

The power of identification: peer support in recovery from mental illness

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(Received 17 July 2008; accepted 1 January 2009)

Peer support has been described as facilitating individuals' recovery from mental illness and offering useful support, hope and encouragement. The aim of this study was to explore how individuals with experience of severe mental illness in Sweden perceived peer support facilitating their recovery. The results from the grounded theory analysis of 27 in-depth interviews illustrated that despite diagnoses of severe mental illness, often described in terms of an inability to interact with other people, the identification when meeting others with similar experiences were powerful. The participants described how peer support meant an end to isolation and became an arena for identification, normalization, connection and being important to others. Involvement in the peer support group is related to time and recovery stage, and to how the participants in relation to peers pay attention to their own achievements and their recovery progress, also comparing their level of wellness with that of their peers.

Keywords: peer support (PS); recovery; mental illness; gender

Background

Meeting other people with experience of mental illness has been described as facilitating individuals' recovery (Corrigan et al. 2005; Davidson et al. 2004, 2006). Peer support (PS) consists of receiving and giving support founded on the principles of mutual responsibility, respect and a shared experience of emotional and psychological pain (Mead, Hilton, and Curtis 2001). Peer support is built on the premise that people who have faced, endured and overcome mental illness can offer useful support, hope and encouragement to others facing similar problems. Coatsworth-Puspoky, Forchuk and Ward-Griffin (2006) describe how a friendly atmosphere and a sense of feeling welcome and safe within the PS clubhouses provide an arena for growth. Looking at other peers as positive role models gives an emotional insight and encourages the individual to recognize their ability to cope with the illness and develop a sense of self-worth as well as a desire to help others.

Supportive PS relationships also provide a sense of regained social skills, taking control over life, and leaving the patient role behind and instead, becoming a helper within the PS group (Coatsworth-Puspoky, Forchuk, and Ward-Griffin 2006). Peer support clubhouses are often viewed as empowerment settings, being egalitarian and creating a sense in members that the clubhouse belongs to them and that they are needed as contributors (Accordino and Herbert 2000; Mowbray et al. 2006).

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Corrigan et al. (2005) also describe PS programmes as unlimited in time, in contrast to relationships between personnel in psychiatric settings and their patients. The literature reveals a few commonalities among characteristics of clubhouse users. There is an underrepresentation of female members, and the majority of members have diagnoses such as schizophrenia, schizo-affective or other psychotic disorders or bipolar disorder. The typical age of clubhouse members is between late 30s and early 50s (Accordino and Herbert 2000; Macias, Barriera, and Alden 2001).

Davidson et al. (1999) list three different forms of PS that have developed to support people with mental illness, namely naturally occurring mutual support groups, consumer-run services and employment of peers as providers within clinical and rehabilitative settings. The authors describe how these approaches may contribute to recovery in people with mental illness. In Sweden the availability and impact of PS agencies for people with mental illness are limited compared with other European countries and north America. The Nordic welfare system, with a tradition of a large public care system, has given limited significance to user organizations that support people with mental illness. The RSMH, the National Swedish Association for Social and Mental Health, is the largest nationwide user organization. It is organized as a consumer-run service providing consumer advocacy and PS. Besides the RSMH, clubhouses such as Fountain House are run in a few places in Sweden. Also, a few diagnosis-specific consumer-run support groups are offered. This study focuses on members in the RSMH. The aim of the study is to explore how these services are perceived as helpful in facilitating recovery from mental illness. Despite the limited number of PS agencies in Sweden, people recovering from mental illness outline the importance of meeting other people with experience of mental illness as decisive for their recovery (Schon, Denhov, and Topor 2009).

Methods

This study is part of a larger study and represents a secondary data analysis of in-depth interviews with 30 individuals. Individuals considered for inclusion in the study were those who had been treated in hospital and diagnosed as having had a severe mental illness such as schizophrenia, psychosis, a personality disorder or bipolar disorder. A further inclusion criterion was that the individuals had not been treated in hospital during the two years preceding the interviews; however, ongoing out-patient care and/or being on medication did not pose an obstacle to participation. The third criterion had its point of departure in a subjective perspective, meaning that the individuals considered themselves either recovered or in the process of recovery.

Information about the project was spread via RSMH clubhouses and through pamphlets. Some participants contacted the project by phone and some were contacted by the interviewers by mail or by phone. The interviews lasted between one-and-a-half and four hours. All respondents agreed to being audio-recorded. Before the interviews took place, the respondents were assured of the opportunity to read through their own anonymized transcript. After reading the transcript, the respondents gave their written informed consent for using the material for research purposes.

The sample

In all, 30 individuals, 15 men and 15 women, were interviewed. The respondents' age at the time of the interview varied from 33 to 66 years, the majority being between

35 and 55 years of age. Only one of the 30 interviewees had been born outside Sweden. Most of the women were married or had a partner, while only five of the 15 men were married/living with a partner. Two-thirds of both the male and the female respondents had a job at the time of the interview, some working on the open labour market. Most respondents were on income support. The sample had a spread with regard to social class, with the majority being middle class, but some being working class or upper class participants.

The majority of the participants were recruited through the auspices of the RSMH and the level of participation within the organization varied from being employed by the organization to just being a sporadic visitor. Twelve of the men and all of the women were or had been members of a consumer-run PS group (Davidson et al. 1999), with the majority involved in the RSMH, and a few also being involved in other PS groups such as Alcoholics Anonymous (AA) and a voice-hearing group. These 27 of the 30 interviewees are in focus in this study.

Analysis of the interviews

The interviews were analyzed using grounded theory (Strauss and Corbin 1997). The method was a useful tool for generating concepts and analyzing processes of how the participants thought involvement in PS groups affected their recovery from mental illness.

All the narratives of PS were coded verbatim using the NVIVO software. The codes were collected into categories, and preliminary concepts emerged. The categories were compared and a temporary conceptual framework was created. Concepts and categories emerged through a cyclic process of coding and constant comparing of incidents in the data, by which process, concepts and categories relating to the incidents emanated. The memos from the analysis were compared in detail and relationships between categories and concepts were found using different theoretical and emotional codes (Glaser 2001). The theory that emerged through the analysis is based on the concepts that emerged in the NVIVO coding. Even though none of the participants described a process with different stages in experiencing PS, the outlined concepts created a process of five stages that correspond to a reality in which the participants can be placed. The 28 participants were spread across the different stages. This also gives an indication of how they perceived their level of wellness.

Findings

In the analysis the 'power of identification' emerged as the core category. Meeting people with their own experience of mental illness and its consequences was a powerful contributor in the recovery process, confirming and normalizing the own illness experience and past experiences of psychiatric care. The power of identification and the process of identifying also implied creating an illness narrative by listening and talking to other members. Experiencing the power of identification through the creation of a recovery narrative is a self-help strategy in the recovery process and the clubhouse serves as an arena for this purpose. The personal recovery achievements are identified and measured by identification with peers.

This experiencing of the power of identification is largely dependent on time, with the identification process occurring in five intertwined stages. These stages seem to occur in a certain order and are characterized by a process of growing into and out of

identification with peers. These stages also seem to have different effects on the recovery process. In terms of both effects and stages, there were two general gender differences in the material, according to engagement and level of participation in PS groups. More women than men described PS groups as facilitating their recovery, but also more women than men described how they had ‘grown out of’ the PS group. The process of identification starts with ‘meeting peers’, which is when individuals break their isolation and become acquainted with people with experience of mental illness. The second stage of the identification experience, ‘being oneself’, is that part of the process when the individuals start to trust their peers and sense that they are being accepted and a part of a fellowship, whatever their level of wellness. The third stage, ‘helping others’, involves the process of creating a recovery narrative and being important to others, while the fourth stage, ‘coming out’, involves the process of transforming the illness experience to a life experience, by telling it to others. The fifth stage, ‘being between identities’, describes the process of ‘growing out of’ the identification but many of the participants did not yet have a link to other networks. These five stages will be presented in the following.

Meeting peers

The first stage of experiencing the power of identification took place when the participants broke their isolation by visiting a clubhouse or a peer group of people with experience of mental illness. The clubhouse became a ‘breathing hole’ away from home, or, as one of the participants said, ‘Even if I felt ill, I could get out and go there [to the clubhouse]’. This was described as an important step in the recovery process: ‘It’s about fundamental human needs: meeting other people, going out and talking to somebody’.

Several of the participants described initially feeling resistance towards visiting a clubhouse and especially an inability to see themselves as ‘having anything in common with mentally ill people’. Despite this interpersonal stigma, once in the clubhouse the participants perceived their peers’ level of wellness as higher than their own at this stage, and saw their peers as living proof of the possibility of overcoming the illness and living with its consequences.

The participants collected knowledge about the illness from their peers and several of the participants gave examples of how they received ‘valuable’ and ‘concrete advice’ on how to cope with the illness from this experiential knowledge, which hadn’t been available to them anywhere else.

Being oneself

The second stage of experiencing the power of identification began with the participants starting to trust their peers and sense that they were being accepted and were becoming a part of a fellowship despite their low level of wellness. During this stage the participants still perceived their peers’ level of wellness as higher than their own, giving them hope of recovery. At the same time they appreciated a sense of equality among all peers despite variations in wellness, as one said:

People didn’t turn away or thought it was hard to talk about [the illness], or started to talk about something else. They welcomed me, showed understanding and recognition. The engagement made me grow.

The mutual experience of mental illness and of being patients in psychiatry was described as a bond among the members of the clubhouse. The peers understood the challenges of mental illness and recovery that family members or friends without experience of mental illness lacked. This development of trust, and this sense of connection and equality also implied a normalization of the illness experience. Before participating in the PS group, several of the participants understood their illness as a unique experience of being 'the craziest person in the world'. Developing trust with peers and sharing stories of the illness was perceived as a normalization of the illness narrative. The participants realized that they were not alone in their illness experience, or in feeling concern over the recovery and possible side-effects of medication. Some of the female participants described how the mutual experiential knowledge also took away shame: '[Meeting] other people with similar experiences takes away the victim blaming and shame of being the only one in the world'.

Several of the women in the sample also underlined the importance of being believed, in terms of both the illness experience and the experiences of hospitalization. One of the female participants described this as follows: 'It was the first time I met others and discussed everything without risking to be locked up and without people raising their eyebrows or getting scared'.

Helping others

During the third phase in experiencing the power of identification the participants developed dual roles of creating their recovery narrative and becoming important to others. Creating and recreating a recovery narrative was described as a continuous process: 'I think it is really important to be able to talk about the experience. That way you get new ideas and have to think and think again. It is a constant process of development'. This process took place in the clubhouses and in the PS groups and the participants described how they considered their level of wellness as similar to or a bit higher than that of their peers. Several of the participants also described how during this stage they assumed the ideologies and slogans of the peer organization as a tool for making meaning of the illness, e.g., 'Recovery from severe mental illness is possible' and 'Recovery is a right'. They described feelings of connectedness and how they formed part of a collective work of the group and as such were important to others: 'First of all you feel you are not alone when you're able to help others. Then you are not worthless. It is a life necessity to feel necessary'. During this stage the participants felt they had found a social niche in which they became active resources to others, leaving behind the passive role of a 'consumer' or 'service user'. They received feedback from their peers about their efforts to support others, and felt socially valued in the group, something which was perceived as having promoted the personal recovery process. Some of the men described how during this phase they had received 'commissions of trust', e.g., as accountants or as chairman of the PS organization. Having been awarded these positions was described as having contributed to an enhanced self-esteem and a 'receipt of personal capacity' or 'personal value'.

Coming out

The fourth stage of experiencing the power of identification reflects the process of transforming the illness experience to a life experience and telling it to others outside the PS organization. Approximately half of the participants talked about activities

taking place during this fourth stage. This stage also included getting involved in advocacy work towards psychiatry and politicians.

The participants told how they had been asked to tell their recovery narrative in larger contexts and how this had been valuable and they had been given positive feedback. They valued this feedback differently to, and often higher than, that received within the peer organization. Getting positive feedback from people outside the PS organization enhances self-esteem. Some of the participants said they had felt 'personal worth' and gratitude for being 'able to contribute' to society.

During this process the participants considered their level of wellness as higher than that of most of their peers. They described how the members in the PS network had had a 'different recovery pace' and how they (the participants) had looked upon themselves as 'working for them' (their peers). Despite this perceived high level of wellness the recovery process was still described as being central to the participants' life:

During these first six months being the head of the group, I didn't hear any voices at all and just thought it was wonderful. And I could say that to others, which made me so strong. It was a giant step in my recovery. All those years thrown away in other people's eyes become a resource. A life capital that can be helpful to others.

Some of the participants who had been given leadership responsibilities within the PS organization described a sense of 'giving back' help to others or 'paying off' some of the support they had received themselves, in the peer group but also from psychiatry.

Being between identities

The final stage in experiencing the power of identification was described as a transitional period when identification with peers started losing power and the participants started to grow out of the peer role. Some of the participants said their activities in the PS organization had been reduced at this stage, as work in the labour force or engagement in other clubs took precedence. But among those who remained, the majority of the female and some of the male participants described how they still remained in the PS organization despite this development because of the lack of links to other networks. About being between identities, one of the participants said the following:

I think I lack intellectual stimulation. There is no eye contact with people on my own level [at the clubhouse] ... The experience is a little empty ...

And I am also a member of the district committee and there it's the opposite. There it is a lot of politicians without empathy going through the items very rapidly, and I don't feel at home there either ...

They described difficulties in 'finding healthy friends' and a tendency to feel an 'outsider' within the peer organization because of their high level of wellness and the wish to expand towards other, healthy networks in society. Some of the participants described how the personal recovery achievement was at times reduced by other peers who were jealous, and how their past diagnoses had been questioned by other peers who did not believe in recovery from severe mental illness.

Conclusion

The aim of this study was to explore how individuals in recovery from mental illness perceive PS to facilitate their recovery. In interviews, data were collected on a specific

form of PS organization, namely the RSMH, a consumer-run organization without focus on vocational activities. A quantitative study of a larger sample is needed to validate the findings presented. Another limitation was that the sample had similarities with other PS groups, with membership based on age (Accordino and Herbert 2000), ethnic group (e.g., native whites) (Davidson et al. 1999) and diagnosis of severe mental illness (Mowbray et al. 2006). Although quite in contrast to other studies, more women than men in our study described PS groups as facilitating their recovery. This may partly be explained by differences in organization and focus of the clubhouses in different countries. In north America an underrepresentation of women in clubhouses is explained by the vocational focus of the clubhouse, seen as more relevant to men (Mowbray et al. 2006), a focus not present in the RSMH in Sweden. Rather, the focus in the RSMH is PS as emotional exchange and consumer advocacy, which in some studies has been described to attract women to a greater extent than men (Davidson et al. 2006).

Despite these limitations the results show the importance of meeting others in recovery to experience the power of identification. Despite diagnoses of severe mental illness, often described in terms of an inability to interact with other people, the results illustrate the power of identification when meeting others with similar experiences. The participants described how PS means an end to isolation and becomes an arena for identification, normalization, connection and being important to others. Involvement in the PS group is related to time and recovery stage, and to how the participants in relation to peers pay attention to their own achievements and their recovery progress, also comparing their level of wellness with that of their peers. The findings are in line with those of other studies identifying phases of growing within supportive PS relationships (Coatsworth-Puspoky, Forchuk, and Ward-Griffin 2006; Davidson et al. 2006). This study agrees with studies that have revealed additional stages of growth within a peer organization and within society in general (Coatsworth-Puspoky, Forchuk, and Ward-Griffin 2006; Davidson et al. 2006). The results point to the need for opportunities to grow even further than becoming a professional peer.

Some of the participants described an institutionalization of the PS group, due to the lack of alternatives in society, and related how the power of identification can in such cases diminish and in fact become detrimental to the recovery process. In Sweden and the other Scandinavian countries, there is an obvious need for a variety of PS organizations offering alternatives and contributions to traditional psychiatric hospitalization and social interventions. Peer support programmes have an important impact in facilitating people's recovery processes and provide a base for further growth and a possibility for people in recovery to participate in all aspects of community work, such as having a job. In a few places in Scandinavia there have recently been developments of engaging consumers in staff positions within psychiatric care. This does not necessarily mean that the same process of identification would be initiated as in consumer-run PS groups. Still, this may be the beginning of making use of PS in a broader sense, providing the positive impact on individuals' recovery found in this study and underlined by other studies (Corrigan et al. 2005; Davidson et al. 2006; Mowbray et al. 1997). People who have experienced, endured and recovered from mental illness seem to be able to give useful support, hope and concrete advice to others facing similar conditions.

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