The Role of Family Empowerment and Family Resilience on Recovery from Psychosis

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Abstract

Most of the studies on the family of psychotic illness focus on the negative sides of family life, such as high expressed emotion, family burden and stigma. Very few studies look at the positive aspects of the family such as empowerment and resilience. This study aims at investigating the role of family's empowerment, and well-being on predicting the recovery of the patients. Ninety nine families of psychotic patients were assessed using the Family Empowerment Scale, and the Connor-Davison Resilience Scale. Meanwhile the patients' recovery was assessed using Brief Psychiatric Rating Scale. Regression analysis yield result that family empowerment and resilience accounted for a significant amount of variance in patient's recovery. It is concluded that family condition influences patient's recovery. This research suggests that it is important to increase family empowerment and resilience as part of the treatment for psychotic patients.

Key words: family empowerment, family resilience, recovery, psychosis

INTRODUCTION

Recovery from psychosis, particularly schizophrenia, has long been debated. According to Kraepelian perspective, schizophrenia is believed to be a deteriorating illness. However, a series of outcome studies began to provide empirical evidence of recovery from schizophrenia. Long-term follow-up studies in the US and Western Europe confirmed that the course of schizophrenia is heterogeneous (see McGlashan, 1988; Angst, 1988 for reviews). People with schizophrenia did not always deteriorate as Kraepelin had observed. Even individuals with a chronic condition who had experienced long periods of hospitalization were found later in life to be relatively free of psychotic symptoms, as shown in the well-known Vermont Longitudinal Study in the US (Harding *et al*., 1987a & b). This study began in 1950 and involved 269 subjects recruited from the local mental hospital. They were described as mostly chronically ill, severely disabled, and long-stay patients. In the 32-year follow-up study the researchers found that one half to two-thirds had considerably improved or recovered. They achieved quite a high level of functioning which the research team had

not predicted: “Their achievement is even more remarkable given their original levels of chronicity” (Harding *et al*., 1987b:723).

Evidence of recovery is even more striking in the case of ATPD (Acute and Transient Psychotic Disorder). From a number of long-term follow-up studies Marneros and Pillmann (2004:155) concluded that, when compared with those who had schizophrenia, patients with ATPD show a more favourable outcome according to many different indicators. They have fewer negative and positive symptoms, less residual syndrome, less social disability, better global functioning, and better employment status. Although they may have several relapses, patients with ATPDs can achieve full remission between episodes (Singh *et al*., 2004).

In the study of first episode psychosis, a high rate of recovery is also evident. Loebel *et al*. (1992) conducted a one-year follow-up study with 70 patients who experienced a first episode of schizophrenia and received standard medical treatment. They found that 74% were considered to be fully remitted. Gitlin *et al*. (2001) found that 80% of individuals with a recent onset of schizophrenia achieved a clinical remission of both positive and negative symptoms during their first year of treatment. Higher rates of recovery were found in a study by Edwards *et al.* (1998), in which 91% of people with recent onset of psychosis were in relatively complete remission after one year of assertive case management, anti-psychotic drug use, and cognitive behavior therapy. Similarly Cullberg *et al*. (2002) documented a successful treatment of first episode psychosis with fewer days of in-patient care and less neuroleptic medication when combined with psychosocial treatment.

The body of evidence of recovery in first episode psychotic illness has stimulated interest in investigating the very early stages of the development of schizophrenia. A specific field of study has emerged known as ‘early psychosis’ (see McGorry & Jackson, 1999; Birchwood *et al*., 2001). A number of research centers and clinics focusing on early psychosis have been developed throughout the world, such as the Early Psychosis Prevention and Intervention Center in Melbourne, Australia (McGorry et al., 1996), the Nova Scotia Early Psychosis Program in Dartmouth, Canada (Whitehorn *et al.,* 2002), the Swedish Parachute project in Stockholm, Sweden (Cullberg *et al*., 2002), and some centers in Asian countries. This area of study not only focuses on the first presentation of psychotic illness, but also includes the idea of prevention. Furthermore a program of early detection for high-risk people, when the illness is in the ‘prodromal’ stage, has also been developed (Young *et al*., 2004).

A number of studies has also identified and classified variables that correlate with recovery. For example, Liberman *et al*. (2002), in their literature search, delineated 10 factors

associated with symptomatic, social, and educational or occupational recovery. This includes: (1) family or residential factors, which include the presence of supportive family members or other caregivers who encourage and positively reinforce the individual's progress, (2) absence of substance abuse, (3) shorter Duration of Untreated Psychosis (DUP), (4) good initial response to neuroleptics, (5) adherence to treatment, (6) supportive therapy with a collaborative therapeutic alliance, (7) good neuro-cognitive functioning, (8) absence of the deficit syndrome, (9) good pre-morbid history, and (10) access to comprehensive, coordinated and continuous treatment. Liberman *et al*. (2002) arranged these factors into a diagram to provide a cognitive map as follows:

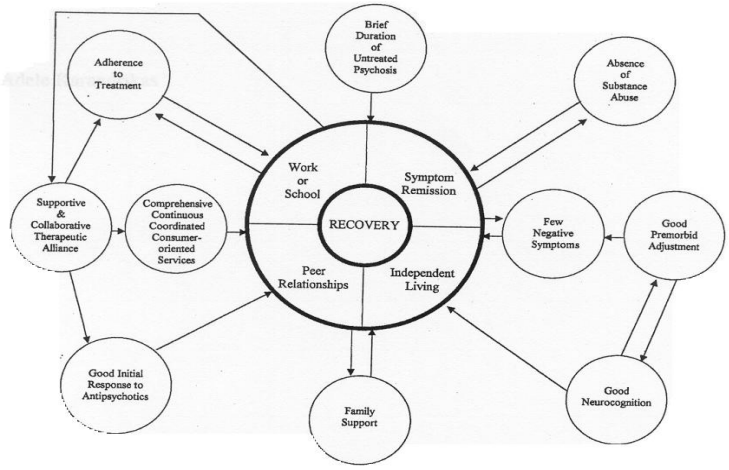

Figure 1. Map of factors associated with recovery (Liberman *et al*., 2002:267)

From the above diagram it is clear that family is one of the most important factors influencing the recovery from psychotic illness. In the context of Indonesia, recent studies conducted by local psychiatrists in Java have examined the effectiveness of family interventions on the outcome of affective disorder (Sudiyanto, 1998) and on schizophrenia and bipolar disorders (Sukarto, 2004). Subandi (2006) has also identified family processes which influence the recovery of psychotic patients. In this paper, we focus on two important family aspects, namely family empowerment and family member resilience.

Family Empowerment

Most of the studies on the family of psychotic illness focus on the negative sides of family life, such as expressed emotion (EE), family burden and stigma. A large number of studies indicated that EE has been demonstrated to be a reliable psychosocial predictors of relapse in psychosis. A meta analysis conducted by Butzlaff & Holey (1998) suggest that EE is a robust predictor for relapse in schizophrenia. It is interesting to note that in the early development, there were five aspects of EE which consists of both positive and negative emotions. The positive emotions include warmth and positive remarks, while negative emotion consists of critical comment, hostility and emotional over involvement, positive emotion. However, in the later development EE concept focuses primarily on negative aspects disregarding the positive aspects. It is inline with the positive psychology movement (Seligman & Csikszentmihalyi, 2000) that this study looks at the positive aspects of the family of psychotic patients by focusing on the issue of empowerment and resilience.

In Western context, the concept of empowerment initially originate from political field (Yamada & Suzuki, 2007) which is associated with a particular group being oppressed such as women's and gay rights movements and other self-help organizations struggling for their position in the society (Lloyd, 2007). Within mental health area, the idea of empowerment firstly emerged among consumer or ex-patient movement (Young et al., 2000; Rush, et al. 2006). They began by publishing their experience of being hospitalised. For example, in the mid 19th century, Elizabeth Packard published her story of being forced to be hospitalized by her husband (Schiff, 2004). In 1935, the well-known story of Clifford Beers, who received a terrible treatment in a mental hospital which then initiated mental health movement in the US. In the 1970s a number of consumer groups began to flourished, such as Survivors Speak Out, the National Self-Harm Network, the Hearing Voices Network, Mad Pride and Mad Women. They struggled for changing mental health system which more empowering the patient.

Only recently that the idea of family empowerment emerged (Taub, et al. 2001). The central idea is how family of mentally ill takes control over their own lives, reducing the stigma and discrimination. Family empowerment has been defined as "a process by which the families access knowledge, skills and resources that enable them to gain positive control of their own lives as well as improve the quality of their life-styles" (Singh, 1995, p. 13).

The concept of family empowerment within mental health system has been studied extensively. It is regarded as a critical component of services for family of children with mental health disabilities (Resendes et al., 2000). In the Vanderbilt Family Empowerment Project (Heflinger et al., 1997) the researchers developed a model which predict that

increased knowledge, skill, and efficacy lead to the family to get involve in the mental health system and produce more positive outcome. A long with this model, Rendesdez et al (2000) found that care givers who had more competency, knowledge, and self efficacy influenced a better patients functioning compare to family who were less empowered. This suggests that self efficacy of the family play an important role in the outcome of patients.

Family Member Resilience

It has been consistently reported that family caregivers experienced high levels of burden and suffering. Terms used to describe their experiences include: traumatic, catastrophic, painful, devastating, bewilderment, turmoil, and chronic sorrow (Marsh, 1992; Pejlert, 2001). The words loss, grief, and mourning also often appear in this context. Families are dealing with actual loss and symbolic loss: the loss of hopes and expectations for their sick family member (Lefley, 1987; Marsh & Johnson, 1997). The experience of suffering is not only felt by family caregivers of people with long-term schizophrenia. Caregivers of people suffering from first episode psychosis already have to deal with high levels of distress (Tennakon *et al*., 2000). The most common burden experienced by family members is stigmatization. Finzen (cited by Schulze & Angermeyer, 2003) called stigmatization as a 'second illness,' an additional suffering experienced not only by the sufferer but also the family members.

Experiencing such levels of burden, family members often use many kinds coping strategies. Many different kinds of resources, including psychological, social, cultural and practical resources (Scazufca & Kuipers, 1999), make them able to get them resilience in the adverse situation.

The concept of resilience has been developed in line with the movement in positive psychology (Seligman & Csikszentmihalyi 2000) which focuses on the strength rather than weakness or pathologywhich has been the traditional approach in psychology. Resilience often been defined as the ability to adapt, cope, endure hardship, and rebound from adversity (see Walsh 1998; Walsh, 2003, Deegan, 2005). It is only recently that the concept of resilience is applied in the context of people with chronic and serious physical and mental illness. Deegan (2005) argued that when individual with psychiatric disabilities are struggling to recover from mental disorder, he or she can be viewed as resilient.

One of the sources of resilience for family whose one of the member suffer from psychological disorder is spirituality (Greeff & Loubser, 2008), and finding the meaning behind the adversity. In his study on family with autism, Bayat (2007) suggested that making

meaning out of adversity is an important factor in family resilience. They found that resilient families often made positive meaning out of adversity and articulated many contributions and lessons learned as a result of disability. The types of these lessons ranged from being personal or social; spiritual and inspirational. By doing this, they were able to change their world view to a positive outlook of life. Similarly, within family context, Walsh (1998) found several factors which contribute to family resilient includes making meaning of adversity, affirming strength and keeping a positive outlook, and having spirituality and belief system. The current research aims at understanding whether family resilience together with family empowerment predict recovery for mentally ill patients.

METHOD

A total of 99 family members completed surveys and their mentally ill family member. They were recruited from the psychiatric department of Sarjito local general hospital. The research team collected data by visiting all of the participants at home. After signing the consent form to participate in this research, participants were asked to fill out two instruments to assess their empowerment attitude and resilience. For educated participants, they filled the instruments by themselves, but for participants who had difficulty in reading the instrument, the research team assisted them to understand and let them to choose their response. Research team also conducted a clinical interview to assess the recovery level of the patients.

The Family Empowerment Scale (FES) (Koren et al., 1992) was used to assess parents' empowerment. The FES consists of 34 items rated on a 5-point Likert-type scale from 1 (*not true at all*) to 5 (*very true*). The scale has been designed to measure family empowerment at various system levels (individual, service system, and community). The FES consists of 34 items rated on a 5-point Likert-type scale from 1 (*not true at all*) to 5 (*very true*). This scale has been translated from English to Indonesia language and back translated from Indonesian language into English. The Indonesian version of this scale has been shown to possess internal consistency (item-total correlation between .277 – .651) and reliability Cronbach Alpha .917.

To assess family resilience, the Connor-Davidson Reslience Scale (CD-RISC) is applied. The CD-RISC contains 25 items, all of which carry a 5-point range of responses, as follows: not true at all (0), rarely true (1), sometimes true (2), often true (3),and true nearly

all of the time (4). The scale is rated based on how the subject has felt over the past month. The total score ranges from 0–100, with higher scores reflecting greater resilience. This scale has also been translated from English to Indonesia language and back translated from Indonesian language into English. The Indonesian version of this scale has been shown to possess internal consistency (item-total correlation between .277 – .651) and reliability Cronbach Alpha . 858.

To assess patient recovery, the Brief Psychiatric Rating Scale (BPRS) is used (Overall & Gorham, 1962; Faustman, 1994). The Indonesian version of the BPRS has been used widely, both for research and clinical practice (see Sudiyanto, 1998; Sukarto, 2004). This instrument consists of 18 items rated on a seven-point Likert scale (0 = no symptom to 6 = extremely severe), and assesses four dimensions: anxiety/depression, positive symptoms, negative symptoms and mania. The earlier version of BPRS consists of 16 items (Overall & Gorham, 1962). In a recent version it consists of 24 items (Ruggeri *et al*., 2004). In this research I used the Indonesian version used by Sukarto (2004), which consist of 18 items (Faustman, 1994).

RESULT AND DISCUSSION

Participants of this research consisted of mentally ill patients and their primary care givers. The patients were between ages 19 to 65, with a mean age of 33.95 years (SD = 9.72). The gender of participants were almost equals, 58 were female and 41 were male. Mean for the patients' length of illness were 9,05 years (SD= 7.405). They were diagnosed as having schizophrenia schizoaffective disorders. The primary caregivers could be the mother, the mother or the siblings provided that they play a significant role in taking care of the patients. Educational background of the family caregivers were University level (11.8%), high school (49.4%), middle school (25.9%), primary school (12.9%). The result of simple regression analysis is shown in Table 1 and 2.

Table 1.

Predictors	Mean	SD	Beta	VIF	R^2	Sig.
Family	108.849	25.102	0.225	1.179	0.087	0.012

Empowerment						
Family Resilience	92.717	12.277	-0.299	1.179		

Table 2.

	Sum of Squares	df	Mean Square	**F**	**Sig**
Regression	618.327	2	309.164	4.598	.012
Residual	6454.400	96	67.233		
Total	7072.727	98			

The above tables indicates that regression analysis yield result that family empowerment and resiliency accounted for a significant amount of variance in patient's recovery (R Square= .087, p= .012). This means that family empowerment and resiliency predict the recovery of psychotic patients

Two important points emerge from this study. First, it is evident that recovery from psychotic patient can be predicted from the family condition. This is inline with the previous research, particularly EE research where high family EE predict relapse. Discharge patients returning to families with high EE are more likely to get relapse compare to patients who return to low EE families. Having conducted a meta-analysis of 27 studies Butzlaff & Hooley (1998) concluded that EE is a significant and robust predictor of relapse in schizophrenia. Conversely, patients illness condition also has influence on family mental health. Family may experience psychological burden, stress and depression. Thus, the dynamic interaction between psychotic patients and their family caregivers is pivotal. Both parties influence one another (Subandi, 2002)

Second, it is in line with the focus of positive psychology that this sudy emphasize the positive aspect of mental illness. Rather than focusing on relapse this study emphasize recovery. As oppose to family burden, stigma and EE (negative quality) this study found that family positive quality, empowerment and resiliency, influence patience condition. However, it is not clear how the interaction between two variables take effect on recovery. Family empowerment attitude will be translated into greater involvement in the mental heath system, seek care and negotiate with mental health care provider. Empowerment is an important indicator of a family's ability to access and effectively utilize mental health system to meet their needs. A number of studies indicated that empowerment has been shown to be positively related to a number of psychological aspects. Vandervil et al, (1995) in their studies among Latino family in the US caring mentally ill patient, found that empowerment

had positive relationship with patients' duration of illness. This means that the longer family stayed in the US the higher the sense of empowerment, because the family was able to cope and take advantage of new knowledge and information. Zimmerman & Rappaport, (1988) found that empowerment has positively correlate with self efficacy. Meanwhile, Rogers, et al., (1997) found that empowerment improve quality of life of the family, more hours of employment, and community activism and to be negatively related to use of traditional mental health services. Scheel & Singh (1996) found that empowerment is related to lower internal stress, high level of family functioning.

The result of this study also in line with a number of literature. Wagneld (2009) reviewed a number of studies indicating that resilience is associated with outcomes, both physical health and emotional health. Including emotional health is depression, stress, anxiety, and psychosis. Edward (2005) concluded that resilient behaviors provide protection from the experiences of depression and anxiety or stressed. Ridgway (see Deegan, 2005), one of the consumer, concludes that recovery and resilience are two sides of one coin. Family resiliency will then influence their self efficacy and empowerment. It is by the interaction of these two variables that the recovery of psychotic patient can be predicted.

This research concludes that family empowerment and resilience accounted for a significant amount of variance in patient's recovery. This research suggests it is important to increase family empowerment and resilience as part of the treatment for psychotic patients.

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