ratings of the two models of parent coaching. Results are provided in Table 4. According to the statistical analysis, there was a significant difference between the ratings ($\underline{z}$=2.903, $\underline{N}$-Ties=12, $\underline{p}$=.002). Information on the raw scores provided in Figure 3 indicates that 11 of the 12 coaches rated the sensitized model higher than the existing model of parent coaching. Statistical analysis support acceptance of the directional hypothesis that coaches would perceive the sensitized model of parent coaching to be more effective in providing them with enhanced capacity to impact mastery experiences of parents, compared to the existing model.

Figure 3

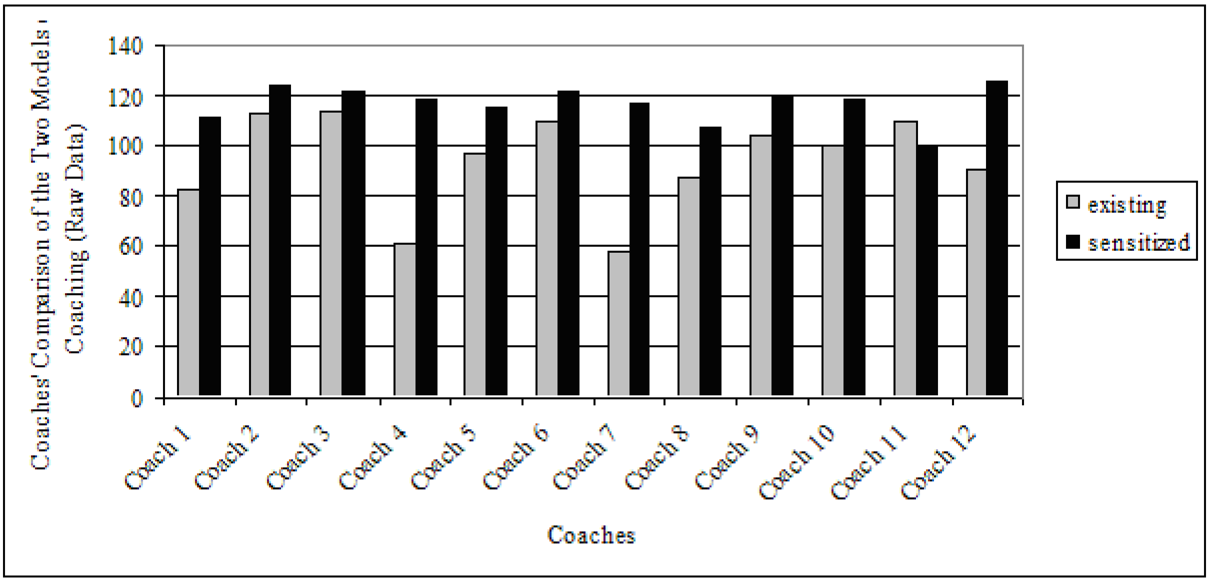


Table 4
Results of Paired Samples Test

N	*Z*	*N-Ties*	*P*
12	2.903	12	.002

Discussion

According to the results, coaches perceived that the sensitized coaching model better equipped them to influence parental mastery experiences. Content analysis revealed further facets of the sensitized model that differentiated it from the existing model, as perceived by the coaches.

In the sensitized model, sub-skills are operationally defined in an objective, achievable, and measurable way. Thus, a composite task that could look overwhelming was broken down into objective and achievable component goals, enhancing the coaches' ability to facilitate experiences of success for the parents. According to Evers et al. (2006), a key coaching competency is for the coach to help the coachee set goals that are valued, specific, realistic, and attainable. These aspects are in-built in the sensitized coaching model, enhancing both the coach's and the coachee's capacity to set and achieve goals, both essential for mastery experiences.

According to the coaches, supplementing their feedback with data, with emphasis on helping the parent monitor progress, is a salient feature of the sensitized coaching model. In-order-to make consistent progress, the coach should be able to help the coachee monitor and evaluate his/her performance (Graham et al., 1994). The data, when used as a performance monitoring system, allow coaches to meet this criterion. Additionally, the data help coaches motivate parents and act as a motivational system for themselves.

The coach's ultimate goal is for the coachee to demonstrate sustained performance by achieving the competence and confidence to engage in self-reflection, self-correction, and generalization of skills and strategies to new situations, beyond the realm of the coaching environment (Flaherty, 1999; Kinlaw, 1999). Through the generalization opportunities on the sub-skills in the sensitized model, the coach facilitates the parent contacting mastery experiences in different contexts of parent-child interactions, across locations and time. In addition, systematic fading of coach's support, achieved by following a prescribed ratio of models vs. independent attempts by parent, helps buffer over-dependence on the coach and increases independent implementation of the sub-skills by the parent.

Coaches went back to conducting coaching with the existing model of coaching once the study was completed. As a follow-up, this author sought their input on how their experiences with the sensitized model continue to influence their current practice as coaches. According to their input, they are more diligent in task-analyzing the skills being coached to arrive at sub-skills, and operationally defining the sub-skills in measurable and achievable terms. They are also more aware of the need to make use of an objective system of tracking and sharing parental strengths and challenges throughout the course of the coaching. Systematic fading of prompts with the goal of minimizing parents' dependence on them continues to influence the current practice of the coaches.

Conclusion

The outcomes of this study reinforce the benefits of sensitizing the core practices of coaching to enhance the capacity of the coaches to influence mastery experiences of parents of children with autism. Since mastery experiences have the most powerful influence on self-efficacy and since self-efficacy can influence the quality of care that parents provide to their children as well as the degree of enjoyment they derive from the parenting experience (Coleman and Karraker, 1997), the practice of sensitizing traditional coaching models could have far-reaching benefits for families of children with autism. However, it is necessary to apply the model to a large sample size of coaches across different programs for children with autism to better understand its strengths and weaknesses. In addition, this model needs to be compared with other models of parent coaching in existence for parents of children with autism.

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The International Journal of Psychosocial Rehabilitation
Volume 14, Number 2
July 2009– June 2010

Disability in schizophrenia and its relationship with duration of illness and age of onset

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Citation:
Ali A. (2009). Disability in schizophrenia and its relationship with duration of illness and age of onset. ***International Journal of Psychosocial Rehabilitation. Vol 14 (2). 37-41***

Acknowledgments:
The author is grateful to Dr Masroor Jahan, Associate Professor of psychology, Ranchi Institute of Neuro-Psychiatry and Allied Science, Ranchi, Jharkhand (India) for hers help and guidance during the study.

Abstract

Schizophrenia causes considerable disability in a person's functioning.. The present study was designed to investigate disability in schizophrenia and to see its relationship with age of onset and duration of illness. A study sample included 60 schizophrenic patients from Ranchi Institute of Neuron-Psychiatry and Allied Sciences, Ranchi (Jharkhand), India. Disability Assessment Scale developed by Dr. P.B. Behere and Dr. K. Tiwari (1991) were administered to know the level of disability. It was found that majority of the patients were having moderate level of disability in personal, social, occupational, physical and general area. Duration of illness has a significant correlation with personal areas of disability and age of onset has significant ($p<0.05$) positive correlation with personal and occupational area of disability. This study showed that most of the schizophrenic patients have moderate level of disability in all the areas. Age of onset, duration of illness have an effect on disability.

Key words: Disability, Schizophrenia, Age of onset and Duration of illness

Introduction

A commonly accepted prevalence rate for schizophrenia is that it affects approximately 1% of the population at any time, but epidemiological studies differ (Andreasen, 1984; Torrey, 2001). A review of recent major epidemiological studies concluded that schizophrenia occurs in all populations with a prevalence rate in the range of 1.4 to 4.6 per 1000 (Jablensky, 2000). Schizophrenia usually starts during young age and is frequently associated with deterioration from the previous level of functioning .Schizophrenic patients are reported to have multiple psychological and physical impairment (King and Nazareth, 1996). Impairments are more marked in these patients who have continuous or deteriorating course. In schizophrenic patients deterioration takes diverse forms and results in various functional deficits leading to social isolation and poor occupational functioning. The peak age of onset of schizophrenia is 15-30; however, approximately 15% of persons with the disorder may experience initial symptoms after age 45 (Harris & Jeste, 1988). Psychiatric illnesses like schizophrenia, bipolar affective disorder and obsessive-compulsive disorder, impact negatively on the academic, occupational, social and family functioning of the patients. Schizophrenia may cause disability leading to restrictions on many domains of daily life such as hygiene, self-management, vocational and leisure activities, and family and social relationships.

Defining disability is not an easy task, and it is becoming clear that no single definition can cover all aspects of disabilities. According to the International Classification of Impairment, Disability and Handicap (ICIDH, 1980), disability is interference with activities of the whole person in relation to the immediate environment. Disability associated with mental illness is a major contributor to the global burden of disease. As per the National Sample Survey Organization (NSSO) 1991 statistics, 1.9% of India's population is disabled in one way or the other. Study of disability associated with mental disorder therefore becomes a matter of prime importance. The purpose of this study was to assess disability in schizophrenia patients and to see its relationship with age of onset and duration of illness.

Material and Method

The study was carried out in in Ranchi Institute of Neuro-Psychiatry and Allied Sciences, Ranchi (Jharkhand).Based on purposive sampling technique, samples of 60 subjects with diagnosis of schizophrenia were selected. The study was conducted on schizophrenic patient who were selected from in patient unit of RINPAS, Knake, Ranchi. All the patients had been diagnosed by a psychiatrist in accordance to the DCR-ICD-10 criteria at the time of their entry into the hospital. Following inclusion and exclusion criteria was taken into consideration: Age range between 18 to 60 years of both the gender and having no active psychopathology. Patients with any organic involvement, who have any significant physical illness and with co morbid disorder were excluded.

Assessment:

Socio-demographic and Clinical Data Sheet: It is semi-structured Performa especially designed for this study. It contained information about social demographic variables like age, sex, education, marital status, religion, employment status, domicile background etc. It contains information about clinical profile of the individual with schizophrenia.

Disability Assessment Scale: Disability Assessment Scale in a standardized scale developed by Dr. P.B. Behere and Dr. K. Tiwari (1991). It measures the level of disability covering five areas of disability viz. Personal, Social, Occupational, Physical and General. There are total 46 items in the scale, consists of 10 items each in personal, social and occupational area and 8 items in Physical and General Areas. Each item has 4 alternative answers and scores for each item ranges from 0-3, where

0-	indicate no disability
1-	indicates mild disability
2-	indicates moderate disability
3-	indicates severe disability

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

Patient was identified on the basis of DCR ICD-10 diagnosis criteria. Informed consent was taken from the patient as well as from the informant before eliciting relevant information and the nature and purpose of the study was explained. All the subjects who were selected for the present study were interviewed and then assessed with the help of semi-structured clinical data sheet .Thereafter disability assessment scale were administered to know the severity level of disability of each subject in all the areas viz. Personal, Social, Occupational, Physical and General.

Analysis:

The statistical package for social sciences (SPSS), version 13.0 was used for the analysis of the data of this study. Percentage and correlation was used to examine the data.

Results

Table 1 shows clinical profile of sample. Majority of the patients were having 21-30 years (53.3%) as age of onset of illness and duration of illness more than two years. Table 2 show nature and severity of disability of schizophrenic patients in personal, social, occupational ,physical general area and it was found that majority of the patients were having moderate level of disability in all the areas . Duration of illness has a significant correlation with personal areas of disability. Age of onset has significant ($p<0.05$) positive correlation with personal and occupational area of disability (table 3).

Table 1: Clinical Profile of Patients

Variables		N (%)
Age of onset	Up to 20 years	4 (6.7)
	21 – 30years	32 (53.3)
	31-40 years	22 (36.7)
	41-50 years	1 (1.7)
	51-60 years	1 (1.7)
Duration of illness	Up to 1 year	30 (50)
	1 – 2 years	11 (18.3)
	More than 2 years	19 (31.7)

Table 2: **Showing nature and severity of disability of schizophrenic patients in personal, social, occupational, physical general area**:

Level of disability	**Personal Area** N=%	**social Area** N=%	**occupational Area** N=%	**Physical Area** N=%	**General Area** N=%
Normal	(7) 11.7	(2) 3.3	(9) 15.0	(6) 10.0	(7) 11.7
Mild	(24) 40.0	(21) 35.0	(21) 35.0	(25) 47.1	(19) 31.7

Moderate	(28) 46.7	(36) 60.0	(27) 45.0	(24) 40.0	(30) 50.0
Severe	(1) 1.7	(1) 1.7	(3) 5.0	(5) 8.3	(4) 6.7

Table 3
Correlation between various areas of disability, duration of illness and age of onset

Variables	Disability personal	Disability occupation	Disability social	Disability physical	Disability general
Duration of illness	.263*	.062	.074	.036	-124
Age of onset	.298*	.269*	.038	.100	-134

* Correlation is significant at the 0.05 level.

Discussion

Schizophrenia is definitely the most disabling psychiatric disorder. Long-term hospitalization has been recognized as an important factor contributing to the disability associated with schizophrenia (Johnstone et al, 1981). Following deinstitutionalization a number of studies have found decrease in disability associated with the illness and improvement in social functioning (Dickey et al, 1981; Barbato et al, 2004). Disability has been found to be affected by characteristics like age of onset, duration of illness, severity and type of symptoms, duration of untreated psychosis, cognitive deterioration, and intellectual functioning (Alptekin et al, 2005).Irrespective of the setting, most of the schizophrenic patients have moderate disability (Parker and Hadzipavlovic, 1995). Our finding was also similar that most of the patients included in the study were having moderate level of disability. Thara and Raj Kumar (1995), in prospective study reported moderate disability in schizophrenics, who had remained stable over a period of time with minimal fluctuations. Most of the patients with schizophrenia having duration of illness between 2-5 yr had moderate to severe disability (Indra et al, 2005). In our study, it was found that duration of illness has a significant correlation with personal areas of disability an age of onset has significant ($p<0.05$) positive correlation with personal and occupational area of disability .Thara and Joseph, 1995 found that the socio-demographic and clinical variables like gender, age of onset, mode of onset, duration of illness and premorbid functioning which are related to course and outcome have also been reported to have an effect on disability. The study had a few limitations like a small sample size, absence of longitudinal assessment and lack of randomization. The findings are difficult to generalize considering a small sample. Future studies are needed to assess the effects of psychiatric interventions that could ameliorate the long-term prognosis of social disability in patients with schizophrenia. The relationship between disability and socio-demographic variables like family structure, family income etc., needs to be evaluated in further studies.

Conclusion:

Disability has been found to be affected by characteristics like age of onset and duration of illness in schizophrenia.

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The International Journal of Psychosocial Rehabilitation
Volume 14, Number 2
July 2009– June 2010

Shortfalls of Treatment for Patients with Schizophrenia: Unmet Needs, Obstacles to Recovery

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Perese EF & Wu YB (2010). Shortfalls of Treatment for Patients with Schizophrenia: Unmet Needs, Obstacles to Recovery. ***International Journal of Psychosocial Rehabilitation. Vol 14(2). 43-56***

Abstract

Background: Recovery-oriented programs such as Assertive Community Treatment (ACT) achieve improvement in many areas; however, impaired functioning is often unchanged and results in unmet needs, obstacles to patients' goal of recovery. Objectives: Determine if there is change in participants' unmet needs after 12 months of ACT. Study design is descriptive and longitudinal. Results: On admission, 20 to 30% of participants identified unmet basic survival needs--food, clothing, housing, finances, and medical/dental care; 32-52% for friends, transportation, and meaning to life; 77.5% for group membership; and 95% for a role. At 12 months, fewer patients had unmet survival needs. Personal safety need was unmet for 27.5%. There was no change in unmet group membership, meaning to life, and role needs. Fewer participants reported unmet needs for friends identifying ACT team as friends. Conclusion: ACT is effective for basic survival needs and health care needs but not for social connectedness needs. .

Key words: Assertive Community Treatment (ACT), schizophrenia, recovery, unmet needs

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Introduction

For a long time, the future for patients with schizophrenia was a life longsentence to a chronic illness with no hope of recovery (Spaniel, Gagne & Koehler, 2003). Treatment goals were compliance with medications, reduction of hospital admissions, and adjustment to a chronic illness (Marder, 2005). By the 1990's, patients and families were repudiating those goals (Deegan, 1996; Ramon, Healy & Renouf, 2007) and advocating for recovery, the same treatment goal held for patients with medical illnesses (Ahern & Fisher, 2001). Now, recovery is accepted as the desired outcome of psychiatric treatment (Ramon et al. 2007).

The goals of recovery are for patients to return to a meaningful social role, develop relationships, re-claim a sense of self identity, and become participating members of the community (Ahern & Fisher, 2001; Lysaker & Buck, 2006). The process of recovery involves changes that patients make—keeping hope alive; accepting the need to be actively involved in promoting healing; developing self-confidence, courage and responsibility; finding a new meaning or purpose in life; and rebuilding social connectedness by taking on new roles in relationships, work, and the community (Jacobson & Greenley, 2001). The process of recovery also involves factors external to the patient such as mental health care providers' attitudes of compassion, respect, and belief in patients' ability to achieve healing and the provision of recovery-oriented services. Recovery-oriented services include management of patients' symptoms and distress, meeting patients' needs, promoting rehabilitation, and protecting patients' rights and personal safety (Anthony, 1993; Jacobson & Greenley, 2001).

Comprehensive treatment programs such as Assertive Community Treatment (ACT) that promote the goal of recovery have been found to reduce the hallucinations, delusions, and depression experienced by patients with schizophrenia but are less effective in reducing the problems related to impairment of functioning—deficits in self-care, academic difficulties, inability to work, problems with social interactions, and inability to develop and maintain intimate relationships (McGorry, 2005; Hyman & Insel, 2007). Patients' residual impaired functioning often leads to unmet needs with greater impairment of functioning linked with higher rates of unmet needs (Becker, Leese, Krumm, Ruggeiri, Vazquez-Barquero & the Epsilon Study Group, 2005).

The nursing theory of adaptation, Modeling and Role-modeling (M & RM), (Erickson, Tomlin & Swain, 1983) that guides this study proposes that patients meet their needs through attachment to others; to community institutions such as those that provide health care; and to valued causes and beliefs. When needs are met, patients develop internal resources such as hope and a sense of self-competence that enable them to cope adaptively with the challenges and stressors associated with their illnesses (Bray, 2005). When needs are unmet, or only partially met, patients' potential to adapt is diminished and they may use maladaptive coping or require more health care services and compensatory interventions (Erickson, 2006).

The needs of all humans include basic survival needs (food, clothing, housing, transportation, financial resources, and personal safety); health care needs (mental health care, physical health care including dental care); and social-connectedness needs (friends, a group to belong to, a role in life, and a meaning or purpose in life) (Hansell, 1976). Although needs are often considered to be hierarchical (Maslow, 1970), Hansell (1976) believes that needs are cantilevered rather than hierarchical with each need supporting all other needs. One unmet need adversely affects all needs, ability to adapt to stressors, and achievement of well-being.

Unmet needs among patients with severe mental illness such as schizophrenia

Basic survival needs: food, clothing, housing, transportation, finances, and personal safety.

Among patients with severe mental illnesses such as schizophrenia, needs for food and clothing are not often reported as unmet (Becker, et al. 2005). For example, only 7% of patients with severe mental illness reported an unmet need for food in the study of Grinshpoon and Ponizovsky (2007). Patients may live at home or in supervised housing where food and clothing may be provided for them and some may obtain food and clothing from soup kitchens or drop-in centers. Ashcraft, Anthony and Martin (2008) believe that recovery begins with appropriate housing. The need for appropriate housing was found to be unmet for 46% of patients with schizophrenia (Kovess et al. 2005). Similarly, transportation is a frequently occurring unmet need (Grinshpoon & Ponizovsky, 2007). Financial resources are often not adequate to live on (Ware, Hopper, Tugenberg, Dickey & fisher, 2007). Beebe (2002) reported that 27% of patients with schizophrenia living in the community identified financial problems, lack of sufficient funds to get by. For over 30 years, researchers have described the unmet need of patients with schizophrenia for personal safety, safety from abuse and victimization (Krauss & Slavinsky, 1982; Lehman & Linn, 1984; Perese, 1997) with Teplin, McClelland, Abram, and Weiner (2005) reporting victimization rates of 25% to 38%, 12 times the rate for the general population.

Health care needs.

In comparison to the general population, patients with schizophrenia have more health problems and a 20% shorter life span (Salokangas, 2007; Leucht, Henderson, Maj & Sartorius, 2008). About 50% have at least one medical condition such as diabetes, obesity, chronic obstructive pulmonary disease, cardiovascular disease, or HIV infection (Connolly & Kelly, 2005; Baki, Meszaros, Stutynski, Dimmock, Leontieva, et al. 2009). They also have more dental and eye problems than the general population (Dixon, Postrado, Delahanty, Fischer & Lehman, 1999). However, despite this increased vulnerability, they are less likely to receive preventive care and needed dental care than the general population (Salokangas, 2007; McCreadie, Stevens, Henderson, Hall, McCaul, et al. 2009).

Social- connectedness needs.

Social connectedness, the reciprocal relationships that individuals have with others, provides support and a sense of belonging and is associated with health and well-being (Ware et al. 2007; Social Connectedness: Social Report 2008). Social connectedness develops from the roles that individuals play in life as partners, friends, teammates, workers, and participants in community and spiritual activities. Among patients with schizophrenia, social connectedness has been found to be a strong predictor of positive response to treatment (Harvey, Jeffreys, McNaught et al. 2007) and patients believe that social connectedness is a key factor in promoting recovery (Happell, 2008).

Friends.

Many authors have described the lack of friends among patients with severe mental illness (Bellack & Muesser, 1986; Torrey, 1988). For example, among patients with severe mental illness who belonged to the National Alliance for the Mentally Ill (NAMI), 62% identified an unmet need for a friend (Perese, 1997). In describing the effect of lack of friendship among patients with severe mental illness, Wheaton (1997) says that it is the sense of isolation, the loneliness, and the lack of someone to talk with that is most troublesome. More than half of patients with severe mental illness describe problems with loneliness (Clinton, Lunney, Edwards, Weir & Barr, 1998) in comparison to one-third of the general population (Lauder, Sharkey & Mummery, 2004). Recently, Beebe (2010) reported that 42% of patients with schizophrenia living in the community identified loneliness as a problem.

Role.

Role in life is often associated with employment, filling the role of a worker and co-worker (Buizza, Schulze, Bertocchi, Rossi, Ghilardi, et al. 2007). Unfortunately, among patients with schizophrenia, unemployment is high with a rate of 72.9% reported by Rosenheck, Leslie, Keefe, MeEvoy, Swartz, et al. (2006). Patients with severe mental illness believe that work enables them to have pride in themselves, to develop coping strategies for managing psychotic symptoms so that they can work, and to re-establish a sense of identity. They believe that work promotes recovery (Dunn, Wesiorski, & Rogers, 2008).

Meaning or purpose to life.

A sense of meaning or purpose to life encompasses both spirituality and religiousness (Mohr & Huguelet, 2004; Huguelet, Mohr, Borras, Gillieron, C. & Brandt, P-Y., 2006) and is associated with a sense of well-being (Stolovy, Lev-Wiesel, Doron & Gelkopf, 2009). Patients with schizophrenia describe religion as being an important part of their daily life (Huguelet et al. 2006); and, they often use religion to cope with the symptoms of their illness and with daily problems (Tepper, Rogers, Coleman et al. 2001). The role that a sense of meaning or purpose plays in recovery is related to its ability to facilitate a reconstruction of a sense of self-identity and to build social connectedness (Roe & Chopra, 2003; Mohr & Huguelet, 2004).

Although meeting their needs has been identified by patients with severe mental illness as the first step toward recovery (Recovery, 2003), there is little information about need satisfaction as an outcome of recovery-oriented programs such as ACT. Cadena (2006) suggests that meeting needs should be a core component of treatment programs and that it should be evaluated as an outcome of treatment.

Purpose

The purpose of this study was to determine if participation in Assertive Community Treatment (ACT) by patients with schizophrenia for one year was associated with a decrease in specific unmet needs.

Method

The research was guided by two questions:
1. What percentage of patients with schizophrenia on admission to ACT had specific unmet needs—food, clothing, transportation, housing, financial resources, medical care, dental care, a friend nearby, a friend talk to, a friend who could help, a group to belong to, a role in life, and, a meaning/purpose in life?
2. Was there a difference in percentage of patients with specific unmet needs between admission to ACT and after 12 months of ACT?

Setting and sample

Setting. The setting was an ACT program operated by a not-for-profit Behavioral Health Services Organization in an urban area of Western New York. ACT is distinguished from other comprehensive programs for patients with severe mental illness by several features. ACT uses a team approach. The team is multidisciplinary and includes psychiatrists, social workers, nurses, rehabilitation specialists, case managers, and peer counselors. It serves as the primary provider of all patient services and, because of this feature, has the ability to rapidly provide services—food, clothing, housing, medical care, financial resources, and legal aid-- often within hours of the patient being admitted to ACT. It provides services in community settings such as in the patients' homes, group homes, or hotel rooms. It is pro-active using outreach to assist patients to participate in treatment, live independently, and move toward recovery (Assertive Community Treatment Association, 2009).

ACT is considered to be the gold standard of care for patients with schizophrenia (Kovess, de Almeida Jose, Carta, Dubuis, Lacalmontie, et al. 2005; McGorry, 2005). There is strong evidence that ACT reduces hospitalizations and length of stay in hospital (Barry, Zeber, J., Zeber, J.E., Blow, & Valenstein, 2002; van Os, 2009) and improves psychiatric symptoms (Barry et al. 2002), functioning (Dixon, 2000), housing stability (Phillips, Burns, Edgar, Mueser, Linkins, et al. 2001), and quality of life (McGrew, Bond, Dietzen, McKasson & Miller, 1995). There is weaker support for ACT's ability to improve social adjustment and vocational functioning (Burns, 2001). Some researchers have questioned the compatibility of ACT and recovery suggesting that fidelity to certain ACT principles—team approach, outreach, and high intensity of services—may interfere with patients' choices (Drake & Deegan, 2007). However, others believe that ACT can incorporate principles of recovery—consumer choice, hope, respect, compassion, and patience—and that ACT is well suited to the recovery model (Salyers & Tsemberis, 2007).

Sample.

After obtaining approval from the University at Buffalo's Institutional Review Board and the agency's clinical director, the 71 patients in the ACT program were offered the opportunity to join the study. Fifty-six (79%) agreed to participate and signed consent forms. As reported previously, there was no significant difference in age, race, marital status, living situation, employment, dangerousness, arrests/incarcerations, hospital readmissions, and functioning between patients who agreed to participate and those who refused (Perese, Wu & Ram, 2004). The initial interview was done soon after admission to ACT, within days if possible; but occasionally it would take longer to arrange a time when the patient would be available to be interviewed; e.g., two to three weeks after admission. In individual interviews, the senior author assessed the participants with the Buffalo Client Assessment Inventory (BCAI) that was developed by the authors. The BCAI includes structured questions and 10 brief self-report instruments including ones that measure specific unmet needs. At 12 months, participants were interviewed again using the same instruments.

The results of the study of the 56 participants were presented in an article that described outcomes such as psychiatric symptoms, distress, functioning, dangerousness, and stability of housing (Perese et al. 2004). Data obtained about specific unmet needs and the changes in specific unmet needs after treatment were not presented. Among the 56 participants, 40 had been given a diagnosis of schizophrenia by a psychiatrist on admission to ACT. Data related to the unmet specific needs of these 40 participants with schizophrenia is presented in this study.

Variable: specific needs

The specific needs measured in this study are those that Hansell's (1976) considered to be essential for survival. They have been operationalized as need for: food, clothing, transportation, housing, financial resources, medical care, dental care, friends (a friend nearby, a friend to talk to, and a friend who could help), group membership, a role, meaning/purpose in life, and personal safety. These needs have also been identified by patients with severe mental illness as needs that must be met in the first step toward recovery.

Study design

This was a descriptive, longitudinal study of data obtained as part of a larger, comparative study (Perese et al. 2004). Data about specific unmet needs had been obtained but not examined nor reported .

Instrumentation

Record review was used to obtain data on demographic characteristics, employment status, housing, psychiatric diagnosis, danger to self or others, hospital admissions during year prior to ACT, and victimization during year in ACT. The *Social Support Index (SSI),* (Bell, LeRoy & Stephenson, 1982), was used to measure unmet needs for a friend who is nearby, a friend who can be relied on to provide help, and a friend who you can talk to about problems; for a group membership; and for a sense of meaning or purpose in life. The response choices were yes, needs were reported as met, or no, not met. The *Meeting Basic Needs Scale* (Ellis, Wilson & Foster, 1984) that has a score range of 7-28 with higher score indicating more *unmet* needs was used to measure the need for: food, clothing, transportation, housing, financial resources, medical care, and dental care. Needs that were reported as always met or met most of the time were considered to be met. Needs that were reported as sometimes met or not at all were considered to be unmet. The need for a role in life was determined to be met if patients responded that they were employed, or in school. The need for personal safety was determined to be met if review of the record revealed no history of victimization during the year in ACT.

Results

Demographic characteristics

The participants were predominantly male and in the 30 to 49 year age group with more participants in the African American group than other groups combined. Nearly half had not completed high school. More than three-fourths had never married and the others were divorced, widowed or separated. Nearly all, 95%, were unemployed or totally disabled. The two participants (5%) who responded that they were working were not working in competitive or sheltered situations. They said that they earned their living by doing odd jobs. Participants were more likely to be living in stable housing (house, apartment, room, group home, board-and-care) than in unstable housing (homeless shelters, streets, motel, or with a friend). Nearly all (91%) had been hospitalized during the year before admission to ACT with one-fourth hospitalized more than three times. One-fourth of the participants had engaged in behavior that was dangerous to others. All had a Global Assessment of Functioning (GAF) score below 40, a score that indicates severe distress and impairment of functioning. (See Table 1.)

Table 1. Demographic, clinical and community adaptation characteristics on admission to ACT (n=40)

Gender		n (%)
Male		32 (80)
Female	Age	8 (20)
18.29		
30-49		3 (7.5)
50 and >	Race	29 (72.5)
Black		8 (20)
White		
Hispanic		25 (62.5
Marital status		13 (32.5)
Single		2 (5)
Divorced, widowed, separated		
Education		31 (77.5)
Less than high school		9 (22.5)
High school		

Some college	18 (47.4)
College degree	16 (42.1)
(Missing data for 2)	3 (7.9)
Employment/school	1 (2.6)
Employed	
Unemployed	
Disabled for work	2 (5)
Living situation	12 (30)
Stable housing (apartment, room, board and care)	26 (65)
Unstable housing (homeless, streets, shelters, with friends, motel/hotel)	28 (70) 12 (30)
GAF	
20	
25	
30	4 (10.0)
35	8 (20.0)
	23 (57.5)
Admitted to psychiatric hospital during year prior to ACT	5 (12.5)
0 hospitalizations	
1-3 hospitalizations	
More than 3 hospitalizations	4 (10)
	26 (65)
	10 (25)

Global Assessment of Functioning (GAF): 50-41 indicates serious distress and dysfunction; 40-31 indicates severe distress and dysfunction, 30-21 indicates inability to function in most areas; and 20-11 indicates dangerousness to self or others (Rosse & Deutsch, 2000).

Unmet needs at admission to ACT and after 12 months of ACT

The baseline assessment of specific needs was done as soon after admission to ACT as possible, usually within days of admission. Within basic needs, 17.5% to 40% of participants reported unmet needs with unmet needs for housing (30%) and transportation (40%) greater than for food (22.5%), finances (20%), and clothing (17.5%). Within health care needs, the unmet need for dental care (27.5%) was greater than that for medical care (17.5%). Within social connectedness needs, a greater number of participants identified unmet needs for a role in life (95%), a group to belong to (75%), a friend who could help (62.5%), a friend to talk to (48.7%), and a meaning or purpose in life (42.5%) than for a friend nearby (37.5%). (See Table 2.).

Only 29 of the 40 participants were available to be interviewed at 12 months. One subject had died, four had been admitted to a long-term psychiatric institution, one was admitted to a nursing home, two were incarcerated, two had been discharged for not participating, and one was still with ACT but was not available to be interviewed.

The available data suggest that there was a decrease in the percent of patients with unmet needs for housing (5.0%), financial resources (7.5%), and medical care (7.5%). Although there was no decrease in the percent of patients with an unmet need for a friend near by, there was a decrease in unmet needs for a friend who could help and a friend to talk to. (In responding to these questions, participants often identified ACT team members, especially peer counselors, as friends who could help or friends they could talk to.) On review of the participants' records at 12 months, it was found that 11 (27.5%) of the participants had reported incidences of victimization such as: beaten in a fight, a stab wound, assaults, accosted for money, sexual molestation, mugged and purse taken, and having winter coat stolen during the year that they were in ACT.

However, there was no systematic method of collecting data on victimization. Counselors recorded information about victimization when patients reported it. (See Table 2.)

Table 2. Percentage of patients with unmet needs on admission to ACT and at 12 months after admission

Need	**Unmet needs at admission to ACT (n=40)**	**Unmet needs at 12 months (n=29)**
Food	22.5	10.0
Clothing	17.5	17.5
Transportation	40.0	29.7
Housing	30.0	5.0
Financial resources	20.0	7.5
Medical care	17.5	7.5
Dental care	27.5	22.5
A friend near by	37.5	34.5
A friend who could help	62.5	30.0*
A friend to talk to	48.7	37.5*
A group to belong to	75.0	72.4
A sense of meaning to life	42.5	45.0
A role in life **(employment, married, student)**	95.0	95.0
Personal safety	not available	27.5%

* Patients frequently identified members of the ACT team as a friend who could help or a friend to talk to.

Discussion

Limitations. Generalizability of the findings of this study is limited by the small sample size and the fact that the sample consisted of volunteers. The researchers had no control over the selection of the sample. A further limitation is the high rate of attrition. Only 29 of the 40 participants with schizophrenia were available to be interviewed at 12 months. Because four participants had been readmitted to an inpatient psychiatric unit, two were in jail, and two were discharged for non-participation in ACT, it is likely that the eight participants no longer in the study had greater severity of their illnesses or were less responsive to ACT than the participants who remained in the study. Another limitation is that there was insufficient power to detect differences from admission to 12 month assessment. Despite these serious limitations, the data are presented in order to add to the available information about the unmet needs of patients with schizophrenia living in the community and to the information about the outcomes of ACT.

In response to research question one, the percent of patients with unmet needs at the time of admission to ACT differed according to the category of need and also by specific needs within a category. For example, among basic needs--food, clothing, finances, and housing-- unmet needs were reported by 17% to 30% of the participants. This relatively low rate of unmet needs may be due to ACT's ability to provide patients with food, clothing, small amounts of money or vouchers, and housing very quickly, often within hours of being admitted to ACT. The basic need for transportation was reported as unmet by 40% of the participants; and, because participants often added the comment that they walked everywhere, it is likely that the unmet need was higher. One explanation for the high unmet need for transportation is that more time is required for ACT to obtain bus passes than the time required to meet other basic needs. Within health care, medical care was reported as unmet by only 17.5% of the participants but dental care was unmet for 27.5%%. Because of an agreement with a primary care group, ACT was able to arrange for medical care very quickly but it took much longer to arrange for dental care. This finding supports previous reports of lack of dental care for patients with schizophrenia.

Unmet needs were highest in the category of social connectedness—meaning to life, friends, group membership, and role in life. More than 40% reported an unmet need for a sense of meaning or purpose in their lives at the time of the interview. Often they would add comments about what they had once wanted to do in life or that once they had belonged to a church. Conversely, the finding that 60% had a sense of meaning or purpose supports the reports of the importance of religion or spirituality for patients with schizophrenia. In relation to the unmet need for friends, more participants had a friend who lived near by than had friends whom they could talk to or ask for help. However, participants often added that the friend nearby was the person who served them coffee in the coffee shop. The unmet need for a friend who could be depended on for help was highest, 62.5% of the participants. Although the literature has reported that patients with schizophrenia often have small social networks and lack friends, this study identifies the high rate of the specific unmet need for a friend who could provide help. That three-fourths (75%) of the participants identified an unmet need for a group to belong to, to do things with, or just to hang out with poignantly depicts their lack of connection to social or community activities. Almost all of the participants had an unmet need for a role in life as defined by this study— employed or in school. However, it is likely that many of the participants fulfilled roles not defined in this study—partners, helpers, peace-makers, mentors, and others. For example, Ware et al. (2007, p 472) suggest that role in life should include "living a worthy life". Thus, on admission to ACT, many of the participants had unmet needs that were potential obstacles to the goals of recovery--to return or develop a meaningful social role, to build relationships, to re-claim a sense of self identity, and to become participating members of the community Research question two asked if there was a difference in the percentage of participants with specific unmet needs between admission to ACT and after 12 months of ACT. The available data suggest that there was a marked decrease in the percent of patients with unmet needs for housing, finances, and medical care. It seems that, over time, ACT was able to help patients to find appropriate housing, secure financial resources, and receive on-going medical care. Although there was only a slight decrease in the percent of patients with an unmet need for a friend near- by, there was a greater decrease in unmet needs for a friend who could help and a friend to talk to. However, participants often identified ACT team members, especially peer counselors, as the friends who could help or friends they could talk to. Thus, it does not appear that the participants built new friendships outside of the ACT team. There was a slight decrease in the unmet need for group membership and a slight increase in the unmet need for a sense of meaning or purpose in life. There was no change in role in life. Overall, the data suggest that for social-connectedness unmet needs—friends, group membership, meaning to life, and a role in life--there was little or no response after 12 months of ACT. This finding supports previous reports of ACT's weaker ability to improve social adjustment and vocational functioning.

The results of this study suggest that recovery-oriented ACT programs for patients with schizophrenia should add interventions that target unmet needs non-response to ACT. For example, ACT could add support groups, discussion groups, or other socializing opportunities such as coffee clubs and could link patients with self-help groups such as psychosocial clubs or ready made friends such as those provided by Compeer or Befriending organizations to address the unmet needs for friends and group membership. The unmet need for personal safety could be addressed by the ACT team assessing for bullying, harassment, victimization, and exploitation at each patient visit and by providing interventions such as crime prevention programs--similar to programs for acquaintance rape and family violence-- and teaching "street smarts" to reduce victimization. The unmet need for a role in life such as employment is challenging to address. The causes are multifaceted—lack of entry level jobs, fear of losing financial entitlements and health coverage, deficits of educational preparation, lack of prior work experience, and limited social skills. In this study, because the ACT program was already promoting vocational rehabilitation and supported employment, it seems likely that more than 12 months are required to see a change in employment. Finally ACT programs can seek the help of spiritual leaders and parish nurses to create bridges to help patients meet their needs for meaning to life.

After the study was completed, the researchers shared the findings with the ACT team emphasizing that unmet social connectedness needs appeared to be non-responsive to treatment and that there was a need to address the unmet need for personal safety. In response, the ACT team developed discussion groups and coffee clubs for the patients that were well received by the patients.

Conclusion

Some of the unmet needs of patients with schizophrenia, such as the unmet need for social connectedness, are obvious obstacles to the goals of recovery--patients returning to or achieving meaningful social roles, relationships, and membership in their communities. However, because needs are cantilevered, each essential to the other and to overall functioning and well-being, every unmet need is a deterrent to recovery. For example, unmet needs for money, transportation, and desirable housing affect the need for social connectedness and thus for recovery. This study found ACT to be effective in meeting basic survival needs, with the exception of the need for personal safety, and health care needs; but, ACT was less effective in meeting social connectedness needs.

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The International Journal of Psychosocial Rehabilitation
Volume 14, Number 2
July 2009– June 2010

Healthcare Professionals and Service User's Perception of Mental Health Support Workers.

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Citation:
Pace B. (2010). Healthcare Professionals and Service User's Perception of Mental Health Support Workers. ***International Journal of Psychosocial Rehabilitation. Vol 14(2). 57-66***

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Abstract

As a part of the ongoing investigation of how mental health support workers are perceived in a New Zealand context this paper explores the perceptions of healthcare professionals and service users. Both healthcare professionals and service users have a significant impact, and are impacted by this paraprofessional group. As such it is fundamental to include their viewpoint in order to develop a credible conceptualisation of the mental health support work role within New Zealand's healthcare system.

Introduction

Contemporary research (Pace, 2009a) examining the role and function of support work has provided an initial conceptualisation for this developing mental health discipline. This conceptualisation suggests mental health support work to be a non-clinical profession. Logsdon and Davis (2004) echoed the perception viewing paraprofessionals as the first point in the continuum of healthcare services offered, providing further support for the conceptualisation of support work as a non-clinical profession. Pace (2009a) also identified primary roles of support and advocacy for mental health support workers as suggested within the job title form the principle function based on the successful development of therapeutic relationships with a strong emphasis on strengths-based practice and recovery principle. In order to continue the conceptual develop of the support work role additional avenues of investigation are required to ensure the credibility of the final conceptualisation. Pace (2009a) suggest the necessity for both healthcare professionals and mental health service users to be included in the development process as the support worker role impact significantly on two groups.

Professional Perceptions

Recent research conducted by Mackenzie (2006) offers an insight into the consideration of health care professional for the use of paraprofessional staff as a means of overcoming their increasing workload. Mackenzie delivers this consideration through the use of a well placed case study. Both managerial and practicing staff were engaged through the use of semi structured interviews to elicit their perceptions regarding the use of the paraprofessional. Mackenzie identified two areas of concern: 1. The potential for staff vulnerability and 2. Co-management of paraprofessionals by the health and voluntary organisations involved in service delivery. Such co-management could prove to be problematic if there was not an effective communication system in place to adequately manage non-registered and usually lesser trained paraprofessional staff. In line with the required management system Mackenzie's review of relevant literature identified the implementation of a new role within existing health care structures to be potentially challenging. The discussion Mackenzie provides suggests, from a global perceptive, the need for further development of policy and codes of practice to adequately support and utilise these paraprofessionals in the health care system.

Edwards and Jahns (1990) considered the professionals primarily supervisors' perceptions of paraprofessionals, as well as how the paraprofessionals perceived themselves as allied health care professionals. The results of this investigation revealed no major difference in the perceptions of either the paraprofessionals or supervising professionals on the majority of actual tasks performed. However, Edwards and Jahns did offer comment with regard to differences in perception of how tasks should ideally be performed. The author of this paper suggests that this difference in task performance could be the result of differing professional disciplines with potential differences in level and type of qualification, and overall competence. Smith, Prosser and Joomun (2007) also suggested the need to address issues, including level of qualification and expressed concerns regarding the supervision requirements of support workers; a concern not identified in Edwards and Jahns (1990) earlier work.

Service Users Perceptions

Through the evaluation of a new health initiative Smith, Prosser, & Joomun (2007) investigated service users' perceptions of health support workers using focus group discussions and a series of semi-structured interviewes. The objective of the investigation was to determine the effectiveness and acceptability of services offered by support staff. The findings indicated that both service users and service visitors appreciated the involvement of the health support workers. Similarly in earlier research Corcoran (1985) investigated patient's perceptions of paraprofessional and professional therapists. Corcoran suggested that the patients were more willing to seek help from paraprofessional then professional therapists, with areas such as trustworthiness and expertness showing no significant difference. Both articles offer strong support for the use and employment of paraprofessional staff, indicating, for the most part, that both service users and visitors are comfortable with their involvement in health and social services. The utilisation and potential benefits of paraprofessionals is further reflected in den Boer, Wiersma, Russo, and van den Bosch's (2005), viewed from a managerial position

Like Mackenzie (2006), den Boer *et al.* (2005) examined the employment of paraprofessional as a means for a cost effective method to reducing the burden for health professionals, with particular reference to their effectiveness in the delivery of psychological treatments for depression and anxiety disorders. Within this study the focus was on perceptions of the service user, rather than the professional as was the case in Mackenzie (2006). Paraprofessionals involved within den Boer *et al.* were employed as mental health care workers, paid and voluntary, with no qualifications in regard to the delivery of psychological treatment. Analysis indicated no statistical difference between the delivery and effectiveness of treatment between professional and paraprofessional groups. However, the analysis of the preferred group from the client's perspective favoured paraprofessionals supporting the earlier work of Corcoran (1985).

The objectives of the current investigation were to identify the role and function of mental health support workers as perceived by service users and healthcare professionals, and to identify the level of acceptance of paraprofessionals as members of the mental health care community.

Method

The research was based on a qualitative methodological approach utilising both focus groups and semi-structured interviews. Focus groups were held for health care professionals and individuals, semi-structured interviews for mental health services users. All participants were located in the Waikato region of New Zealand's North Island. Four focus groups were run with registered health professionals. The focus group sessions ran for a duration of 45 minutes, consisting of twelve open-ended questions. Interviews were conducted by a service user who had been trained in the use of interview techniques. The rationale for this data collection approach was to minimise anxiety levels the services user may have experienced had the interviewer been a healthcare professional. The questions used both within the interviews and focus groups were similar in content to those used in Pace (2009b).

Participants

The research consisted of two groups: registered health professionals (Sample One) and mental health service users (Sample Two). An additional two small groups, Validation groups, were formed comprising of members from Sample One and Sample Two. Sample One consisted of one Occupation Therapist, two Psychologists, three Social Workers, and 14 Community Mental Health Nurses (*N* = 20).

Table 1. Statistical information for discipline, registration period, and duration working for mental health services.

	Years Registered		**Year working in mental health services**	
Discipline	**Mean**	**SD**	**Mean**	**SD**
Occupational Therapist (*N* = 1)	9	n/a	6	n/a
Psychologist (Clinical) (*N* = 2)	18.5	4.95	17	7.07
Social Worker (*N* = 3)	17	12.12	9	10.44

Nurse (*N* = 14)	15.43	11.88	15	12.18
Total (*N* = 20)	15.65	10.53	13.85	10.88

Sample Two consisted of 20 mental health service users who were currently engaging with a mental health service which employed mental health support workers as staff.

Table 2. Statistical information of current diagnosis and duration of mental illness.

	Total	**Duration of Illness (Years)****	
Diagnosis Type (Current)*		**Mean**	**SD**
• Schizophrenia	10	11.6	6.98
• Schizophrenia/ Intellectual disability	2	16	-
• Schizoaffective	2	7.5	0.70
• Autistic Spectrum	4	13.25	6.65
• Personality Disorder	1	20	-
• Mood Disorder	1	8	-
Total	20	12.2	6.2

* Only the current diagnosis was recorded. Several research participants had other ‘historical’ diagnosis also.
** Duration of mental illness as indicated from first diagnoses, even if not current diagnosis recorded.

Table 3. Statistical information indication current service used and duration.

	Total	**Duration in Service (Years)**	
Type of Service (Current)		**Mean**	**SD**
• Residential	14	7.22	4.28
• Community	6	2.97	2.3
Total	20	5.94	4.24

Date Analysis

Thematic analysis (Hsieh & Shannon, 2005; Berrios & Lucca, 2006) was conducted for the identification of commonalities with the discussion and interview groups, similar to the method used in Pace (2009b). Major themes were identified through the analysis of the narrative notes and transcripts after multiple viewing. The first viewing was to gain a sense of familiarity with the information (Ryan, Garlick, & Happell, 2006). The interview notes and transcripts were then analysed for the identification and subsequent coding of major themes. A final reading of the information was made to test the accuracy of the coding in line with the identified themes.

Research Validity Measures

Based on the model used in Pace (2009b) two focus groups (Sample Three and Sample Four) were formed to offer validation for the findings concluded from the thematic analysis. Each focus group consisted of 4 participants who had been involved in the focus groups or semi structured interviews. The focus groups were directed to provide feedback on the researcher's analysis of the narratives collected during the original interviews. For Sample Three the mean time for employment as a mental health support worker was 4 years and 4 months. In Sample Four the mean time utilizing mental health services was 13 months.

Results

Sample One (Healthcare Professionals) Results

The data analysis suggested the following key themes as identified by healthcare professionals.

1. Rehabilitation
2. Care giving
3. Supporting activities of daily living
4. Advocating for clients
5. Level of skill/competence

Each will be discussed and illustrate with quotes where appropriate.

1. Rehabilitation

Many of the healthcare professionals considered support workers to be fundamental to the recovery/rehabilitation process, stipulating they were able to offer themselves as significant individuals in the service users' life in the absence of family or friends.

> "*To help support the rehabilitation or recovery process and action the care plans we* [Healthcare Professionals] *set for them."*

> "*To make clients move forward … ensure they take their medication."*

2. Care giving

Perceptions surrounding the care or supportive nature of support work became polarised for the healthcare professional sample which resulted in this particular theme being divided into two components: 1. Care giving, and 2. Supporting activities of daily living. Care giving was viewed as a paternalistic model which removes the autonomy of the service user, suggesting support work is a 'baby-sitting' role.

> "*I can't say that I know what support workers do. My opinion is that they should do more to care for the service users … such as cleaning their homes and making sure they shower daily… that type of task."*

> "*I believe that a key feature of the support role is to ensure clients live in a safe clean environment and provide for them accordingly."*

3. Supporting activities of daily living

In contract to the paternalistic model offered through care giving numerous references were given to the collaborative nature of support work, suggesting that the paraprofessional work along side rather than for the service user.

> "*… to walk beside the consumer and support and guide them when needed."*

4. Advocating for clients

Based on the experiences and contact with support workers professionals decided there was a strong emphases on the role of advocacy.

> "*To advocate on behalf of the client when they are not able to speak for themselves."*

5. Level of skill/competence

With reference to the level of skill and competence perceived for mental health support workers a variety of views were expressed dependent on how their overall role was viewed, as stated in points two and three above. A clear division emerged from the narratives: those who perceived support workers to be under qualified and those who thought no qualification were needed.

> *"Support workers as a group need to be better qualified for the role which they have in the psychiatric sector."*

> *"Can the necessary skills and practice knowledge be taught at Certificate level and who is supervising their practice…or clinical responsibility?"*

> *"A basic caregiver programme should cover it. Why would they need more than that?"*

Sample Two (Service Users) Results

Analysis of Service User interviews revealed the following themes. Each will be discussed and illustrated with the use of quotes where appropriate.

1. Help to find employment
2. Assist in goal achievement
3. Care giving
4. Supporting activities of daily living

1. Help to find employment

Employment was identified as a significant function of the support work role with several of the research participant commenting on the value of have a support worker to guide them through the process of applying for work.

> "*I like it when* [support workers] *help me to get a job. When I'm working I feel so good and normal ... you know ... like I fit in."*

> "[Support worker] *came with me to an interview at* [company]. *I didn't know what to say, but* [support worker] *helped me out."*

2. Assist in goal achievement

Goal completion was also identified as a significant function of the support worker's role, ranging from short through to long-term goal development and implementation across a variety of domains.

3. Care giving

As with the Healthcare Professional, Service Users appeared polarized over the caregiver verse supportive nature perception of mental health support work. Several of the participants viewed support workers as a domestic aide who should perform tasks included meal preparation and house work.

> "*I think that its* [support worker] *job to look after me. Make sure that I tidy my flat and do the shopping and clean my room, bed, and stuff.*"

4. Supporting activities of daily living

Contrary to the statements made in point three above, services users also viewed support workers as critical elements to their general well-being and ongoing recovery, viewing them in a more professional capacity.

> "*At times when I'm not well it's good to know that* [support worker] *is going to be around to look after me. And my cat too.*"

> "*I like knowing that* [support worker] *is there to support me through the dodge times… helps me to stay on the road, you know, ah.*"

Discussion

What is of particular concern is the polarised view of the role and function of support work, from both the perception of the service users and healthcare professionals. Within both sample groups a large proportion viewed support work as similar to a caregiver role, whereby a support worker becomes a domestic aide. As a function of the support workers position, domestic duties performed in this manner would clearly undermine the recovery principles and strength-based focus central to mental health support work. What is clearly evident in the literature (Pace, 2009a) is that support workers are to work in collaboration with services users to assist them in becoming self-sufficient. Performed daily tasks and duties for service users may offer some benefits in the short-term but fail to do so over the long-term.

Apart from hindering the service user's recovery, this caregiver perception also undermines and devalues the work mental health support workers engage in. As articulated in original conference presentation (Pace, 2007) which sparked the current research (Pace, 2009a, b), support workers can form a valuable source of information and support for healthcare professional if provided with the opportunity. The research presented at the 2007 New Zealand Collage of Mental Health Nursing Conference suggested that support workers are able to support health professionals through the sharing of resources, information and experience.

Issues regarding level of qualification and supervision of support workers were raised as a significant concern by healthcare professionals. Two issues were raised at polar ends of the same continuum. Healthcare professionals viewed either support workers as currently under qualified for their role and function in psychiatric care or that no such qualification is required. This immediately follows on from the professionals' view of the support workers' role and function. If focus is given to the concerns of support workers being under qualified, reference can be made to the discussion offered in Smith, Prosser, and Joomun, (2007), Mackenzie (2006), and Edwards and Jahns (1990), all of whom expressed similar educational concerns. In light of the low level of qualification required, discussions surrounding risk and clinical responsibility were entered into. Healthcare professionals demonstrated a degree of apprehension with reference to clinical 'type' duties and where clinical boundaries lie, particularly as support workers in New Zealand currently do not come under a registration body. Mackenzie (2006) also raised this as an area of vulnerability.

In addition to the qualifications required and as a potential solution to the clinical responsibility dilemma, a particular force was given to the supervision and its place in mental health support work. Recent research (Sutcliffe, 2007) has investigated this topic indicting that supervision can hold a critical role in the development, quality, and therapeutic engagement of staff towards service users. Sutcliffe does clearly state that in this instance support work is a non-clinical role. However, boundaries are often crossed (Pace, 2009a) making the role of supervision as described by Sutcliffe even more critical for the safety and well-being of professionals, support workers and service users.

These findings clearly indicate the need for mental health support workers as a group to improve their professional profile to ensure that both healthcare professionals and service users have a clearer understanding of support work and its position in the health sector. It also offers assistance for current discussion surrounding a registration process for mental health support workers as a means of minimising potential risk and increasing the profile and credulity of this fledging discipline. Further investigation is however required to determine what a registration body for support work may look like and its potential impact on the field.

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The International Journal of Psychosocial Rehabilitation
Volume 14, Number 2
July 2009– June 2010

Substance Abuse Among Sesotho Speakers

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Citation:
Mosotho L, Louw AP, & Calitz FJW (2010). Substance abuse among Sesotho speakers.
International Journal of Psychosocial Rehabilitation. Vol 14(2)67-81

This study was supported by National Research Foundation (NRF)-South Africa.

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Abstract

Substance abuse is one of the biggest challenges facing South Africa today. Social deviances such as poverty, crime and other social disintegrations are consequences of a high prevalence of substance abuse. This research investigates clinical manifestations of substance abuse among Sesotho speakers. A sample 106 participants diagnosed with substance abuse was evaluated using the Psychiatric Interview Questionnaire. Alcohol is found to be the most widely abused substance, followed by nicotine and cannabis. The participants presented with a wide range of cognitive, affective and hypothalamic symptoms.

Key words: Culture, substance abuse, mental health, clinical manifestations

Introduction

Substance abuse is defined as the abuse of alcohol and drugs which may be culturally determined, and it varies between socio-cultural groups (Abbott & Chase, 2008). Substance abuse is a major cause of social deviances such as crime, domestic violence, poverty, decreased productivity, family and marital disintegration, exacerbation of chronic and fatal diseases (e.g. HIV-Aids, tuberculosis, diabetes and cancer) in

South Africa, according to the South African National Drug Master Plan (1999). Kraus et al. (2009) describe high levels of alcohol intake as one of the main sources of social harms and problems. The situation is aggravated by the fact that most parents do not feel free to discuss drug-related issues with their children. Substance abuse is therefore, to a large extent, a concealed psychological disorder. Excessive use of alcohol is likely to lead into risky behaviour such as practising unprotected sex which may expose individuals to the risk of contracting deadly diseases such as HIV-AIDS (Morojele, et al., 2005).

Just like in most, if not all other countries, alcohol is the most commonly abused substance in South Africa. It adversely affects millions of South Africans, many of them being innocent victims. However, South African socio-economic and political changes have made the country attractive to investors and foreign trade; for this reason, the region has been turned into a world drug centre, luring international crime syndicates. Also because of its climate and many isolated geographical areas, South Africa is one of the biggest producers of cannabis in the world. It is thus understandable why South Africa has become a regional and international hub for trafficking various types of narcotic drugs. Another common but often neglected form of substance abuse in South Africa involves over-the-counter and prescription medication, which is highly prevalent (Myers et al., 2003).

Nevertheless, most research on substance abuse in South Africa has been in urban areas, leaving certain rural areas and cultural groups in particular, neglected.

The aim of this study was to find out how substance abuse-related disorders are clinically manifested among Sesotho speakers in Mangaung – Bloemfontein, South Africa.

Epidemiology

Brady and Randall (1999) report that although the occurrence of substance abuse and dependence is more common among men than women, the prevalence rates show that a diagnosis of substance abuse is not gender specific. The literature has shown that substance abuse among men and women is not clearly specific as far as differences are concerned. Men usually begin to abuse substances earlier than women do. In the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR, 2000) and ICD- 10 (WHO, 1992) the epidemiology of specific substance abuse disorders is not clearly detailed.

Parry (1998) rightly points out that there are no reliable systems that can facilitate the thorough collection of data on substance abuse in South Africa. The available information is usually obtained from research conducted in an isolated location and from information gathered through police arrests and seizures. However, at the same time it is generally noted that substance abuse is rapidly permeating the poorer sectors of South African society (Morojele, 2000). Despite this precarious situation, Flisher and Stein (2000) report that most South African mental health professional societies do not address substance abuse as a priority issue. This point of view comes after they have observed and reviewed the conferences organized and conducted by professional societies such as the South African Society of Psychiatry, the Psychological Society of South Africa, the Epidemiological Society of Southern Africa, and the South African Association of Child and Adolescent Psychiatry and Allied Disciplines. This does not imply, however, that valuable research on substance abuse in South Africa has not been conducted. For example, Peltzer et al. (2002) state that it is difficult to estimate accurately the prevalence of substance abuse in South Africa. This may be due to, according to the present authors, the social and geographical complexity of South Africa. It was found that the prevalence of substance abuse, especially alcohol (22,2%), tobacco (12,0%), cannabis (6,6%), opiate type drugs (6,9%) and inhalants among university students in Limpopo Province, was very similar to those found in Kenya, East Africa. The results showed that alcohol, followed by nicotine and marijuana was the most commonly abused substance.

In the Western Cape, research was conducted to investigate the incidence of alcohol intake among pregnant women attending antenatal clinics in various health establishments. Croxford and Viljoen (1999) reported a disturbingly high rate (42,8%) of alcohol ingestion among pregnant women. About 46,0% of the participants admitted smoking, whilst combined abuse of alcohol and nicotine was 29,6%. Still in the Western Cape, Peden and Bautz (2000) investigated the link between substance abuse and physical trauma in Cape Town. It was found that about 60,0% of patients reporting with injuries tested positive for the presence of alcohol. The injuries were inflicted through traffic accidents, interpersonal violence and self-inflicted injuries. Van der Spuy (2000) goes further arguing that substance abuse, in general, is one of the major causes of high rate of trauma in that 7,0% of the drivers with higher blood alcohol concentration are responsible for 29,0% of non-fatal and 47,0% of fatal driver injuries. Intoxicated pedestrians also account for 40,0% of the national traffic death toll in South Africa. Cannabis and Mandrax accounted for 41,8% of injured patients.

Attempting to shed light on over-the-counter and prescription medicine abuse, Myers et al. (2003) argue that over-the-counter and prescription medicine abuse should be considered a major social and health risk and burden. It was found that benzodiazepines and analgesics are the most commonly abused drugs in Cape Town. Women were more prone to abuse these drugs than men.

The Province of KwaZulu-Natal is no exception as far as substance abuse is concerned. Taylor et al. (2003) studied the prevalence and associated factors of substance abuse among rural pupils in this province. It was found that there was high rate of substance abuse among these learners. Alcohol (52,9%) was the main substance of abuse, followed by cannabis (16,9%), while 13,0% admitted to smoking more than one cigarette per day. Furthermore, Brook et al. (2006) considered personal attributes and peer substance use as the main driver of the highest percentage of the variables in the abuse of substance among young people. It seems that even health professionals are not immune to the dangers of substance abuse. Marais et al. (2002) investigated the prevalence of alcohol abuse among medical students at the University of the Free State. It was found that 28,3% of medical students at sixth-year level abused alcohol excessively. Bateman (2004) reviewed research projects on substance abuse among medical practitioners in South Africa. However, the studies only focused on medical professionals who suffered from substance dependency and were therefore a highly selected group. The research, nonetheless, confirms that a significant percentage of medical professionals develop substance dependency during their training years.

It is clear that alcohol is the most commonly abused substance in South Africa. Next to the already mentioned consequences of substance abuse (accidents, aggressive behaviour, etc,) the correlation between substance abuse and the development of mental disorders and violent behaviour should not be underestimated. For example, there are ongoing debates on the link between substance abuse and psychosis. The fundamental question is what precipitates what? Brink et al. (2003), upon investigating the impact of substance abuse on psychosis, reported that such abuse has a significant effect on the onset of Psychotic behaviour among patients in the Western Cape. The finding was that a significant percentage (27%) had used or abused substances more than once a week in the three months prior to their becoming psychotic. The conclusion was that substance abuse is very common among Psychiatric patients.

In a review article, Padayachee and Singh (2003) link intimate violent behaviour with substance abuse. The argument is that substances, especially alcohol, play a role in the incidence of domestic violence. However, people’s response to substance abuse differs from culture to culture. It is argued that violence caused by substance abuse is assimilated socially rather than caused by involuntary reactions.

Culture and substance abuse

Culture is an assimilated system of beliefs, values, rules, meanings, and practices that are transmitted from one generation to the next in patterned ways (Flaskerud, 2000). Culture therefore expresses and reflects the manner of looking at, perceiving, and experiencing the world. Swartz (2008) emphasizes that there are discrete cultural groups globally, and the issue is about the appropriateness, correctness and accessibility of adequate mental health services in a culturally diverse society such as South Africa with officially eleven ethnic groups and languages. Against this background, it is understandable that culture plays a vital role in the development of certain attitudes and behaviours towards alcohol and other drugs (Zickler, 1999; Grob, 1992).

Heath (2001) rightly points out that it is globally recognized that various cultural and ethnic groupings use a wide variety of alcohol and drugs in many different ways. Mental health professionals are often not well equipped to work with clients from cultures different from their own (Amodeo & Jones, 1997). Mental health services providers should be able to recognize, appreciate, respect and engage cultural issues of the people they are treating (Quintero et al., 2007). Moreover, Withy et al. (2007) point out that substance treatment programmes require culturally tailored-made approaches to be effective and successful. Room et al. (1996) go further, emphasizing the urgent need for the development of a cross-culturally applicable diagnostic criteria and assessment tools that can be appropriately used in different cultures.

Though some significant changes have been observed in various cultures, nonetheless, there are still some expectations based on gender regarding drinking behaviours and drunkenness, meaning that it is somehow acceptable for males to be seen drunk (Kulis et al., 2003).The most common substances of abuse worldwide are alcohol, cannabis, cocaine, ecstasy, heroin, LSD and mandrax. Pharmacologically, alcohol is considered a depressant drug. For many, the abuse of alcohol is a multi-factorial process related to genetic, psychological and socio-cultural forces Batel (1996). Each culture has its own unique interpretation and perception of alcohol abuse. Mental illness, guilt and tolerance thresholds are manifested differently in different cultures.

In many cultures, beverages of alcohol make up significant and valued dimensions of life (Barry III, 1982). In the main, most literature places excessive emphasis on alcohol, albeit those other hard and harmful drugs have already penetrated many communities.

Room (2001) categorizes drinking behaviour into two dimensions: “wet” and “dry” societies. According to the nosology in dry societies, alcohol is taken apart from everyday life as a unique valuable commodity for special occasions, hence drinking is traditionally sporadic, is often used during special days or weekends, with a high proportion of drinking involving drunkenness. But “wet” societies use alcohol as part of everyday life, and such use usually accompanies meals. An example of alcohol that is often used in “wet” societies is red wine which is often used during meals.

Drinking behaviour in various societies has been viewed in different ways in the world. Alcohol is a substance with psychoactive ingredients. For that reason, access to alcohol may be restricted. On the other hand, alcohol is seen as part of nutrition rather than a drug, and therefore, access to alcohol may be relatively unrestricted (Schmidt & Room, 1999). There are also cultural variations in the regulation of quantity, duration and behavioural dimensions of drinking and drunkenness. People across the globe may differ significantly in the degree to which particular substance-related problems are viewed as serious issues in their communities. Other cultural aspects of drinking include the problematization of dependence, drinking-related states and experiences, the extent to which attention is paid to the potential involvement of substance in adverse situations and the reality of culture specific presentation of alcohol disturbances that are not properly captured in either the DSM-IV-TR or the ICD-10.

The continuum between normal and abnormal (pathological) drinking was explored by Bennet and Janca (1993), who focused on how people from various cultural backgrounds distinguish between normal and abnormal drinking which might be labelled harmful, abusive, heavy, dependent and pathological consumption. It is also mentioned that people within the same culture display different ideas and experiences regarding alcohol consumption, whether these are normal or pathological. It was found that people (sample) from Greece and Spain agreed that normal drinking was possible and was a very important aspect of their cultures. Arizona respondents gave mixed views concerning normal drinking and pathological drinking. The first group of respondents argued that normal drinking was not possible, hence normal drinking equalled binge drinking, while other negligible numbers of respondents believed that normal drinking was possible because it was more apparent in other cultures than among the Navajo themselves. In Bangalore, India, it was reported that respondents generally argued that normal drinking was not possible within their cultures.

Brannock and Schandler (1990) investigated cultural and cognitive factors among groups of black, white and Hispanic adolescent drinkers. White respondents manifested more frequent drinking behaviour than black and Hispanic groups. However, there was a significant difference between Blacks and Hispanics as far as drinking behaviour was concerned. Whites drank more socially, and drank in response to distress, while black respondees reported less drinking among friends and peers.

In Dallas, Houston and San Antonio, a comparative study on the link between aggressive criminal activities and substance abuse among Mexican American, black and white arrestees was carried out. The purpose was to predict the outcome of aggressive crime on the basis of substance abuse (both hard drugs and alcohol) and cultural group variables within the total male sample of 2,364 (Valdez et al., 1997). It was found that Mexican Americans were more likely to be arrested for aggressive crimes than either African Americans or European Americans. However, effects of both illicit drugs and alcohol were found to be similar for all ethnic groups. This means that although hard drug abuse and aggressive behaviours receive most of the attention across the globe, alcohol itself is still the prominent substance responsible for violent behaviours across the range of ethnic groups consisting of Hispanics, Blacks and Whites. Alcohol is evidently linked to domestic violence, especially among middle class men.

In Singapore, in the Far East, Hong & Isralowitz (1989) conducted a cross-cultural study on alcohol consumption behaviour among Singapore college students. The assumption was that Singapore Indian college students would display higher rates of drinking problem behaviour than Chinese students. The findings were that about 70,0% of Chinese participants mentioned that they consumed alcohol in comparison to 63,0% of the Indian respondents who used the substance. Regarding gender, 80,0% of Chinese males and 60,0% of females used alcohol. Making a comparison, it can be stated that a slightly lower percentage of alcohol users were found in the Indian sample. Chinese students liked beer while Indians preferred red wine. There were differences in the effects of substance abuse among Chinese and Indian respondents in terms of having a hangover, vomiting because of drinking, driving a car under the influence of alcohol, social and occupational impairment such as missing a class because of the after effects, and causing disharmony in interpersonal relationship. Indians displayed a tendency of more problematic behaviour than the Chinese sample.

Testing the cross-cultural applicability of Jellinek's Progression Technique in a sample of Navajo men and women, Venner and Miller (2001) found the following as far as the progression of alcohol problems was concerned: that in general, Navajo respondees tasted alcohol for the first time around age 16; violation of legal, social norms and rules took place in the early twenties, and the first experience of blackout occurred in the mid-twenties. Many happenings centred around 28 years of age, events that were related to social and interpersonal relationships, while they carried on with their drinking habits despite problems. First hospitalization, attempts to quit drinking and nutritional neglect occurred by their early thirties. Aspects typical of dependence appeared later in the progression. Changes in tolerance and the drinking of non-beverage alcohol such as mouthwash or hairspray were the last to be reported. Symptomatologically, the participants (20 out of 46) experienced loss of interest in life, heavy drinking episodes lasting for at least two days. They also reported a decrease in moral standards and vague spiritual desires, physical withdrawal symptoms such as being afraid and tremors. Most importantly, Navajo women experienced hallucinations at the beginning of their progression. Feeling bad about drinking, experiencing augmented tolerance and quitting for a while occurred in at least 20 ordinal positions later for the Navajo.

Once more, in the United State of America, the study was conducted among primary care patients with alcohol problems, comparing whether race made any difference between two groups of participants (African Americans and Whites) with respect to consumption, severity, consequences, readiness to change and coping behaviour. Conigliaro et al. (2000) reported that in comparison to white patients, African-American respondents presenting with alcohol problems, and enrolled in a brief intervention programme, met all the criteria for alcohol dependence or drug dependence, but displayed the same levels of alcohol consumption compared to white patients. There was a marked increase in drug dependence among African Americans compared to Whites who met criteria for drug dependence (43,0% versus 35,0%). Again, it was discovered that alcohol and drug abuse were more serious among African Americans than Whites. However, there was no difference in alcohol consumption rate between the two groups. African-American patients reported more symptoms of dependence and less consumption than white patients. In relation to readiness to change, both groups were equally ready to change their drinking behaviour, but African Americans were more highly concerned about the consequences of alcohol on their health and life in general.

A similar study was also conducted in the USA focusing on the prevalence, incidence and stability of dependence-related problems and social consequences among Whites, Blacks and Hispanics: 1984 – 1992 (Caetano, 1997). The findings were that Hispanic men displayed a higher incidence of frequent heavy drinking, much more than other ethnic groups and women. Again the higher incidence and stability of dependence problems were found to be more prevalent among Hispanic men than Blacks and Whites. Stability referred to an indicator of chronicity, while the incidence denoted the proportion of people who did not report a disturbance in 1984, but did so in 1992. The dependence-related disturbances are: salience of drink-seeking behaviour, loss of control, withdrawal and tolerance symptoms as well as relief drinking. In general, the results showed that Blacks displayed a higher incidence of both dependence-related and social consequences, as well as more marked stability of social consequences compared with whites. Social consequences refer to financial difficulties, social and legal problems, health-related issues, marital dysfunction, as well as social and occupational impairment.

In California, the sub-tribes of Chumash Indians use Datura, which is a hallucinogenic substance (Grobstein & Rios, 1992). This decoction is used in pubertal custom to celebrate the passage of the youth into adulthood. The potion consists of the leaves, roots and stems, which are soaked in water.

There have been several reports on wide varieties of illicit drugs such s cannabis, cocaine, Lsd, ecstasy, mandrax and heroin in South Africa. There is a new home-made drug called methcathinone popularly known as “cat”, which is a cocktail of methamphetamine mixed with other substances (Lillah, 2003). This drug is secretly prepared in the kitchen by anyone with a recipe and sold exclusively in a white powder form. It can be diluted in liquids or mixed with other substances in capsule form in order to be injected intravenously. The most dangerous part of this drug is that it is deadly addictive. Common symptoms include increased energy, euphoria, flight of the mind, feelings of invincibility. The side effects are reported to be terrible and include, tremors, insomnia, somatic symptoms, dehydration, sweating, nasal disturbances, anxiety, rapid heart rate, and loss of weight; at worst, the addicted person may present with paranoia, convulsions and various forms of hallucinations.

It was against this background that it was decided to study how substance abuse-related disorders are clinically manifested among Sesotho speakers in Mangaung, South Africa.

Methodology

The Mangaung Township in Bloemfontein, South Africa, was selected as the geographical area for the completion of the research. For this exploratory descriptive study, the participants consisted of 106 Sesotho speakers diagnosed with substance abuse. They were drawn from the population of patients visiting various health establishments in the area. All patients presenting to a specific health facility who qualified, during the period when the researchers were based at the facility, were included. The time periods varied from one month to two years. The participants were evaluated and diagnosed by a multi-professional team which typically consisted of a psychiatry doctor (registrar), clinical psychologist and a psychiatric nurse (in certain areas, social workers, occupational therapists and/or physiotherapists also formed part of the team). The DSM-IV-TR criteria for substance abuse were used as the inclusion criteria. The participants were between 18 and 65 years of age, and both genders were represented. Written informed consent was obtained from each participant.

A semi-structured interview, based on the Psychiatric Interview Questionnaire (PIQ) used by the Department of Psychiatry at the University of the Free State, was used to elicit the information (Mosotho et al., 2008). The PIQ is based on the *Clinician's Thesaurus: The Guidebook for Writing Psychological Reports* (Zuckerman, 2000) and *Outline of the Psychiatric History and Mental Status Examination* (MacKinnon and Yudofsky, 1986). The PIQ provides data on preliminary identification (including demographic information), main complaints, personal description, history of present illness, psychiatric review of systems, previous mental illness, past personal history, a mental-status examination consisting of: appearance, attitude and behaviour, thought processes, perception, mood and affect, consciousness, orientation, memory, tempo, intelligence, mode of thinking, judgment and insight, as well as hypothalamic and autonomic functioning (Mosotho et al., 2008).

Qualitative methods were used to describe the experiences of the participants regarding their symptoms, as well as a way to elucidate the quantitative data. Qualitative methods that were used consisted of two types of data collection: the open-ended interview and clinical observation. The interview data consist of direct quotations from participants about their experiences, feelings, emotions, opinions and knowledge, while observation data refer to detailed description of participants' activities, behaviours, actions and full range of interpersonal interactions and organizational processes that are part of observable human experience (Patton, 1990). Individual interviews were transcribed, and information gathered was grouped into themes. Themes are written in the subject's own words or transcribed as closely as possible (or a close rendition of the subject's account). These themes were divided into psychological symptoms, physical (somatic) symptoms, as well as behavioural and social symptoms. Quantitatively, a descriptive statistical analysis was performed to provide indications of frequency (incidence) of identifying demographic characteristics, signs and symptoms of mental illness, and socio-cultural variables associated with substance abuse that are covered in the questionnaire.

The study was approved by the ethics committee and the council of the University of the Free State. The pilot study was conducted on 40 patients to investigate the practical feasibility of the research. Based on the pilot study findings, minor adjustments on coding of the questionnaire were made.

Results and Discussion

About 54,0% of the participants were aged between 18 and 35 years. The elderly (aged between 46 and 65) were most affected by substance abuse disorders. This finding confirms what was reported by Widlitz and Marin (2002) that elderly people are also prone to develop substance addiction and dependence. However, this issue is more likely to be overlooked and ignored by health professionals. The fact remains; nonetheless, that substance abuse is common in the general population and encompasses people of all ages and all socio-economic levels (Weaver et al., 1999). As far as gender is concerned, it was found that about 70,0% of the participants were males. This corresponds well with international literature and research findings that substance abuse is usually higher among males than females (Kulis et al., 2003).

As far as education is concerned, it was found that relatively few participants had passed grade 12. These low educational levels are understandable. It could also be that substance abuse negatively affects an individual’s social and mental functioning. Almost 60,0% of the subjects were single. A possible explanation could lie in the fact that most South African youth do not marry before the age of 30. Also, the fact that so many of the participants were unemployed and could therefore not provide the necessary financial security to their families, probably also played a role. It is disturbing that a significant percentage of participants who were diagnosed with serious substance abuse disorders were students. This result supports the findings by Marais et al. (2002) who reported a prevalence rate of more than 25,0% of alcohol abuse among medical students in the Mangaung area. The dominance of Christianity among the participants corresponds well with the distribution of religions in South Africa. Another significant finding was that more than 40,0% of the participants were involved in criminal activities. This is in agreement with what was reported by Padayachee and Singh (2003) and Heffernan et al. (2003) who also found a relatively high incidence of various crimes among substance abusers.

Alcohol was found to be the main substance abused by the participants, followed by nicotine and cannabis respectively. About 40,0% of the participants abused more than one substance. The higher prevalence of alcohol, nicotine and cannabis relative to other hard drugs such as heroin, cocaine, crack and the like, might be attributed to accessibility and affordability of the afore-mentioned drugs in the community. Taylor et al. (2003) found a similar trend in KwaZulu-Natal Province and the Eastern coastal region of South Africa. However, this finding is in contrast with other regions and cultural groups in South Africa. Nearly 90,0% of the participants did have some form of social support system. This is in accordance with findings by other researchers that the social support system of individuals suffering from mental disorders is adequate in the developing world, leading to a better prognosis and course than is the case in developed nations (Dani & Thienshaus, 1996; Sartorius et al., 1980; Jablensky et al., 1992).

The findings concerning the primary symptoms are presented in Table 1. As it was impossible to determine the cause, it should be noted, however, that the reported symptoms could not necessarily be linked unequivocally to substance abuse, because they could have been symptomatic of another underlying mental disorder. The inclusion criteria for classifying symptoms as primary revealed a prevalence rate of at least 20,0%. Only dividing symptoms into somatic and psychological categories would have been regarded as overlapping and superficial. However, for practical and discussion purposes, it was decided to make the distinction between primary symptoms (20,0% and more) and secondary symptoms (less than 20,0% but more than 5,0%).The frequencies are the sum total of the symptoms reported by the participants as well as those observed by the researcher.

Table 1: Primary Substance Abuse Symptoms expressed by Sesotho speakers

Psychological Symptoms			
Aggression	32,1	Auditory hallucinations	73,1
Disorientation	23,0	Visual hallucinations	55,0
Poor concentration	77,1	Hallucinosis	27,2
Irrelevant answers	25,5	Illusions	23,0
Derailment	24,5	Inappropriate affect	27,4
Suicide ideation	20,0	Restricted affect	23,6
Delusions of persecution	36,8	Irritability	50,0
Delusion of grandeur	20,8	Anxiety	35,0
Memory impairment	53,0	Agitation	40,6
Poor insight	58,0	Poor judgment	53,0

Concrete Mode of thinking	67,0	Insomnia	71,0
Overeating	21,0	Poor libido	51,0
Somatic Symptoms			
Constipation	43,4	Palpitations	43,0
Headaches	50,0	Excessive sweating	59,0
Dizziness	52,0	Anxiousness	60,4

Table 1 shows that there was significant comorbidity and over-lapping of symptoms such as impaired concentration, poor memory, auditory and visual hallucinations, irritability, insomnia and decreased libido. These symptoms were also found in other mental disorders, especially schizophrenia and major depressive disorders among Sesotho speakers (Mosotho, et al, 2008). However, it was found that the contents of hallucinations in the participants were not clearly defined as it was the case among patients suffering from depression, anxiety and schizophrenia.

Because substance abuse and especially alcohol abuse could lead to various physical conditions, a marked deterioration in general health, malnutrition, poor personal self-care and hygiene were also observed. It was therefore somewhat surprising that participants expressed more and a wider variety of psychological than physical symptoms. Cognition was affected more severely than mood, affect and behaviour. Behavioural and social deviations such as violent and aggressive acts, violation of social and legal norms seemed to have been more frequent when a combination of substances was abused. These seemed to be alcohol and cannabis in particular. A significant number of the participants also expressed difficulties with absenteeism at work, decreased productivity, poor labour discipline as well as general impairment in social, academic, occupational and mental functioning. Moreover, they also experienced financial difficulties, consequently neglecting their family and social responsibilities.

Next to the primary symptoms, there were also secondary symptoms which could not be ignored. The symptoms were classified as secondary as they contributed less than 20,0%, but more than 5,0%. These symptoms varied markedly in terms of diversity and severity. Those secondary symptoms are shown in Table 2.

Table 2: Secondary symptoms of substance abuse expressed by Sesotho speakers

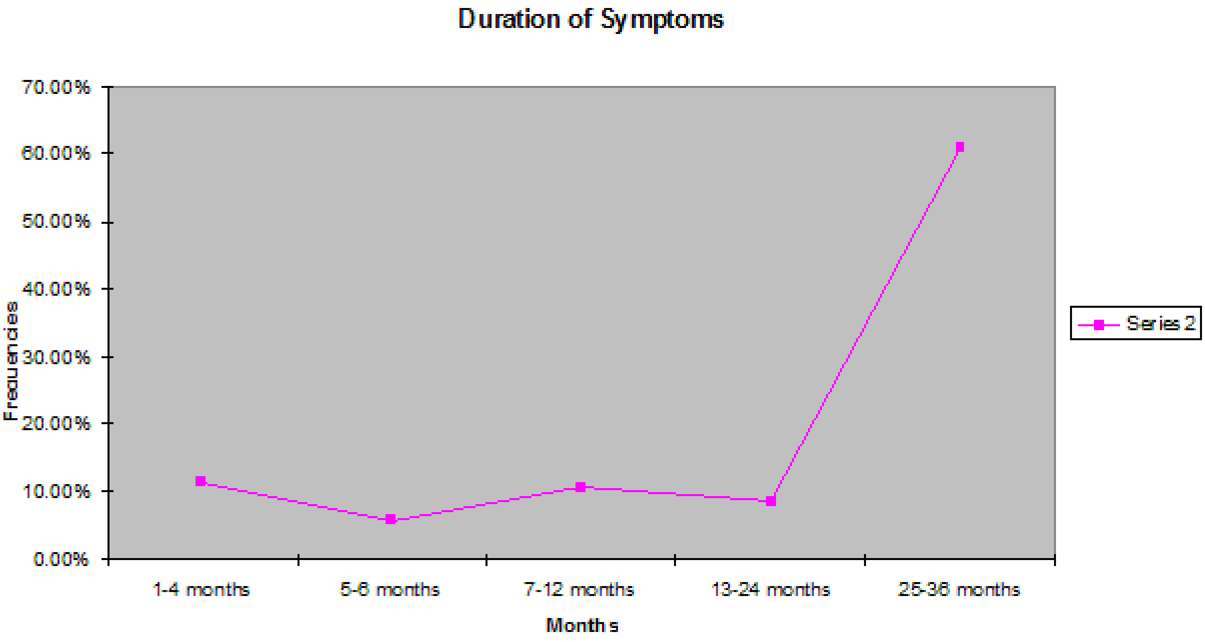
Tangentiality
Loosening of associations
Derailment
Flight of ideas
Pressure of speech
Poverty of speech
Blunted affect
Walking around naked
Expansive mood
Elevated mood
Depression
Alexithymia
Apathy
Guilt feelings
Acting out
Bad smell
Hot head
Delusions of reference
Bizarre delusions
Olfactory hallucinations
Gustatory hallucinations
Somatic hallucination
Depersonalization
Labile affect
Dysphoric mood
Mood swings
Euphoria
Anhedonia
Panic
Shame
Fainting
Nerves
Boiling brain
Fear

Poor personal hygiene
Stress
Poor academic performance
Numbness
Decreased productivity
Lack of willpower
Family negligence
Weakness
Stiffness of the neck
Loss of weight
Short tempered
Talkative
Crying
Stealing behaviour

Red eyes
Deterioration
Loss of control
Talking with heart
Poor motivation
Walking around aimlessly
Itching sensations
Visual disturbances
Social withdrawal
Running away from home
Intoxicated
Feeling dull
Vomiting
Secretive

The variety of secondary symptoms is conspicuous. However, this finding is in line with other researchers who also reported a wide range of symptoms in substances abusers (Brink et al., 2003).
The duration of the primary and secondary symptoms of substance abuse among the participants is shown in Figure 1.

Figure 1: Duration of symptoms in substance abusers



It is clear that the majority of participants experienced the symptoms for significant periods of time. In more than 60,0% of the samples, the symptoms have persisted between two and three years. This finding is disturbing because substance abuse negatively affects basically all spheres of human functioning, these being the psychological, mental, physical and social domains (see Tables 1 and 2).

As far as treatment is concerned, a relatively high percentage (66,5%) of the participants simultaneously consulted both Western-trained mental health professionals and traditional/spiritual healers for their ailments. Although it was found that in the majority of cases the Western model of treatment was the first choice, the finding confirms the significant role played by traditional medicine in South Africa (Mkhize, 2003).

Conclusion

The general consensus is that substance abuse is one of the major social and health problems, not only in South Africa, but throughout the world. It was found in the present study that alcohol was the most commonly abused substance in Mangaung, followed by nicotine and cannabis respectively. This finding was in contrast with other results in South Africa where the prevalence of hard drugs such as heroin, cocaine, ecstasy and mandrax was much higher among their research participants. Sesotho speakers expressed a wide range of symptoms. The finding that the participants had suffered for a relatively extended time from the symptoms was worrying. Regarding treatment, the important role of traditional healers and medicine in the Mangaung area was confirmed.

Although the present study has revealed significant findings, these results should, however, be interpreted with caution. Firstly, the participants were almost exclusively from one area of the Free State Province, while Sesotho speakers are widely dispersed throughout the province, other parts of South Africa and Lesotho. The generalization of the results should therefore be interpreted cautiously. Another factor to be taken into consideration is that within the Sesotho-speaking population there are many sub-cultural differences. The point is that different groups of Sesotho speakers within the same geographical areas may differ significantly. Additionally, it should be taken into account that the data gathering to a large extent relied on self-report which, as is generally accepted, often does not capture the real situation. This is especially true in the case of substance abuse which in many cases is a criminal offence in South Africa. Nevertheless, the study remains significant because it does contribute to important data in a field that has been largely neglected in South Africa.

Dealing with the substance abuse problem among Sesotho speakers will not be easy. Next to fighting the abuse of alcohol, as in most cultures, the high incidence of cannabis is an additional aggravating and complex factor. The use of cannabis by black South Africans, and therefore also Sesotho speakers, has been part of cultural practices for centuries (like for example, wine drinking among Whites in especially the Western Cape). It is also used in certain cultural rituals, while there is a strong belief in the healing power of the drug. The cultural prescriptions regulating the use of cannabis no longer serve to protect people as it did historically. The fact that cannabis is also cheaper than both alcohol and nicotine adds to the dim picture.

Special programmes that take the unique cultural value systems into consideration should therefore be developed. However, such programmes can only succeed if they are based on thorough empirical research concerning specific targeted groups. Such research is therefore strongly recommended.

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The International Journal of Psychosocial Rehabilitation
Volume 14, Number 2
July 2009– June 2010

What are the required competencies of the "effective" psychiatric rehabilitation practitioner? Comparing perspectives of service users, service providers and family members.

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Citation:
Roe D, Telem A, Baloush-Klienman V, Gelkopf M & Rudnick , A.(2010). What Are The Required Competencies Of The "Effective" Psychiatric Rehabilitation Practitioner? Comparing Perspectives Of Service Users, Service Providers And Family Members. ***International Journal of Psychosocial Rehabilitation. Vol 14(2). 82-94***

Abstract

Background and objective: Research findings and conceptual developments have generated growing optimism that with appropriate resources and opportunities many persons with serious mental illness (SMI) can achieve recovery and related community integration. It is essential to identify how front line psychiatric rehabilitation service providers (PRPs) can facilitate this process. This study aimed to identify the skills, knowledge, attitudes, and values required from the effective PRP. Method: During the first stage, focus groups were conducted with a group of service users , a group of family members and a group of PRPs. Based on these and on a review of the literature, we found interpersonal, professional, rehabilitation, planning and evaluation skills, and access to community resources to be the major competencies required of the PRP. This list was developed into a questionnaire and administered to 34 service providers, 35 service users, and 33 family members which required a forced choice rating of each of the competencies based on their degree of importance. Results: There were few differences in the way service providers, service users, and family members rated the importance of these competencies. Conclusion: Key stakeholders (service users, service providers and family members) appear to agree in general about the key competencies required from the PRP, suggesting that the needed competencies may be universal and independent of cultural context. Implications for training and education are discussed.

Key words: competencies, practitioners, psychiatric rehabilitation, stakeholders

Introduction

Historically, services for people with serious mental illness (SMI) in Israel included mainly psychotropic medication and limited psychotherapy often dispensed during long psychiatric hospitalizations, some of which lasted decades. A milestone in the development of psychiatric rehabilitation services (PSRS) was reached with the recent legislation concerning the rehabilitation in the community of people with psychiatric disabilities (The Rehabilitation of Psychiatrically Disabled Persons in the Community Act., 2000). The legislation specifies a "basket" of PSRS to be provided to service users who meet eligibility requirements, As a result, in the last decade more than half the psychiatric hospital patients in Israel were discharged into the community, resulting in a decrease from 1.17 per 1,000 people hospitalized in psychiatric hospitals in 1996 to 0.45 in 2008 (Aviram, in press). Currently, approximately 14,000 persons with psychiatric disabilities who meet eligibility requirements are receiving PSRS in the community. The provision of adequate services in the area of psychiatric rehabilitation requires service providers with appropriate competencies. The importance of identifying these competencies is manifest in reports by supervisors of rehabilitation service providers on the need for efficiency on the job (Marrelli et al., 2005). For example, in a survey conducted among 81 employers of PSRS in the U.S., one third ranked their employees as "unprepared," lacking experience, lacking procedural knowledge in work with consumers, having deficient interviewing skills, being unable to plan rehabilitation programs, and deficient in group leading skills (Fishbein & Holland, 1993). Lack of competencies among a broad segment of service providers is perceived as a barrier to recovery and community integration for persons with SMI (Kevin, 2007; Marrelli, Tondora & Hoge, 2005; Morris & Stuart, 2002; Young et al., 2005). There is thus, a clear need for identifying the competencies required from rehabilitation service providers (note that in this paper, as in practice, the term competencies is used both broadly, to address various types of professional abilities, and narrowly, to address observable abilities).

The United States Psychiatric Rehabilitation Association (USPRA) provided a useful definition (2007) of psychiatric rehabilitation (PSR) and of the goals of PSR services, but far less attention has been paid to define the PRPs who provide these services. In order to improve the training and education of PRPs, it is important to characterize the competencies - approaches, skills, knowledge, and values - required from them.

A small number of empirical studies have focused on such efforts. In a study that attempted to identify the competencies required from PRPs (Coursey, 2000), a 28-member panel of experts was assembled, with varied backgrounds in mental health and rehabilitation. The panel found 12 sets of competencies required from psychiatric rehabilitation service providers. In another comprehensive study (Young, Forquer, Tran, Starzynski & Shatkin, 2000), 37 competencies were found in seven different areas. Finally, the International Association of Psychosocial Rehabilitation Services (IAPSRA, 2000), initiated a panel of six experts of the Association to identify and determine the professional, personal, and interpersonal competencies required from graduates of psychiatric rehabilitation programs. The objective of the panel was to initiate the first steps in determining areas of professional responsibility for students obtaining certification in psychiatric rehabilitation. To this end, a test was devised to examine the areas of responsibility, knowledge, values, and competencies of psychiatric rehabilitation service providers. Subsequently, 1,000 service providers were asked to validate the test, its clarity, and its relevance to the field. Following the work of the panel, several areas were specified as defining the criteria that every person entitled to a certificate as a psychiatric rehabilitation professional must meet (IAPSRS, 2000).

Collectively, the reviewed studies emphasize the importance of competencies related to the relationship between the rehabilitation practitioner and the consumer; to the ability to diagnose and evaluate; to advance rehabilitation and facilitate empowerment; to provide therapeutic, family, and supportive interventions; and to advance resources and coordination (Coursey et al, 2000; Young et al., 2000; IAPSRS, 2001). Competence is also needed to emphasize the fact that the rehabilitation process is unique and individualized, and for the rehabilitation practitioner to shape, evaluate, and document the interventions. Also important are skills needed for the rehabilitation practitioner to cooperate within the organization and with other organizations and to conduct professionalism and follow ethical norms and toward the endeavor to expand knowledge and develop a professional creed. Finally, important skills are related to the service providers' ability to seek support from colleagues and remain updated regarding the professional literature.

In order to improve the qualification process of PSR service providers, and consequently, the quality of the services they offer, it is necessary to define with greater precision the competencies - approaches, skills, knowledge, and values - required from them. This is particularly so as the previous studies, as noted above, focused on professional experts as primary sources of information and validation,whereas service users and their family members should also have a say in this matter, particularly in order to upkeep a recovery orientation (DHHS, 2003). The purpose of the present study, therefore, was to identify the skills, knowledge, attitudes, and values required from the effective PSR practitioner considering multiple perspectives of key stakeholders.

Method

Research design. This mixed design study combined qualitative focus group studies and a quantitative study. Both were informed by three different groups of stakeholders: service users, service providers and family members (of consumers). Written informed consent was obtained from all study participants.

Qualitative Focus Group Studies

Study sample

Three groups of stakeholders met separately:
Rehabilitation service providers' group. Two groups which together included 19 service providers (14 women and five men aged 23-40) from the field of psychiatric rehabilitation included service providers from various disciplines (social work, psychology, occupational therapy, community mental health workers). They had a bachelor's degree or more advanced education and worked in a variety of rehabilitation agencies and organizations, such as hostels and assisted living arrangements, and at rehabilitation centers that agreed to take part in the focus group about the effective PSR practitioner.

Service user group. This group was made of 11 service users with SMI (3 women and 8 men aged 28-40) receiving rehabilitation services.

Family members' group. This group consisted of 8 family members of service users (7 women and 1 man, aged 45-60), actively involved in their family member's life and in touch with the PSR service providers.

Study process

The 3 focus groups were convened in 2007. All participants agreed to take part in discussions, which were based on a semi structured group interview guide, about the effective rehabilitation practitioner in mental health care. Participants were asked open ended questions such as "What do you think makes for an effective psychiatric rehabilitation practitioner" and "What knowledge, values and skills would you expect an effective psychiatric rehabilitation practitioner to have"?. The focus groups convened once for an hour and a half under the guidance of the 2nd and 3rd authors.

Method of analysis

Qualitative study.

The discussion of the focus groups was audiotaped and transcribed. The 3 first authors performed a cross-case content analysis (Patton, 1990), identifying and coding themes across cases. Subsequently, they examined their individual analyses comparatively, discussing differences and seeking agreement on prominent recurrent elements and central themes and assembling them into categories of skills, knowledge, attitudes and values.

The data obtained from the focus groups answered the first research question: What skills, knowledge, attitudes and values are required from effective PSRs according to the three groups of stakeholders (service users, service providers and family members).

Quantitative Study

Study sample

The study sample was divided into three groups of stakeholders:
Rehabilitation service providers' group. This group included 34 service providers (28 women, 6 men aged 26-60), who provide front line PSRs to people with SMI. The sample of service providers were of various disciplines (social work, psychology, occupational therapy, community mental health workers) and had a bachelor's degree or more advanced education. They worked in a variety of rehabilitation agencies and organizations.

Service users' group. This group was made of 35 service users with SMI (21 women and 14 men aged 24-52) receiving psychiatric rehabilitation services. This group was sampled from a wide range of PSRs (such as residential and employment services) and was recruited through convenience sampling, some at an annual consumers' conference and others through various PSRs.
Family members' group. This group consisted of 33 family members of service users (20 women and 13 men, aged 26-81), actively involved in the consumers' lives and in touch with rehabilitation service providers. They were recruited by convenience sampling through various psychiatric rehabilitation services.

The total number of participants in the quantitative study was 102.

Research tools

Study Sample Characteristics Questionnaire

Items common to all three groups: gender, age, marital status, employment.
Items for Service users: education, independence (measured by degree of independence from the point of view of living arrangements), psychiatric diagnosis, age at onset of disorder and number of hospitalizations.

Items for rehabilitation service providers:

Education, area of specialization, seniority.

To evaluate the service providers' attitudes toward rehabilitation and consumers, we used the Psychiatric Rehabilitation Beliefs, Goals, and Practices Scale (PRBGP; Casper, Oursler, Schmidt & Gill, 2002). This questionnaire has shown excellent convergent and discriminant validity (Casper, 2005).

Evaluation of the importance of competencies

To evaluate and compare the importance each stakeholder group afforded regarding the different competencies of the rehabilitation practitioner in mental health care in the Israeli context we generated a tool, the Competencies of the Rehabilitation Practitioner Questionnaire (CRPQ), based on the results of the qualitative portion of the study and the relevant professional literature (see Appendix 1). This questionnaire included the essential competencies of the rehabilitation practitioner that were mentioned in the focus groups and in the literature, which we classified into 5 dimensions: (a) interpersonal, addressing the modes of communication of the rehabilitation practitioner with the consumer; (b) professional, relating to knowledge skills addressing mental illness and psychiatric disability, medications and their side effects, and professional ethics; (c) evaluation and planning, relating to proper resource management and documentation, and evaluation of the consumer's situation; (d) access to social resources, relating to a holistic approach to the human condition and wide knowledge of existing services being offered to this population; and (e) rehabilitation (or recovery orientation), relating to the optimism of the service providers and their faith in the persons who they serve. The questionnaire was administered to the 3 stakeholder groups. All participants ranked the items of the CRPQ on a 5-point scale (from 5=most important to 1=least important). So as to avoid having participants respond the same way on each of the items a forced choice method was used, whereby the same rank score (e.g., 4) cannot be given more than once to a different skill. After all the questionnaires were completed, the competencies of the effective rehabilitation practitioner were grouped into two categories: more important (ranking of 4-5) and less important (ranking of 1-3).

Data analysis

We used descriptive statistics to characterize the groups of participants. In the quantitative study to test the relations between the various stakeholder groups and the ranking of competencies we performed $\chi 2$ tests. In addition, we performed t-tests and $\chi 2$ tests to assess the relationship between demographic, professional and clinical characteristics and the rating of competencies. Significance was set at .05.

Results

We present here first the results of the qualitative study, followed by the results of the quantitative study which elaborated upon the qualitative findings.

Qualitative Study

The competencies of the rehabilitation practitioner from the point of view of the three focus groups and the professional literature is presented hereunder. No differences were observed in the competencies presented by the three groups, and all points could be found in the professional literature and included the following 5 categories. Interpersonal skills: These include a positive and empathic approach toward service users and their wishes, their backgrounds, and their peer group (Young et al., 2000). The focus groups also stressed the importance of conducting an honest, clear, and structured dialogue with the consumer (Young et al., 2000; Coursey et al.,2000; IAPSRS, 2001).

Professional skills: These include having knowledge about disorders, various methods of treatment, medicines and side effects (Young et al., 2000; Coursey et al.,2000; IAPSRS, 2001). The need for professional ethics, knowledge about consumer rights and services offered to service users (Young et al., 2000; Coursey et al.,2000; IAPSRS, 2001) was also noted. Service providers were also required to be able to identify difficult situations that require intervention and to be able to take measures to minimize deterioration (Young et al., 2000).

Evaluation and planning skills: These include the ability to conduct bio-psychosocial interviews, complete functional and health evaluation forms (denture, hearing, vision) (Young et al., 2000). Evaluation of the consumer's state at any given moment and assistance in identifying situations that enable growth and the gaining of strength was also considered as central (Coursey et al.,2000; IAPSRS, 2001).

Skills related to access to community resources: These include understanding of the effect of the socio-economic status on the rehabilitation process (Young et al., 2000); access to information and economic, employment as well as social services that support the rehabilitation process in the community (Young et al., 2000; Coursey et al.,2000; IAPSRS, 2001). The importance of assistance connecting the consumer with other sources of support (focus groups, Young et al., 2000; Coursey et al.,2000; IAPSRS, 2001), and coordination and supervision of these sources in order to promote the rehabilitation process (Young et al.,2000) was also noted. Follow-up and connection of the consumer with medical resources, and maintenance of continuous treatment (Young et al., 2000; Coursey et al.,2000; IAPSRS, 2001) and the need for struggle against situations that discriminate against the service users in the community (IAPSRS, 2001)was also stressed.

Skills related to rehabilitation (or recovery orientation): including optimism, faith in the potential of the consumer to grow and gain strength, and help in building hope and self-empowerment was noted, holistic approach (Young et al.). Assistance to service users in identifying and defining their wishes and ambitions in a wide range of domains (focus groups, Young et al., 2000; Coursey et al.,2000; IAPSRS, 2001) was considered important. The ability to Teach service users a range of skills related to leading an independent life, such as management of financial resources, identifying and coping with crisis situations, establishing social relations and acclimating within various frameworks, as independence from case worker develops, was also identified (Young et al. 2000) .

Quantitative Study
Analysis of stakeholder groups and characteristics of the research groups:
As mentioned, the research sample was divided into 3 groups: rehabilitation service providers, service users and family members. Tables 1 show the main characteristics of each group separately

Table 1. Description of the stakeholder groups

	Service Users (n=35)	Service providers (n=34)	Family members (n=33)
	N (%)	N (%)	N (%)
Gender			
Female	21 (60)	28 (82.4)	20 (66)
Marital Status			
Single	22 (62.9)	8 (23.5)	3 (9)
Married or lives in couple	3 (8.6)	24 (70.6)	21 (64)
Divorced	10 (28.6)	2 (5.9)	5 (15)
Widower	0 (0)	0 (0)	4 (12)
Employment			

Employed	26 (75)	100 (100)	15 (45.5)
Unemployed	9 (25)	0 (0)	13 (39.4)
Pension			2 (6.1)
Did not answer			3 (9)
Employment kind			NR
Independent	4 (12)		
Employee	4 (12)		
Supported employment	7 (20)	4 (11)	
Sheltered factory	10 (29)		
Hostel		12 (35)	
Supported community		2 (5.9)	
Protected work	1 (2)	9 (26)	
Other		7 (23.8)	
Living status		NR	NR
Independently	12 (34)		
With family/ friends	8 (22)		
Hostel	4 (8)		
Protected Living	11 (31)		
Education			NR
10 years or less	3 (7)		
12 years	11 (31)		
Professional diploma	11 (31)		
Supported academic ed.	1 (2)		
Academic	9 (24)		
B.A		20 (59)	
M.A		14 (41)	
Income		NR	NR

Below average	21 (61)		
Average	9 (25)		
Above average	5 (14)		
Psychiatric diagnoses		NR	NR
Schizophrenia	10 (29)		
Bi – polar	6 (18)		
Depression	4 (11)		
Borderline	4 (11)		
Schizoaffective	4 (11)		
Don't know	3 (9)		
Don't want to say	4 (11)		
Age, Mean (Sd)	37.79	32.43	59.4

NOTE: NR= not relevant

No differences were observed between the three stakeholder groups regarding the demographic data, except for family stakeholder group, which was found to be scientifically older in comparison to the two other stakeholder's groups (service users and service providers (One-Way Anova f(2)= 62.77 P< 0.001). Assessing the relations between demographic, clinical and professional attributes of the stakeholder groups and the ranking of the competencies (see table 2) of the effective rehabilitation practitioner, no significant relation was found.

Distribution of the Competencies of the Effective Rehabilitation Practitioner

When assessing the relative importance participants gave to the different competencies, results show that interpersonal, professional, and rehabilitation skills were ranked as more important than planning and evaluation skills and skills for accessing social resources.

Table 2. Mean score and mean ranking of importance of the complete sample (N=102)

Type of competence	**Score**		**Rated as Important**		**Rated as Less Important**	
	Mean	**SD**	**N**	**%**	**N**	**%**
Interpersonal skills	3.71	1.35	66	64.7	36	35.3
Rehabilitation skills	3.48	1.39	55	53.9	47	46.1

Type of competence	**Score**		**Rated as Important**		**Rated as Less Important**	
	Mean	**SD**	**N**	**%**	**N**	**%**
Professional skills	3.20	1.25	46	45.1	56	54.9
Skills for accessing social resources	2.55	1.16	23	22.5	79	77.5
Planning and evaluation skills	2.10	1.28	15	14.7	87	85.3

Ranking of the Competencies of the Effective Rehabilitation Practitioner: Differences Between Stakeholder Groups

To test the hypothesis that there are differences in the way in which rehabilitation service providers, consumers, and family members evaluate the competencies of the effective rehabilitation practitioner we performed five 3 X 2 $\chi2$ tests assessing whether on the five competencies the 3 stakeholder groups rated each of the competencies as being differentially important. Results are presented in Table 3.

Table 3. Ratings of importance of Competencies between the three stakeholder groups.

Competency	Importance	Family members (n=33)		Consumers (n=35)		Rehabilitation practitioners (n=34)		$X(^2)$
		N	%	N	%	N	%	
Interpersonal skills	Important	18	55	24	69	24	71	2.24
	Less important	15	45	11	31	10	29	
Professional skills	Important	14	42	21	60	11	33	5.46†
	Less important	19	58	14	40	23	67	
Planning and evaluation skills	Important	8	24	4	11	3	8	3.63
	Less important	25	76	31	89	31	92	
Skills for accessing social resources	Important	12	36	6	17	5	14	5.39
	Less important	21	64	29	83	29	86	
Rehabilitation skills	Important	14	42	15	42	26	77	**10.44
	Lessimportant	19	57	20	58	8	23	

Note: df=2; † $p< .10$, * $p< .05$, ** $p< .01$

Relation between the Ranking of Competencies and the Attitudes of the Rehabilitation Service providers

Members of the service providers' group were asked to complete the PRBGP to test whether various attitudes toward rehabilitation and service users was related to their ranking of the competencies of the effective rehabilitation practitioner. Using t-tests comparing those who rated each competency as important vs. less important on the total score of the PRBGP, we found no relation between the rating of importance of competencies and the PRBGP total score.

In sum, analysis of the results shows that except for rehabilitation and professional competencies, which were assessed as more important by service providers and service users respectively, members of the various research groups hold more or less the same opinion regarding the effective rehabilitation practitioner.

Discussion

The quality of PRS provided depends to a large extent on the person providing them. The need for research that attempts to identify the competencies of the PRP arose in the past decade, primarily in the US (Young et al., 2000; Coursey et al., 2000; IAPSRS, 2001). In the literature, the key competencies of the rehabilitation practitioner are distributed over a wide range of areas: personal, interpersonal, professional, legislative, and cultural. There have been only a few empirical attempts, however, to study this topic in a systematic manner.

The present study investigated this issue in Israel, using mixed methods as well as exploring and assessing the perspective of three groups of stakeholders: consumers, service providers, and family members. Findings indicate that on the one hand there is broad agreement about the required competencies of rehabilitation service providers in the field of mental health care, and on the other hand there are some differences in the ranking of the degree of importance of these competencies. Interestingly, the uniformity among the three groups of stakeholders regarding the importance of competencies of the rehabilitation practitioner was greater than the differences. This finding is somewhat surprising, given that many studies in the literature report disagreements between service providers and service users. Studies that compared the attitudes of service providers and service users found differences with respect to a broad range of areas such as matters having to do with treatment (Roe, Lereya,& Fennig, 2001), rights (Roe, Weishut, Jaglom & Rabinowit, 2002), and the strength of the therapeutic alliance, which has far-reaching consequences for the effectiveness of the therapy (Junghan, Leese, Priebe & Slade, 2007).

The qualitative portion of the present empirical study examined the competencies of the effective rehabilitation practitioner from the points of view of three focus groups (consumers, service providers, and family members). In this portion of the study no differences were found in the competencies of the effective rehabilitation practitioner. This finding may reflect the fact that psychiatric rehabilitation strives to include as many relevant stakeholders in all forms of planning and implementation of services, which when successful may manifest itself in agreement, as revealed in the current study.

At the same time, a number of differences between groups was identified. A significant difference was found in the ranking of rehabilitation competencies. The service providers group ranked these competencies as more important than did the other two groups. An additional difference between the groups was found in the ranking of professional skills. The group of service users ranked these skills as being more important than did the two other groups. This finding may reveal consumers wish feel safe and well cared by well trained service providers, emphasizing the need for their qualification and training in the relevant professional disciplines. These findings are supported by those of several other studies (Gill, Bagherian & Ali, 2005; Gill & Kenneth, 2005; McReyholds, 2002). For example, in Gill's study (2005) a correlation was found between education in fields relevant to rehabilitation and success on the test that entitles professional workers to a certificate of specialization in the field of psychiatric rehabilitation. In their encounter with consumers, service providers must develop a professional partnership with expert skills above and beyond the basic human partnership. Limitations and implications:

The study has several limitations. The sample was a convenience sample and relatively small. The collected data were based on self reports which may have been subject to various biases. The sample represents a population and services (in Israel) that may not fully reflect populations and services in other countries. The small sample size has also reduced the ability of the statistical analysis to find significant differences between the stakeholder groups. Still, this study is the first to have surveyed PSR competencies and their relative importance from the perspective of non-professional stakeholders, particularly service users, and family members, who should have a major say in relation to the type and quality of services provided to them. Future research should attempt to replicate our findings, preferably with larger samples and in other countries.

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Appendix 1:

The Competencies of the Rehabilitation Practitioner Questionnaire (CRPQ)

The skills mentioned below have been considered by many to be crucial to the rehabilitation service provider. Many people regard all these skills as vitally important.
We would like to know what is in your opinion and from your experience, the most important skill, the second most important skill and so on until the least important skill for the rehabilitation service provider.

For this purpose, please rank the following skills in order of importance from 1 to 5; 5 being the highest level of importance, and 1 the lowest level of importance.

Do not repeat the same number twice. The order or the level of importance, teaches us what skills you would expect from the "ideal" rehabilitation service provider. Remember there is no right or wrong answer.

Thank you for your cooperation

Rank
(   ) Interpersonal ability – this includes positive and empathetic attitudes towards the client and his wishes, his background and the group he belongs to, while providing an equal dialogue, in a clear and coherent way.

(   ) Professionalism – this includes knowledge about the diseases, different ways of treatment, medication and side effects. This also includes professional ethics and an expertise in the rights and in the offered services, as well as identifying crisis situations that demand intervention and action, in order to minimize deterioration.

(   ) Assessment and Planning – this is the ability to conduct a bio-socio-social interview and filling out function assessment forms (dental, hearing and sight).
Assessing the client's situation at any given moment and providing assistance in identifying those situations that enable growth and empowerment.

(   ) Accessibility to social resources – this means understanding the impact of the socioeconomic status on the rehabilitation process, access to financial-vocational information and resources that support the rehabilitation process in the community. Assisting and connecting the client with additional support sources, while coordinating and supervising these sources in order to promote this process. Following –up and connecting the client with various medical services and preserving the flow of treatment. Advocacy – standing up against discriminatory situations in the community.

(   ) Rehabilitative – this includes optimism and faith in the client's abilities to grow and become empowered, while helping him build up hope and self reinforcement. It is an holistic approach, including assisting the client identify and define his wishes and aspirations in a wide variety of areas, teaching the client skills dealing with managing an independent lifestyle such as, managing financial resources, identifying and coping with crisis situations, creating social connections and assimilation in different areas (with decreasing support from the service provider).

The International Journal of Psychosocial Rehabilitation
Volume 14, Number 2
July 2009– June 2010

Rehabilitation Needs of Persons with Major Mental Illness in India

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Citation:
Pillai RR, Sahu KK, Matthew V, Hazra S, Chandran P & Ram D (2010). Rehabilitation Needs of Persons with Major Mental Illness in India. ***International Journal of Psychosocial Rehabilitation. Vol 14(2) 95-104***

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Abstract

Mental health care services are shifting its focus from inpatient to community care. Community based psychosocial rehabilitation programmes are widely advocated to provide comprehensive care to persons with mental illness. Psychosocial interventions suiting the needs of persons with mental illness would be more viable and sustainable in terms of recovery and socio-occupational functioning and integration in the community. This outpatient based study conducted in the North-East Region of India, at Central Institute of Psychiatry, Ranchi attempted to assess and compare the subjective rehabilitation needs of persons with Schizophrenia and Bipolar Affective Disorders. 120 persons with Schizophrenia and Bipolar Affective Disorders (60 from each category) were sampled and studied using Rehabilitation Needs Assessment Schedule (Nagaswami et al., 1985). Results indicate that both the studied groups exhibited multiple needs, thereby emphasizing the role of multifaceted, comprehensive after-care packages, involving concerted efforts of several mental health facilities.

Key Words: Rehabilitation needs, Schizophrenia, Bipolar affective disorder, Remission

Introduction

Assessment of needs in mental illness is an essential step in planning, developing and evaluation of mental health services, to provide requirements of mental health services, to provide requirements of persons with mental illness and to enable them to achieve, maintain or restore an acceptable or optimal level of social independence or quality of life. The persons with serious mental illness constitute an incredibly diverse population, numbering in millions, shares needs unique to themselves in the areas of treatment, rehabilitation, and environmental support. In recent years assessing the needs are given more importance in order to give proper care to the persons with mental illness.

Although the concept of need is used internationally, there is no consensus about the precise meaning of the term. Psychological theories have employed concepts of need as a basis for understanding action, such as Maslow's hierarchy of needs (Maslow, 1954). Mental health professionals; by contrast, use measurement of need to inform service provision. In Britain the National Health Service and community Care Act (1990) defines needs as "the requirements of individuals to enable them to achieve, maintain, or restore an acceptable level of social independence or quality of life" (Department of Health social services Inspectorate, 1991; p.10).This definition equates need with level of social functioning. Thus need arises as a result of social disablement, which occurs when a person experiences lowered psychological, social and physical functioning in comparison with the norms of society (Wing, 1986).

Disability is an important medical and social concept. If a person is unable to perform an activity, which he is otherwise expected to perform because of his illness that is termed as disability. Since psychiatric disorders manifest in social context, disability due to them is generally termed as "social disability" (Taly & Murali, 2001). WHO defines disability as an inability to participate or perform at a socially desirable level in such activities as self care, social relationships, work and situationally appropriate behaviour. The disability caused by mental and neurological disorders is high in all regions of the world. Six neuropsychiatry conditions figured in the top twenty causes of disability in the world are unipolar depressive disorders, alcohol disorders, schizophrenia, bipolar affective disorders, Alzheimer's and other dementia's and migraine (WHO, 2001).

People with psychiatric disabilities experience numerous limitations in everyday functioning, some of which include difficulties with interpersonal situations, (e.g., misinterpreting social cues, inappropriate responses to situations), problems coping with stress (including minor hassles, such as finding an item in a store), difficulty concentrating, and lack of energy or initiative (Bond, 1995). Whether persons with psychiatric disabilities have never learned social skills or have lost them, most of these individuals have marked skill deficits in social skills and interpersonal situations (Bond, 1995).

People with any disabling condition must face the task of adjusting to their conditions, disabilities, and to their environment. A consistent theme over the years in rehabilitation has been the focus on the needs of the individual and the inclusion of the person with a disability in the planning process. Care and protection are not the operational concepts of rehabilitation, but rather partnership, planning, and action steps leading to consumer outcomes. W.H.O. (1995) defined psychosocial rehabilitation as a comprehensive process that offers the opportunity for individuals who are impaired, disabled or handicapped by a mental disorder to reach their optimal level of independent functioning in the community. A more practical description of rehabilitation might be the process engaged in by people with disabilities to define individual or person-specific goals, develop action steps to achieve those goals, and identify resources that can be accessed to meet those goals.

Thus the goal of psychiatric rehabilitation is to enable individuals to compensate for, or eliminate the functional deficits, interpersonal barriers and environmental barriers created by the disability, and to restore ability for independent living, socialization and effective life management. Interventions help the individual learn to compensate for the effects of the symptoms of the illness through the development of new skills and coping techniques, and a supportive environment. They also counteract the effects of the secondary symptoms by restoring a sense of confidence and building on the strengths of each person, emphasizing wellness rather than illness (Hughes, 2001).

Not all people with serious mental illness need psychiatric rehabilitation services. A frequently used method of defining the population in need at any given time is to look at a combination of diagnosis, duration and level of disability The most frequent diagnoses of persons needing psychiatric rehabilitation services are schizophrenia, manic depressive disorders and depression, and severe personality disorders.

Duration refers to the chronicity of the disorder and usually means a series of hospitalizations, a series of relapses of the illness, or symptoms which remain over a period of years. The last criterion, disability, is particularly important for assessing the need for psychiatric rehabilitation services and refers to the impaired functioning of an individual due to the illness (Hughes, 2001).

Assessing forms of ‘felt needs’ are an important constituent in the planning of mental health services (Wig & Srinivasamurthy, 1981). This would suggest that the first step towards programme planning and delivery of after-care services would be the proper evaluation of subjective needs. Assessment helps those persons with mental illness to communicate clearly about their difficulties. The mental health professionals are concerned with assessing the person’s unmet needs that are sufficiently serious to merit interventions by service. For the care-givers, the assessment is an opportunity both to act as advocates for the mentally ill and to help them access support and services, themselves. The other purpose of assessment of rehabilitation needs is to make various social and political concerns aware of the persons with mental illness and initiate them to take necessary steps to improve their quality of life.

There are few attempts in India to assess the rehabilitation needs of persons with mental illness. Nagaswami et al, (1985) conducted a study on Schizophrenia (n=59) and found that employment and vocational rehabilitation were most sought need, psychosocial rehabilitation less so, and accommodation hardly at all. The same study concluded that both men and women had identical needs. Regarding the rehabilitation needs of the patients with bipolar affective disorders a published study could not be found.

Aims & objectives

The primary aim of the current study was to assess and compare the subjective rehabilitation needs of persons with Schizophrenia and Bipolar Affective disorder. Gender deference in the rehabilitation needs also was studied.

Materials & Methods

It was a cross-sectional out-patient based study conducted in Central Institute of Psychiatry, Ranchi, India. Sampling was done in such a way that those fitting to the inclusion and exclusion criteria were included in the study. Equal number of two out-patient groups, 60 each between 18 to 60 years age, equal number from both sex, with diagnosis of Schizophrenia or Bipolar Affective disorder (according to ICD-10 DCR), with two years duration of illness, currently in remission, was selected for the study. A need was felt to exclude persons with gross psychosis, since such persons are known to be unable to express their rehabilitation needs. Psychopathology offers only a limited view of the overall functioning of Schizophrenia (Lukoff et al. 1986). Persons with mental illness with any organic illness, co-morbid diagnosis of any major physical or other psychiatric illness or substance dependence were also excluded. A key informant who was living with the person with mental illness at least since last 2 years were interviewed using the Rehabilitation Needs Assessment Schedule (Nagaswami et al, 1985) for measuring subjective rehabilitation needs.This is designed to collect purely qualitative information on the subjective rehabilitation needs. The questions are open-ended and cover the areas of employment, vocational training/ guidance, accommodation, leisure activities, psychosocial attitudes modification, skills training, any help needed by the family any other area. Except for items 6 & 7, which is asked of the key informant, all other items are asked to the person with mental illness. Initially the person with mental illness is just asked if he or she wants any help aside of during treatment. Subsequently, he or she is asked if there is any specific need in any of the areas outlined above. The instrument is meant for qualitative rather than quantitative data and therefore requires no standardization.

Informed consent was obtained from the participants & the key informants for the study. The case record file (CRF) was reviewed to confirm the diagnosis and to know the necessary clinical variables. Then Rehabilitation Needs Assessment Schedule was administered.

Result and Discussion

(Table 1) Mean age of the BPAD group was 32.8 years and that of the schizophrenia group was 33.4 years indicating that the sample was similar in Age. There is no difference between the two groups in education and marital status. Majority of the participants were Hindus and the rest were Christians and Muslims which indicate the general religious background of the country. The patients belonging to the reserved category and general category were similar in both the groups. There is a difference between monthly incomes of both the groups. Patients with BPAD, with a rural background were more included in the study as compared to patients with Schizophrenia in which the rural urban dimension was equal. A total of 87.5% patients belonging to both the groups together, were engaged in some kind of productive work before the onset of the illness. Currently, only 65.0% patients of both the groups together are employed. Cole et al (1964) had found that 62 percent of the patients they surveyed were employed before admission, but only 43 percent afterwards, thereby showing a substantial reduction in the employment rates before and after admission. A South Australian study also found that 88% of people discharged from a psychiatric hospital remained unemployed (Barber, 1985).

The total number of patients currently unemployed in both the groups rose to 35%, which was 12.5% prior to the onset of illness. Out of these 35% patients, 15.8% attributes the reason for the same to their mental illness. Patients in both the groups being unemployed due to their mental condition invite our attention to this factor. Birley and Hudson (1983) have shown that whether a patient seeks employment will be a function of the correspondence between the work-needs and the work-rein forcers actually experienced. It seems very likely that patient who is been out of work for a long period will not be able to do this well. A crucial comparison that needs to be highlighted is the satisfaction that would be provided by whatever work available and the satisfaction provided by unemployment; the relative satisfaction afforded by different jobs is a secondary matter.

A promising approach which might be of use is stimulated work environment such as sheltered work outside the hospital as a final bridging stage to open employment. Enthusiasm and education regarding value of work and strategies to make enjoyable whatever work available would go a long way particularly for the institutionalised set-ups. Collaboration with NGO’s or the Indian Industries will also help. (Gandotra S et al., 2004)

21.7% patients with BPAD and 20.0% patients with Schizophrenia wanted some help regarding finding employment. Work provides financial remuneration and is a normalizing experience, allowing individuals to participate in society, and may promote self-esteem and quality of life. Furthermore, the vast majority of persons with severe mental illnesses identify paid employment as one of their goals (Rogers et al. 1991).

10.0% patients with Schizophrenia (5.0% male and 5.0% female patients) wanted vocational training. A study by Anthony et al. (1978) shows that rates of competitive employment for persons with schizophrenia remain dismally low -- below 25 percent. In this context, vocational rehabilitation has assumed increasing importance as part of the array of services available for persons with schizophrenia. Vocational training should be directed towards skilled tasks like printing and baking (Nagaswami et al, 1985), specialized industrial work like turner, fitter, etc and unskilled repetitive work is probably best restricted to Occupational therapy. This need calls for an up-to-date occupational therapy infrastructure in the institutional set-ups and sheltered workshops in the community along with trained staff to deal with such population.

95% patients with BPAD and 91.7% patients with Schizophrenia do not require any kind of accommodation. Majority of the patients in both the groups reside in their own house. Carling (1993), had also observed that mental health consumers prefer to live independently in their home with a friend or loved one, rather than in a 'therapeutic' facility. Tanzman (1993), in a review of 43 studies of mental health consumer's preferences, support this viewpoint.

Leisure is not perceived as a major need by majority of the patients. Most of the patients across both the group opted for passive recreations like listening to radio, watching TV, and reading books and magazines. Group-meetings, discussions, physical exercise etc figure out low on the priority list in both the groups. The finding should be interpreted in the light of socio-cultural norms regarding the role of leisure.

Most patients require modification of the immediate family's attitude followed by modification of attitudes of friends and neighbours. This would suggest that psycho educational approaches (Anderson et al 1980) would be a fertile ground of intervention research. Further, the finding also emphasizes the importance of assessing specific family needs in caring for a relative with mental illness. Chien & Norman (2003) in a study found that educational needs perceived as important by caregivers included gaining information about early warning signs of illness and relapse, effects of medication and ways of coping with patients' bizarre and assaulting behaviour.

Care-givers of 14.5% of the total patient population had asked for some kind of help like finding employment for some member, educating other member of the family, vocational training for some member of the family, financial help, etc which merely reflects the social problems of poverty and unemployment. With the available resources, or rather the lack of them, it would be impossible to rehabilitate the family as well, unless voluntary care agencies care agencies are sufficiently motivated in this direction.

The informants of 20% patients with BPAD and 23.3% with Schizophrenia (40.0% male patients and 3.3% female patients) wanted social skills to be taught to the patient. This could be probably due to the negative symptoms among the patients. When negative symptoms persist, it is conventional to recommend use of psychosocial interventions such as token economies, social skills training, life skills training, self instructional training and problem-solving (Slade and Bentall, 1989). The cultural expectation that males should work for the family, should be more social and interactive with people outside the family could be a probable reason for more male patients requiring social skills training.

Implication for mental health professionals

The needs of the patients studied clearly shows the need for a decentralised community based rehabilitation services that are locally available and sustainable. In an Indian context where most of the patients come from rural agrarian background, the scope of providing care under the national mental health programme frame work and developing community participation by raising stake holders in community based rehabilitation activities deserves more importance. Educating patients and their care givers about simple home based rehabilitation practices that can be carried out in homes is seen effective. In this process learning the basic principles of work- behavioural management, identifying various activities in home and around that can be given to the patient as activity and supportive handholding given to the patient and caregivers by professionals, paraprofessionals or trained volunteers can help the patient very well in rehabilitation. Ensuring the patients' rights and upholding the best practices in community participation holds the key for effective rehabilitation.

Conclusion

Majority of the patients in both the groups exhibited multiple needs, thereby emphasizing the role of multifaceted, comprehensive after-care packages, involving concerted efforts of several mental health facilities. The comparison of the rehabilitation needs of the BPAD and Schizophrenia group gives us an insight into the infrastructure required for psychiatric-rehabilitation based on the felt needs of the two groups and their relative proportion. It also calls for strengthening the roots of institutionalised rehabilitation and the interdependence between the two approaches of the institutional and community based rehabilitation.

Individualised tailor made-programme would have to be charted out. Sex should not be a bar to rehabilitation and the emphasis should be on vocational rehabilitation, job-placements, family interventions and various psycho-social therapies. All the patients with BPAD and Schizophrenia should be offered a programme as soon as they recover from their breakdown and help should be sought from voluntary agencies in setting up sheltered workshops and other aftercare services. This, while not solving all the problems of patients with BPAD and Schizophrenia, might be one of the means to an end.

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The International Journal of Psychosocial Rehabilitation
Volume 14, Number 2
July 2009– June 2010

Quality of Life (Qol) and Marital Adjustment in Epilepsy and Comparisons with Psychiatric Illnesses

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Citation:
Vibha P, Saddichha S & Akhtar S (2010). Quality Of Life (Qol) and Marital Adjustment in Epilepsy and Comparisons with Psychiatric Illnesses. ***International Journal of Psychosocial Rehabilitation. Vol 14(2). 105-113***

Abstract

Background: The occurrence of psychosocial problems in epilepsy is common and has severe impact on quality of life. However, the influence of marital adjustment on quality of life in epilepsy and similarities or differences with psychiatric illnesses, with which epilepsy shares several common characteristics, is unknown. The aim of the present study was to therefore explore the relationships between epilepsy, quality of life and marital adjustment and to study differences, if any, with psychiatric illnesses. Using a cross-sectional design, sixty consecutively seen patients with an ICD 10 DCR diagnosis of either schizophrenia or bipolar disorder and thirty consecutively seen patients diagnosed with epilepsy according to the International Classification of Epilepsy were taken up for the study and administered WHO-QOL BREF and the Marital Adjustment Inventory. There was significant difference in income ($p<0.001$), education ($p=0.02$), duration of illness ($p=0.003$) and marital status between the two groups ($p=0.05$). Patients with epilepsy had better social relationships ($p< 0.05$) and marital adjustment ($p <0.001$) as compared to patients with psychiatric illnesses. There was no correlation between quality of life and marital adjustment among both patients and spouses. Conclusions: Couple interventional programs, aimed at improving marital adjustment among spouses may help in improvement of quality of life of patients suffering from epilepsy.

Introduction

Enhancing quality of life has become a major therapeutic goal of modern medicine. Literature suggests that chronic illnesses, in addition to having long treatment regimens, are also burdened by the stigma, family burden, loss of skills, poor quality of life, poor interpersonal relations and poor marital and/or sexual relations [1] associated with them. Epilepsy is one such chronic condition affecting approximately 50 million people worldwide [2] with numerous social and psychological consequences for the afflicted. Epilepsy is an illness that has a great impact on the lives of patients and their caregivers characterized in terms of social isolation, prejudice, and unemployment, or in terms of emotional influences like relationship difficulties and low self-esteem leading to social stigma [3, 4].

People with epilepsy have been observed to be more affected by the loss in quality of life (QOL) than the seizures themselves [3, 5]. Childhood onset of seizures, neurological co-morbidities, psychiatric co-morbidities, disease duration and antiepileptic drug side effects have been reported as important determinants of poor quality of life in such patients [2, 3, 6-9]. Among children, epilepsy can also limit opportunities of education and their day to day functioning [6, 7], by intermittent emotional distress heightened by epilepsy related factors such as unpredictability of seizures, profound social isolation and cognitive/academic dysfunctions due to discontinuous fragmented learning. Guevara and colleagues [11] reported that variables like female gender, poor seizure control, >6 seizures per month, depression, unemployment, sleep disorders, and antiepileptic drugs were significantly associated with lower global scores in QOLIE-31. Further, anxiety and socially avoidant behavior have also been associated with the presence of intractable epilepsy [12].

A case similar to that of epilepsy is that of chronic psychiatric illnesses such as schizophrenia or bipolar disorder. People with schizophrenia or mood disorders have been reported to suffer from distress, disability, reduced productivity and lowered quality of life [13-17]. Some determinants of poor quality of life in schizophrenia reported were age of onset of psychosis, premorbid adjustment, duration of untreated psychosis [15], and the presence of positive psychotic symptoms [18]. An Indian study also revealed that the caregivers of both long term physical illness like intractable epilepsy and psychiatric illnesses like schizophrenia experience high levels of burden in the domains of patient care, finance, physical and emotional burden, family relations and occupation [1].

Marital adjustment, defined as the “state in which there is an overall feeling in husband and wife of happiness and satisfaction with their marriage and with each other” [19] has been reported to be affected both in epilepsy [20, 21] and in psychiatric illnesses [14, 22]. It has been observed that patients with epilepsy tend to have low self esteem which can result in failure to establish good sexual relationships and a lower likelihood of marriage, especially in men. In fact, lack of marital satisfaction may also directly influence the outcome of illness [23], due to deficiencies of marital intimacy. Similarly, in schizophrenia, the duration of illness, type of onset, auditory hallucinations, simple depression at intake, unemployment and economic slide during the course of illness and a relapsing course of illness have been all reported to be related to marital outcome [14].

Therefore, although treatment, both in terms of medical and psycho-social therapies, are intended to reduce the distress and disability that patients suffer, they fail to influence these vital measures, which stays poor inspite of all remedies. Yet, little is known on marital adjustment and quality of life in persons with epilepsy. The present study aims to shed light on this unexplored area by studying quality of life and marital adjustment in epilepsy and the inter-relations between them. It also attempts to compare epilepsy with chronic psychiatric illnesses, such as schizophrenia and bipolar disorder, in the domains of quality of life and marital adjustment.

Methods

Subjects

The target population of this study included consecutive patients seen in the outpatient department of Central Institute of Psychiatry, Ranchi, India with an ICD-10 DCR diagnosis of schizophrenia or bipolar disorder, collectively grouped together as "patients diagnosed with psychiatric illness" and Epilepsy according to the International Classification of Epilepsy [24] made by a Senior Resident or/and Consultant, between the age range of 18 to 45 years, married, with two or more than two years duration of illness, being in remission phase (taken as BPRS [25] score of less than 16 for psychiatric patients) and with no psychiatric or medical co-morbidity.

After institutional review board (IRB) approval, a purposive random sampling technique was employed for recruitment and individual patients were invited to participate after explaining the study and taking written informed consent. All ratings were done by mental health professionals trained in psychiatric social work and raters were kept blind to the diagnosis to prevent bias. The induction of patients continued till a total sample size of 90 was obtained, 30 with epilepsy and 60 with psychiatric illness, which was further subdivided into male and female to prevent representation bias. Further, spouses of these patients were also invited to take part in the study to assess their perception of marital adjustment after written informed consent. However, only patients formed the "Subject group" and the "Spouses group" were analysed with regard to marital adjustment only.

The Dependant Variable

"Quality of Life" was tapped using the WHO Quality of Life-BREF scale developed by Saxena and colleagues [26]. It is a self administered generic questionnaire developed in Hindi and is a 26 items shorter version of the WHOQOL-100 Scale. It covers the domains of physical health, Psychological functioning, Social relationship, and environmental situation. Marital Adjustment was assessed using Marital Adjustment Inventory [27]. It measures marital adjustment in domains of mutual care, mutual understanding, mutual trust, and adequate independence. It has separate questionnaires for Husband and Wife.

The Independent variables

Demographic variables included sex, age, education, religion (Hindu, Muslim, Christian, and other), residence (urban, semi-urban and rural), income, marital status (living together, separated, or divorced), years of marriage, years of separation/divorce, type of family (nuclear versus joint), duration of illness, frequency of seizures (in case of epilepsy) and diagnosis.

Data Analysis

Statistical analysis was performed using Chi- square test for categorical variables and t-test for continuous variables. Co-relations analyses were performed for studying significant variable relations using two-tailed tests. All significance was reported at $p < 0.05$.

Results

Socio-Demographic Characteristics of Epilepsy patients

The total sample size was 30 (table 1), with mean illness duration of 10.53 (+5.73) years. Majority (70%) of the patients were seizure free and were equally divided between males and females with a mean age of 33.96 (+ 6.77) years. They had an average of 9.7 (+ 3.36) years of education and had been married for a mean of 13.56 (+ 5.46) years. Almost all of them were living with their spouses (100%), majority of them had arranged marriage (96.7%) and earning an average of 4460.00 (+ 6687.59) rupees per month.

Socio-Demographic Characteristics of Psychiatric patients

The total sample size was 60 (table 1), with a mean age of 34.48(+ 6.81) years, and equally divided between males and females. They had a mean illness duration of 6.86 (+5.08) years and an average of 8.03(+ 3.07) years of education, being married for a mean of 14.11 (+ 6.72) years. Majority of them were living with their spouse (88.3%), their marriage arranged by the family (96.7%) and earning an average of 900.00 + 1630.74 rupees per month. Since women constituted half the sample, the respondents were mostly housewives (46.7%), and about one-fourth employed (25.0%) with a mean family income of Rs. 7366.66(+ 8043.77). Majority of them were from urban areas (58.3%) and living in a joint family setup (65%).

Comparison of socio-demographic characteristics between the groups
When the two groups were compared on socio-demographic variables (table 1), significant differences were noted in income with patients with epilepsy (p<0.001) having higher incomes, in spite of having a longer duration of illness (p=0.003) as compared to patients with psychiatric illnesses. Further, patients with epilepsy were more educated (p=0.02) and all (100%) were noted to be living together compared to just 88% of those with psychiatric illness (p=0.05).

Comparison of Quality of Life between both the groups

When the two groups were compared in terms of quality of life (table 2), no significant difference was noted between the groups, but when different domains of quality of life were compared, a majority of patients with epilepsy (60.0%) were noted to have better social relationships as compared the majority with psychiatric illness (61.7%) having poor social relations (p < 0.05).

Comparison of Marital Adjustment among patients of both the groups

In the domain of marital adjustment among patients (table 2), significant differences were noted with the majority (60%) of patients diagnosed with epilepsy showing good adjustment with their spouses as compared to the majority with psychiatric illness (73.3%) having poor adjustment (p < 0.001).

Comparison of Marital Adjustment among spouses of both the groups

Similarly, in the domain of marital adjustment among spouses of the patients (table 2), majority (73.3%) of spouses of patients with epilepsy showed a good adjustment with their counterpart as compared to a poor adjustment (47.4%) seen among spouses of patients with psychiatric illness (p<0.001).

Correlation between Quality of Life and Marital Adjustment among patients and spouses No significant co-relations (table 2) were observed between quality of life and marital adjustment among patients and spouses, although a negative non-significant trend was observed among spouses.

Discussion

The study of quality of life in various medical and psychiatric conditions is not an innovative quest; however, this study from India marks probably one of the first studies to directly compare psychiatric illness with epilepsy and to observe the influences of marital adjustment with quality of life in these two groups. With both groups of illnesses following a chronic course and being associated with similar co-morbidities, we believe that these groups are comparable when it comes to assessing quality of life and marital adjustment, both of which can have a significant impact on psychosocial functioning. Further, since we attempted to have equal representation of gender in both groups, we believe that our findings are significant enough and may be generalized for formulation of better treatment strategies that involve the aspect of marital adjustment.

When socio-demographic variables were compared, patients with epilepsy were observed to have higher income and lower unemployment rates than the psychiatric group. Since people with mental illnesses are among the most socially and economically marginalized members of the community, experience high levels of unemployment and may experience disrupted vocational training and normal career development [28], such differences may translate into poorer incomes and socio-economic status. With higher levels of education noted among our epilepsy patients in spite of a longer duration of illness, we believe that the severity and chronicity of mental illnesses can truncate primary, secondary, or tertiary education [28]. However, since other studies have observed otherwise [3, 29], we believe that perhaps cross-cultural differences or the unequal distribution of samples in our study may account for these findings.

We also observed good marital status among all patients with epilepsy. This is in contrast to Agarwal et al [30] who reported poor marital status and high divorce rates among epilepsy patients, in contrast to high rates of marriage (up to 70%) being seen in this population [31, 32]. Since remission of seizures are associated with improvement in marital status [21, 33], such variance in findings may possibly be due to the fact that most of our patients (70%) were seizure free.

Comparison of the overall quality of life revealed no significant difference between the two groups demonstrating that perhaps both illnesses are associated with similar quality of life i.e., majority of the people with psychiatric or epileptic illness have poor quality of life (61.7% and 63.3% respectively). In other words, both types of illnesses have similar impact on quality of life in the domains of psychological, physical and environmental QOL. Poor quality of life among psychiatric patients and epilepsy has already been reported in previous studies [34-37]. However, patients with epilepsy in our study were observed to have better quality of life in terms of social relationships as compared to psychiatric patients, possibly due to the higher employment rates [11] and better marital support [38] contributing to better perceptions of social support.

Marital adjustment between the two groups revealed a significant difference showing that patients with epilepsy and their spouses tend to have better perception of marital adjustment than psychiatric patients and their spouses. We hypothesize that mental illness as a whole hampers the ability of the patient to play the marital role (of husband or wife respectively) leading to poor marital adjustment [39, 40]. Since the marital role comprises cultural expectations associated with the husband or wife, inability to fulfill those expectations could lead to marital dissatisfaction [41]. It can however be argued that such expectations would necessarily be hampered even in spouses, and our study has shown similar findings.

When marital adjustment was correlated with quality of life, no significance was noted, demonstrating that the perception of better marital adjustment among patients does not translate to better quality of life. However, spouses continue to perceive a poor quality of life irrespective of marital adjustment. We hypothesize that spouses may be dissatisfied with the inhibited marital role that patients’ exhibit due to the illness, which reflects in a poorer quality of life. This needs to be confirmed by other studies, yet we believe that addressing the specific concerns of marital adjustment may play a vital role in the outcome of the illness. In such cases, marital therapy, aimed at improving relations between couples, could help the perceptions of marital adjustment thereby improving the overall quality of life.

Although our study was among the first to directly study associations of marital adjustment and quality of life and to compare these variables in two different diagnoses by using standardized and valid scientific tools, we believe that there are certain limitations to our study. The groups were not divided equally in terms of diagnosis and study was from a single-centre. Future studies would need to be multi-centric, involving larger sample sizes, making even cross-cultural comparisons possible.

Conclusion:

Patients with epilepsy have poor quality of life, a finding similar to those suffering from psychiatric illnesses. Although marital adjustment continues to be good for both patients and spouses with epilepsy, it also influences the overall perception of quality of life, perhaps reflecting that inclusion of marital therapy, aimed at couples, may help in overall improvement of quality of life of patients with epilepsy.

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The International Journal of Psychosocial Rehabilitation
Volume 14, Number 2
July 2009– June 2010

Preliminary Psychometrics of a New Scale: A Sense of Acceptance in Community Activities

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Citation:
Solomon P, Lee S, Chatterjee A & McClaine L.(2010). Preliminary Psychometrics of a New Scale: A Sense of Acceptance in Community Activities. ***International Journal of Psychosocial Rehabilitation. Vol 14 (2) 110-118***

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Financial Disclosure: This study was funded by National Institute of Disability Rehabilitation & Research.

Abstract

Background: A sense of acceptance when participating in community activities is considered as the first step toward achieving a sense of belonging for people with severe psychiatric disorders, which is a major component of psychological integration.
Aims: The present study was designed to develop a measure of a Sense of Acceptance in Community Activities (SACA) for persons with severe psychiatric disorders.
Method: Fifty-five study participants were recruited from two Assertive Community Treatment (ACT) teams. To examine internal consistency and content validity of SACA, an item analysis, exploratory factor analysis, confirmatory factor analysis, and correlations with hypothesized concepts were employed.

Results: The SACA has strong psychometric properties, including good reliability, content validity, and construct validity. Conclusions: Given the brevity and ease of administration of the SACA, it is a useful evaluation tool to assess outcomes for interventions designed to increase community integration of persons with severe psychiatric disorders.

Key Words: psychometrics, community integration, psychiatric disability, severe mental illness

Introduction

Community integration of adults with severe psychiatric disorders is a major policy goal in the United States as affirmed most recently by the landmark Olmstead Supreme Court decision in 1999. Yet, all too frequently, this population is physically in the community, but they do not have a psychological or social sense of belonging to the community (Dewees, Pulice, & McCormick, 1996; Granerud & Severinsson, 2006; Prince & Prince, 2002). Although loneliness and social isolation are highly prevalent among those with severe psychiatric disorders, they are frequently reluctant to participate in community resources and activities due to fear of rejection (Elisha, Castle, & Hocking, 2006; Perese & Wolf, 2005). Consequently, an essential goal of community mental health programs, particularly psychiatric rehabilitation programs, is to assist in facilitating greater community participation of their clients (Prince & Prince, 2002). As a part of such efforts in the current atmosphere of evidence based practice, there is a need to be able to measure these programs' effectiveness in achieving community integration of their clients. However, most of the measures of community integration have focused on physical integration, (i.e., participating in community activities and use of community resources), neglecting social (i.e., social interactions and social networks); and psychological aspect of integration (i.e., a sense of belonging and acceptance) (Wong & Solomon, 2002). The present study addressed this gap by developing a measure of a sense of acceptance in community activities for persons with severe psychiatric disorders. In this article, we report on the psychometric properties of the measure Sense of Acceptance in Community Activities, specifically designed for the population served by community-based mental health programs.

Background

Psychological integration has to do with the perceptual aspects of feeling a part of the community or feeling as though one belongs to a group and is a valued and accepted member of the group. Therefore, it is not surprising that some have equated a sense of belonging with the concept of social integration (Hagerty & Patusky, 1995). However, there has been limited development of measures in the realm of psychological and social integration per se. Recently, there is an emerging mental health literature on a sense of belonging, which is an important component of psychological integration. The research in this area has focused on the general population, not specifically on persons with severe psychiatric disorders.

According to Baumeister and Leary (1995), belonging has been identified as a basic human motivation and an integral component of positive mental health. Hagerty and her colleagues (1992) have defined a sense of belonging as "the experience of personal involvement in a system or environment so that persons feel themselves to be an integral part of that system or environment" (p. 173). This concept has two delineated characteristics: "[1] the experience of being valued, needed, or important with respect to other people, groups, or environments, and [2] the experience of fitting in or being congruent with other people, groups, or environments through shared or complementary characteristics" (Hagerty, Williams, Coyne, & Early, 1996, p. 236). Hagerty and her colleagues (1996) note that in the absence of a sense of belonging individuals feel lonely and depressed. Their subsequent research concluded that those with a greater sense of belonging have a greater degree of social and psychological functioning. Deficits in a sense of belonging have been determined to be associated with increased feelings of loneliness (Hagerty et al., 1996), higher levels of depression (Cuijpers & Van Lameren, 1999), and diminished psychological well-being (Coyne & Downey, 1991).

While the goal of community integration or social inclusion is to have persons with a psychiatric disorder feel a sense of belonging in their communities of choice, the first step toward achieving this goal is for them to feel comfortable and accepted when participating in community groups and social activities. Without this level of comfort and an absence of anxiety, it is unlikely that persons with severe psychiatric disorders will utilize or participate in the resources available to them as members of their communities. Consequently, we focused our efforts on developing a measure on a concept that we saw as a precursor to achieving this more ambitious goal, a sense of acceptance when participating in community activities. We defined a sense of acceptance as feeling socially and psychologically comfortable and welcomed when attending events and activities in the community. Given the high degree of stigma and discrimination that those with psychiatric disorder frequently experience, their fears of rejection and feeling of shame may inhibit them from taking advantage of opportunities available to them, including using a variety of community resources. Therefore, they may well avoid utilizing such resources even though they have the potential to reduce their social isolation and feelings of loneliness and increasing their sense of social inclusion. Ultimately, it is expected that such participation by persons with severe psychiatric disorders will likely lead to increasing the size of their social networks and the degree of their social support. We therefore hypothesized that measures of loneliness, stigma, and social inclusion would likely be related to the construct of social acceptance; and if so, would offer evidence of the construct validity of our measure.

Method

Participants

Study participants were recruited from two Assertive Community Treatment (ACT) teams. The Sense of Acceptance in Community Activities (SACA) scale was part of a comprehensive interview schedule that was administered prior to clients entering an intervention study designed to increase their participation in community resources and activities, where clients from one team, which was randomly selected, would receive the intervention and clients from the other team would not. Team staff asked clients about their interest in participating in the study. If clients were interested, they were referred to research assistants who screened for study eligibility: their interest in increasing or maintaining their involvement in community activities and whether they had a severe psychiatric diagnosis (i.e., schizophrenia spectrum disorder or major affective disorder). If eligible and interested, their consent for the study was obtained. This study was reviewed and approved by the Institutional Review Board of University of Pennsylvania.

A total of 137 clients were approached for the study. Of the 137 clients, about 21% of clients (n = 29) refused to be screened and 17% of clients (n = 23) were ineligible for the study. After the screening and determined to be eligible, six clients (4%) refused to participate in the study and fifteen clients (11%) did not show for the interview. Finally, sixty-four clients (47%) were interviewed by trained interviewers. Among them, eight clients were terminated by either interviewers or participants themselves. One client who did not answer the items on the SACA measure was excluded from the present analysis.

The final sample of 55 clients consisted of 50.9 % male (n = 28) and 49.1 % female (n = 27), ages 23-71 with an average age of 43.33 years (SD = 11.64). The majority of the sample was white (50.9%), followed by black (43.6%), and had a diagnosis of schizophrenia or schizophrenia spectrum disorder (70.9 %) with 25.5% having a bipolar or major depressive disorder.

Measurements

A Sense of Acceptance in Community Activities (SACA)

A Sense of Acceptance in Community Activities (SACA) was originally an 8-item, self-report scale. The participants were asked if they feel a part of the community and feel comfortable when participating with strangers in community activities and groups. The items were generated by the first author based on a review of the literature, as well as clinical and research experiences. The items were then reviewed by three experts who had extensive research and/or practice experience with the population. Based on their input, the items were refined. The questions were measured on a four-point Likert scale, ranging from 1 (never) to 4 (often). Item 1, 2, 3, 6, and 7 were reverse-recoded so higher scores indicate higher levels of SACA (see Table 1 for listing of items).

In order to test the construct validity of the measure, the following scales were correlated with the SACA.

Social inclusion

Social inclusion scale assessed the extent to which the respondent had social contact with others. This instrument was a scale in Lehman's Quality of Life Interview (Lehman, 1988) which was developed for this population and has good reported psychometrics. The social inclusion measure is a 6-item scale asking about the extent to which the person had contact with others using a five-point Likert scale ranging from 1 (not at all) to 5 (at least once a day), with a higher score indicating a greater degree of social inclusion. The internal consistency of the social inclusion scale was .68 in the present study.

Loneliness

Loneliness was measured by the UCLA Loneliness scale which was developed to assess subjective feelings of loneliness or social isolation (Russel, Peplau, & Cutrona, 1980). This 20-item measure has reported high internal consistency and good evidence of construct, concurrent, and discriminant validity (Hagerty et al., 1996; Russel et al., 1980). Items were assessed on a four-point Likert scale ranging from 1 (never) to 4 (always), with a higher score indicating a greater degree of loneliness. The internal consistency of the Loneliness scale was .86 in the current study.

Stigma

The Consumer Experience of Stigma Questionnaire (CESQ) was used to measure stigma and seems to have demonstrated validity (Dickerson, Sommerville, Origoni, Ringel, & Parente, 2002). This scale was comprised of two subscales, a 9-item stigma scale and a 12-item discrimination scale. Items were scored from 1 (Never) to 5 (Very Often), with a higher score indicating a higher level of stigma. The internal consistency of the stigma scale was .72. The discrimination scale had a low reliability (.45) in the present study and was therefore not included in further analysis.

Data analyses

Data analyses were designed to examine internal consistency, content validity, and construct validity of SACA. First, in order to examine the extent to which the items were internally consistent with the SACA scale, an item analysis was conducted. Second, to examine content validity, exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) were employed. As for EFA, principal component estimation was used for extracting factors and varimax with Kaiser Normalization technique was conducted as a rotation method. To verify the SACA factor structure, CFA was conducted using LISREL 8.80. Because the variables of SACA were measured using an ordinal scale, robust weighted least squares method was used, which is also more suitable for small sample sizes (Flora & Curran, 2004). Guided by Hu and Bentler (1999), the following model fit statistics were employed: X^2, root mean squared error of approximation (RMSEA; $\leq .06$, acceptable), non-normed fit index (NNFI; $\geq .95$, acceptable), and comparative fit index (CFI; $\geq .95$, acceptable). In order to examine the construct validity of the scale, correlation coefficients with measures theoretically expected to be related to SACA (i.e., social inclusion, loneliness, and stigma) were examined.

Results

Item Characteristics

Descriptive statistics of SACA are presented in Table 1. Means of each of the items ranged from 2.13 to 3.07.

The mean of the total scale items was 21 with standard deviation of 4.73. For all items, the skewness was between –1 to +1, which indicated a normal distribution of the scores. Even though some of kurtosis values were slightly greater than –1, the value demonstrated a close to normal distribution for all items.

Table 1. Item characteristics (N=55)

Item #	***Item***	**Mean (SD)**	***Min-Max***	**Skewness**	**Kurtosis**
1	I don't have many friends to do activities with.	2.40 (0.91)	1-4	.46	-.57
2	I don't feel comfortable attending functions when I don't know anyone.	2.13 (1.09)	1-4	.54	-1.0
3	I am very anxious going to new places alone.	2.22 (1.11)	1-4	.50	-1.04
4	When attending activities in the community, I feel accepted.	2.93 (0.96)	1-4	-.50	-.69
5	When attending activities in the community, I feel like I belong.	2.96 (0.96)	1-4	-.57	-.61
6	When attending activities in the community others make me feel unwelcome.	2.76 (0.94)	1-4	-.05	-1.06
7	When attending activities in the community, I feel like I have nothing in common with anyone else present.	2.53 (0.96)	1-4	.18	-.92
8	When attending activities in the community, I think that I am no different from others in attendance.	3.07 (0.79)	1-4	-.60	.09
Total		21.00 (4.73)	11-32		

Note. A higher score indicates a higher level of Sense of Acceptance in Community Activities (SACA).

Internal consistency

The item-scale correlations were examined using Cronbach's alpha. The overall coefficient alpha for the SACA with eight-items was .76 and the values ranged from .24 to .64. As a result of the item analysis, one item (number = 8), which had a low item remainder coefficient (r = .24), was deleted and this resulted in a minimal increase of the overall correlation coefficient alpha for the scale from .76 to .77. Table 2 shows the internal consistency of SACA.

Table 2. Internal consistency among items (N=55)

Item	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**

1							
2	0.32*						
3	0.33*	0.24					
4	0.35**	0.38**	0.23				
5	0.25	0.27	0.27*	0.62***			
6	0.33*	0.46***	0.14	0.45***	0.22		
7	0.11	0.45***	0.35**	0.38**	0.28*	0.30*	
8	-0.14	0.18	0.19	0.25	0.13	0.22	0.27*

Note. **$^{*}p < .05$. $^{**}p < .01$. $^{***}p < .001$.**

Content validity

Exploratory factor analysis (EFA)

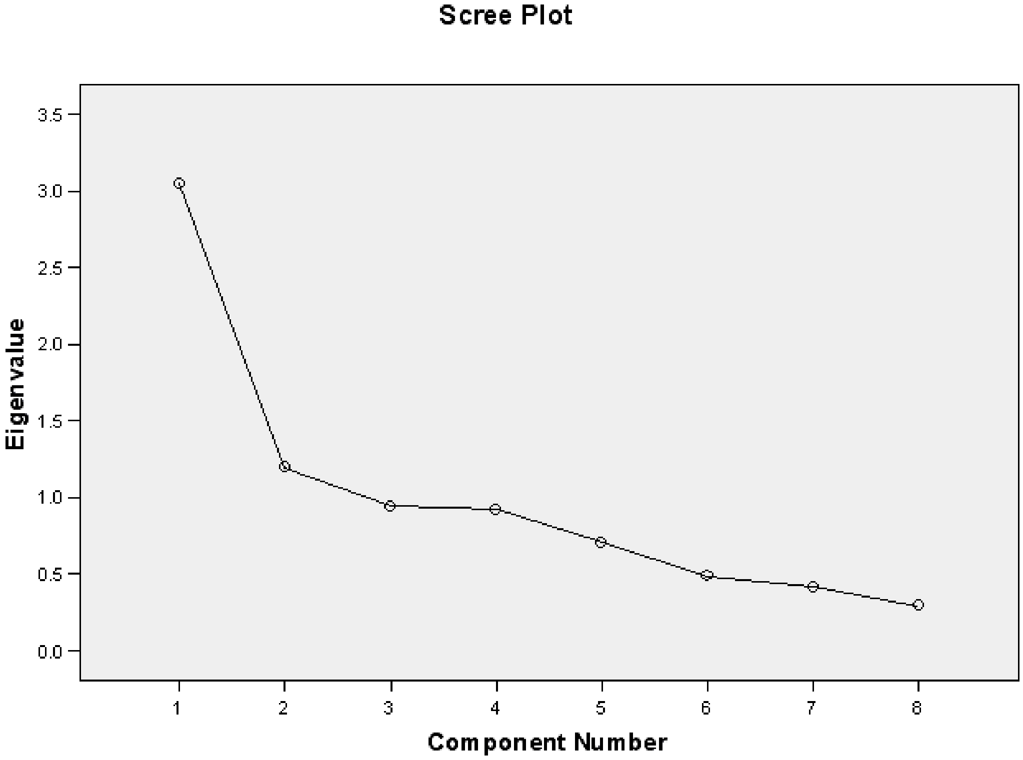
Table 3 presents the results of EFA. Based on the criterion of an eigenvalue greater than one (Kaiser, 1960), two factors were identified in the first EFA model. In terms of factor loadings, seven items had loadings from .53 to .78 with factor 1, and one item (#8) had a loading of .83 with factor 2. The first factor had a higher eigenvalue of 3.0, explaining 38.1 % of total variance where the second factor had an eigenvalue of 1.2, explaining 14.9 % of the total variance. However, even though the eigenvalue of second factor is greater than one, the examination of a scree plot suggests a one-factor solution because there is only one large “break” between component 1 and component 2 (Figure 1) (Hatcher & Stepanski, 1994).

Table 3. Results of the exploratory factor analysis (N=55)

Item number	Factor loading		
	Model 1		Model 2
	Factor 1	Factor 2	Factor 1
1	**.646**	-.576	**.573**
2	**.682**	.144	**.700**
3	**.527**	.053	**.523**
4	**.776**	.113	**.782**
5	**.653**	.012	**.653**
6	**.643**	.117	**.650**
7	**.576**	.442	**.635**
8	.210	**.829**	N / A

Note. Item 8 was excluded in the model 2.

Figure 1. Scree plot



In order to verify the one-factor structure model, the second EFA model was conducted with seven-items. The results of the second EFA indicate all seven items loaded on a single factor, explaining 42.2 % of total variance. In addition, all seven items are moderately or highly correlated with the factor (r = .52 - .78). Therefore, based on the results from the item analysis and EFA, item 8 was excluded in the final model.

Confirmatory factor analysis (CFA)

To verify the one-factor structure with the seven-items derived from the EFA, CFA was conducted. Given the results from the EFA, it was assumed that seven items of SACA would load on a single factor. The results of CFA indicate that a one-factor structure model is acceptable based on a number of goodness of model fit statistics: $\chi 2 = 15.62$ (p = .34), RMSEA = .046, NNFI = .99, and CFI = .99.

Construct validity

In order to examine the construct validity of SACA, several measures that were hypothesized to be correlated with the SACA were employed. Based on the previous results of the item analysis and factor analyses, only seven-items of SACA were used to examine correlation coefficients. The results indicate that social inclusion is positively and moderately associated with SACA (r = .52, p<.0001), while loneliness is negatively and moderately related to SACA (r = -.51, p<.0001). Stigma has negative moderate correlation with SACA (r = -.35, p<.05).

Discussion

The present study was designed to develop a measure of a Sense of Acceptance in Community Activities (SACA). A feeling of acceptance when attending functions in the community was considered as the first step toward achieving a sense of belonging for people with severe psychiatric disorders, which is a major component of psychological integration. Consequently, the development of such a measure as the SACA was deemed as essential. Based on the results obtained, the SACA appears to be a promising measure with strong psychometric properties, having good reliability, content validity, and construct validity.

One item from the original measure was deleted. This item varied from other items in that it dealt with what the respondent thought rather than the respondents' feelings. This finding may indicate a direction for the extension of the measure with additional items that deal with the respondents' thoughts about community acceptance.
The stigma measure did not correlate as highly as social inclusion and loneliness with the SACA scale. This finding may be due to some of the items on the stigma measure tapped a broader context than the other measures (i.e., Have you seen or read things in the mass media about persons receiving psychiatric treatment and their psychiatric disorders which you found hurtful or offensive).

Other strengths of the SACA measure are its brevity, feasibility, and more importantly the fact that the items can be responded to with relative ease by the intended population for whom it was designed, adults with severe psychiatric disorders. Interviewers for the current study reported ease of administration of the measure and found that respondents had no problems responding to the items.

Given the brevity and ease of administration of the SACA, it can serve as an evaluation tool to assess outcomes for interventions designed to increase community integration of persons with severe psychiatric disorders. However, we do recognize that the scale was measured on a limited sample size who may not be representative of those served in community mental health programs. Therefore, there is a need for further research on this measure. Also, the measure in the current study was used in an interview format. It may be useful if this could be employed as a self administered measure. This too would require additional evaluation. It was designed for a low level of comprehension, due to some possible cognitive impairment of the population. But given the potential for a low literacy level of those with severe mental illness, the SACA scale may require further refinement to ensure that the reading level of the measure is consistent with the literacy level of the population.

This measure serves to begin to fill the gap in existing measures to assess community acceptance of persons with severe psychiatric disorders. Given the importance of this goal for psychiatric rehabilitation, more work is needed to develop appropriate measures for evaluating outcomes of programs targeted to increasing community participation. This is a small, but important, step toward meeting this need.

This measure may be a useful assessment tool for mental health providers working with this population. Since a major goal of mental health services and policies is to achieve greater community integration for this population, such a measure will offer direction for assisting clients who are having difficulty in feeling unaccepted when attending community activities. With this knowledge, mental health providers can work with their clients to overcome these barriers, rather than being discouraged from participation. With greater community participation clients will likely increase their social networks, and therefore, have more support resources available in times of crisis rather than totally relying on professional resources.

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