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Challenges for the empowerment of young mental health service users in Norway

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Abstract

Objective. The objective of this study was to explore how principles of empowerment are reflected in the experiences of young users of the mental health service in Norway and to determine challenges to their implementation.
Method. Thirty-two qualitative interviews were conducted with nine users during a 12-month period and analyzed to identify key themes related to their empowerment.
Results. Four themes were identified: the users' wish to have control of their own illness and treatment; their trust in themselves and plans; at the same time, their self-devaluation and vulnerability; and a feeling of powerlessness because of the lack of choice and information within the Norwegian mental health service system.
Conclusion. The young mental health service users in our study had an adequate level of psychological empowerment. However, their empowerment as mental health patients was restricted by environmental factors, most of all the skewed power distribution between users and health service professionals.

Keywords: mental health service users; empowerment; lack of choice; power imbalance; consumerist approach.

Introduction:

User empowerment became an indispensable step in the paradigm shift from a provider- to a user-oriented health care. Empowerment is a strategy designed to improve clinical results, to reduce the negative impacts of system discontinuity, and to provide support to vulnerable user groups (Trummer, Mueller, Nowak, Stidl & Pelikan 2006; Werner & Malterud, 2005).

There is a consensus that empowerment represents a process or characteristic that permits individuals to take charge of their own lives, however, it also opens broader opportunities to influence organizational and societal structure (Rogers, 2012; Zimmermann, 1995). For this article, empowerment for mental health system users is defined as a level of choice, influence, and control that users exercise over events in their lives (World Health Organization, 2010).

A starting point for the empowerment process is a situation of powerlessness or the existence of a power gradient. The process can take different forms and display different context-dependent meanings (Fitzsimmons & Fuller, 2002; Rappaport, 1984; Rogers, 2012; Zimmerman, 1995). For example, the most important meaning of empowerment for patients with chronic kidney disease in Sweden was the creation of trust and learning during meetings of patients with staff (Nygårdh, Malm, Wikby & Ahlstrom, 2012). The underlying and unique feature of empowerment in the mental health field is that users are extremely vulnerable and feel powerless because of their disability (Lord & Dufort, 1996) and from the stigma associated with mental illness (Link, Struening, Neese-Todd, Asmussen & Phelan. 2001).

Some authors explain powerlessness in terms of the objectification of an individual. In other words, he or she assumes the role of an object acted on by the environment (Aujoulat, Luminet & Deccache, 2007). Such objectification also takes place during encounters between mental health professionals and users of mental health services in Norway (Thesen, 2005). The objectification appears to represent a situation where the environmental influence can arrest a process of individual empowerment. The dependence of empowerment of the users of mental health services on relationships with professionals is a research theme of interest in international studies. Recently, such research based on reviews has emphasized the role of two factors in users' experiences of mental health care (Newman, O'Reilly, Lee & Kennedy, 2015): first, the user's acknowledgment of his or her mental health problem and search for assistance; second, the development of a relationship with the service providers. The first issue is linked to the user's psychological empowerment, while the second depends on environmental factors that can possibly influence empowerment such as the existence within the user–provider relationship of trust, care and consideration, power balance and choice.

The influence of environmental factors on users' empowerment can vary among different countries. For example, Schon and Rosenberg (2013) argued that an empowerment process could have its own pattern in Nordic countries where both state and health systems are organized in a distinctly different way from English-speaking countries, where the concept originated. The authors speculated that a strong welfare state in Nordic countries that takes responsibility for health and social issues might discourage users from taking individual responsibility.

Norwegian reports have described users' perspective of their experience of health care, for example about the importance of helpful relationships and recovery orientation by professionals (Borg & Kristiansen, 2004). Researchers have reported a relationship of trust on the part of users to professionals. Furthermore, users and professionals agree that a responsibility for health care should shift to professionals during any critical illness phase (Solbjør, Rise & Westerlund, 2011). Some studies have provided evidence for power inequalities between users and providers in Norwegian mental health service (Rise, Solbjør, Lara, Westerlund, Grimstad, & Steinsbekk, 2011; Solbjør et al. 2011). Solbjør et al. (2011) found from interviews with service providers and users how the very possibility of user participation in decisions on health care was based on the professionals' judgments about their condition. Hansen et al. (2004) have explored the impact of patients' views on treatment planning in the case when their views were seen to conflict with those of professionals. They have found that professionals' opinions regarding users' needs were given more importance and concluded that routines in the mental health system did not support users' empowerment. Tveiten, Haukland, and Onstad (2011) conducted a focus group study on adult patients with mental illness to gain knowledge of their ideas and practices of empowerment during their stay in psychiatric care. It was found that respondents' initiative for participation was not in line with the services provided and that they had problems with being accepted as experts in their own illness. The authors concluded that the empowerment process was influenced by the system (e.g., norms and regulations) and by the type of collaboration the respondents had with professionals.

The objective of this study was to explore how principles of empowerment were reflected in experiences of young users of the mental health service in Norway and in the challenges they met in practice. To what extent and how did the users' influence events related to their treatment and medication? Did anything interfere with the users' motivation to control their illness? What choices did the users have?

Materials and methods

This study was part of a larger research project considering the experiences of mental health service users in the Norwegian system and was based on the same qualitative data. A data collection approach involving qualitative interviews was chosen because such interviews have been described as ideally suited to the exploration of patients' perspectives on their health care experiences (Kvale & Brinkmann 2009).

In the main original study, we analyzed the users' stories about their meetings with mental health services during a period of 1 year (Ådnanes & Steihaug 2013; 2016). Here, we analyzed the data anew with perspectives on user empowerment as a starting point.

Sampling

The participants were recruited from three sources; the primary care mental health services, a user organization, and a secondary school catering for young adults with mental health problems. All our informants, aged between 18 and 30 and comprising eight women and one man, were mental health service users each with one or more mental health diagnoses. Some were also substance abusers, and all had relatively complex treatment and supervisory needs. Five of the informants told us they were diagnosed with a severe mental illness, four with a personality disorder and one with manic depression. Three of the informants not diagnosed with a severe mental illness had been diagnosed with depression, and one was awaiting a diagnosis. Four of the nine informants suffered from post-traumatic stress disorder, and three from an eating disorder. All nine informants reported that anxiety was a more-or-less severe periodic problem. Three reported problems with alcohol, tablet and/or substance abuse, and three had experienced repeated attempts at self-harm. Eight of the informants had taken an overdose either once or several times or otherwise attempted suicide. Seven had long histories as mental health service users (8–16 years), whereas two were relatively new recipients. All except for one informant were receiving a Norwegian work assessment allowance. Seven were taking courses at secondary school and aiming to qualify for higher education; one was studying at college, and one had finished her education as a nurse.

Data collection

The participants were permitted to choose to be interviewed at home, in a public place or at the researcher's office. Seven interviews were conducted in the researcher's workplace, while one took place in a care provider's office and another was interviewed while an in-patient at an institution. The focus of our semi-structured interviews was on patients' experience of the development of their illnesses, treatment,

Ethical issues

Ethical approval for the study was obtained from a Norwegian Regional Committee for Medical and Health Research Ethics (ref. 2010/1144). Informed consent was obtained from the participants prior to the interviews. Data collection and analysis adhered to established principles of confidentiality and anonymity.

Data analysis

To identify the user's degree of empowerment in their relations/meetings with the services and providers, the interview transcripts were analyzed qualitatively. The procedure for analysis was inspired by principles of grounded theory and in line with Crabtree and Miller's strategy of editing and analysis (1999). This strategy is partly guided by data and partly by previous research and theory: here on the topic of empowerment. The analysis procedure started with repeated readings of the interview transcripts to obtain a general impression of the content.

Then, the first author searched for meaningful units and segments related to the research questions, describing important events linked to empowerment or the lack of it. These events were coded and categorized, and organized into explanatory themes. From these themes, quotations describing the various forms/principles of empowerment with each informant were selected. The findings and interpretations were discussed by the authors until an agreement was reached.

Results

The users' wish to have control of their own illness and treatment

The respondents emphasized their wish to exert control over their illnesses and treatments. They wanted to understand their illness and cope with it by taking their own responsibility. Users suffering from side effects from medicines tried to find alternatives online on their own initiative. One of them shared her experience:

"I've stopped taking them all [the prescribed medications] and now I'm waiting for a new prescription. I tried to ask for Valdoxan [an antidepressant] but you can't buy it in Norway."

Another respondent described how she desperately needed to understand her illness after a period of more than 3 years during which medical professionals had failed to reach a diagnosis:

"I wanted to know what it [the illness] was. Was it always going to be like this [as she had been told by the health professionals] – never getting any answers? I felt that I just wanted to give up there and then. I felt that if it was always going to be like this then I wouldn't get through it. If I was going to get myself out of this I had to find a solution. They [the health professionals] were offering me no solutions. It was like putting a plaster on a gaping wound and I couldn't live with that."

Another respondent expressed that she wanted to stay longer on the ward but was refused:

"In order to feel safe, my treatment [at the institution] should have been extended. Because it was too short a time to adapt before suddenly finding myself at home all evening and all night. My psychologist recommended that I apply to get the treatment extended. But then the managers had a meeting about it. There were so many people there and they decided to refuse my request. It felt a little overwhelming at first, but things are all right now."

Trust in themselves and in planning for the future

The respondents' desire to construct their future helped them to be motivated to overcome their illness. The confidence in themselves permitted the users to take initiatives, among other to find better treatment solutions and alternative institutions. Some expressed more-or-less specific plans for a future where they would be free from illness. One described her aims as follows:

"I want to get to sleep without taking the pills. Especially if I'm going to start studying to get a job. If I'm going to start thinking about the future I have to start doing something about it now".

Another respondent was confident that, based on her achievements, she had every reason to be hopeful of success in her future studies:

"I want to start studying at this university in the autumn. I really enjoy studying and the student life, and I know that I'm self-disciplined enough. I did pass my law exam, after all. So, I think it'll work out if I really put everything into it. But I have to get out of this vicious circle that I'm trapped in right now."

A good example of personal growth is the story of one of the respondents who first managed to control her illness and then decided to help other patients with mental health problems. She made a study of user participation tools and became a user representative, participating in seminars and sharing her experiences with patients and their families.

Self-devaluation and vulnerability

Some of the respondents described difficult periods when their mental health condition had worsened and they had lost their motivation to go further with their life plans. Expressions of insecurity can be illustrated by the following comments from a drug-dependent girl with a personality disorder who was initially confident that she could control her condition:

"I just don't know what's wrong with me. What can I do to make things better? I'm only trying to do everything I can to make things better. But nothing I do works. So, I don't know what I need. I've lost my motivation. I'm not an easy person to deal with."

One of the respondents described a feeling of vulnerability after encountering health professionals when being saved by ambulance staff after she had taken a drug overdose. However, she felt that that the professionals acted negligently because of the nature of her condition:

"I must have blacked out on a stairway in the center of Trondheim and they put me in an ambulance. They brought me back, but as soon as I was conscious they threw me out again. 'Just another junkie' they must have been thinking. They treat you very differently when you have a drug problem. That's the attitude of the health services – if you have an addiction problem then it's just your fault, isn't it?"

Powerlessness and a lack of choice and information within the traditional system

The respondents' actions were shaped by their desire to make choices. They collected information about alternative possibilities for medications, therapies, and professionals. The users' choices were restricted by professionals making decisions for them and implying that they should follow their advice. One respondent described how she was forced to take medication even before her diagnosis was established:

"And I was told that the only solution was to start on the antidepressants and that they would help me cope. But I didn't want to take any pills. Because I knew what was wrong with me. I argued with them for a while when I was at the BUP [Child and Adolescent Mental Health Ward] from the time I was 16 until I was 18. It was to and fro with all the medications. They refused to accept that I didn't want them, but they offered no alternatives. It was like them saying that the reason you're like this is because you aren't taking the tablets we're giving you."

Another described a situation during which she experienced a panic attack and felt she needed to rest at night in an illuminated environment but was refused by the institution's staff:

"I suffered from so much anxiety. I didn't dare close my eyes. I couldn't stand having the light off and the woman I shared a room with said that I had to turn off the light because it was lighting up the whole room. I went down the corridor several times to tell them I couldn't sleep but was told to go back and try. I wasn't allowed to lie down in the common room."

Decisions about procedures and treatments were governed by the opinions of professionals:

"And then there's the question about whether they [the doctors] will withhold treatment if you don't consent or aren't interested".

Respondents were clear in their expressions of differences between mental institutions and based their preferences on these understandings. The following is one respondent's comparison of organizational procedures:

"The positive aspect is that at X [an institution] they pay more attention to you than at Y. They pay attention to what you say and do something about it. They try to help and say so if they aren't succeeding."

It became clear that this respondent wished to stay in an institution where staff were more attentive to their patients. However, it was difficult for respondents to find institutions where professional providers displayed appropriate attitudes. One of the respondents shared the following:

"I've been in many places and want to say that the people working here really know their job and want the best for us. I don't know what to say. I could almost scream with happiness that I had the chance to meet them."

Respondents observed that the selection of procedures and treatments were better in recently opened private sector mental health institutions. Such centers offered a choice of different therapies such as Movement groups, Psychodrama, Expression and Motorics groups. Furthermore, most respondents referred to long waiting lists both for treatment and for access to specialized institutional wards. One described a situation in which she was sent home after arriving at the emergency unit after a panic attack. She was refused help because of a lack of staff and summarized her impressions as follows:"
"...because there are so few psychologists in relation to the number of patients. And all the fuss at both the adolescents' and the Y clinics caused them to go on sick leave. In the end, it was first the psychiatrist and then the psychologist who went on sick leave."

Respondents also reported problems with information provision. and neglected to explain the basic aspects of mental illnesses and Staff forgot to inform patients about who would be prescribing their medication after discharge from the ward,treatments or provide warnings about medication incompatibilities. One respondent was not informed about an incompatibility of her medication with alcohol and lost consciousness as a result when she mixed them. She commented:
"I had been taking them [the medications] for two weeks. Afterward, they [the health providers] said that they had warned me not to take the meds if I was going to drink. This is one of the issues that mattered to me. I was so critical of this and couldn't have forgotten about it even after a year and a half. I'm sure they didn't tell me at first, and just as sure that they denied it afterward."

Discussion

In general, our respondents demonstrated a motivation to overcome difficulties posed by their illness and go further with their life objectives. They wished to understand the nature of their illness, asked for a diagnosis and tried to take their own responsibility for illness control, for example, to make their own choices regarding medication or ward stays. Additionally, our respondents had an active position in their assessments of the Norwegian mental health system. They referred to negligent attitudes among staff, long waiting lists, and insufficient information. However, users' requests to control illnesses and treatment were often overruled by the authority of professional providers.

Psychological empowerment

The psychological model of empowerment expresses the empowerment in terms of personal growth needed for dealing successfully with new and difficult situations (Rogers, 2012). Planning ones' future life or expressing a belief in own capabilities by our respondents is an example of this type of empowerment. Aujoula et al. (2007) suggest that the psychological approach conceptualizes empowerment in a similar way to self-determination theory (Deci, Ryan and Richard 2008) that highlights characteristics of competence, relatedness, and self-determination for human motivation and health behavior. Our respondents provided an evidence of being in the possession of these characteristics and this suggests that they had a solid base to make choices. Competence to judge about the changes in the severity of own condition or understanding differences among mental health institutions were clearly displayed in our respondents' observations and this can be also interpreted as an empowerment element. Grundy et. al. (2016) observed as well, that users of the mental health service are aware of variabilities in the severity of their condition. Those authors noted that respondents referred to a continuum regarding different levels of their capacity to participate and wished that professional behavior had been adapted to it.

Self-devaluation.

Temporary expressions of self-devaluation by some of our respondents can be linked to the impact of a critical stage of mental illness. There was no evidence that users missed insight or a capacity to communicate, and a loss of motivation described by one of the respondents was temporary. Researchers have discussed before how phases with the lack of insight in patients decreased expressions of empowerment, for example, a wish to participate in decisions (Solbjør Rise, Westerlund & Steinsbekk, 2013). Indeed, it was suggested that mental illness itself can have a disempowering effect on patients (Oades & Deane, 2012). In any case, the solutions to overcome the impacts of critical phases can be found in providing users with services that strengthen their empowerment. Examples in Norway are represented by mental health centers, where users benefit from also being participants (Elsta & Kristiansen, 2009) or individual plans where service providers develop treatment strategies based on users' own need and objectives, in this way ensuring better participation (Holum, 2012).

A hurting experience during contacts with professionals can contribute to the feeling of self-devaluation described by one of our respondents. Impressions of being stigmatized by the staff of emergency care wards are present in her comments. There is a possibility that perceptions of stigma from professionals and other people in society can cause self-devaluation and self-stigmatization.

Environmental factors.

While the above-discussed findings highlight the presence of markers of user empowerment, at the same time, empowerment is the process of continuous personal growth that requires the existence of a favorable environment (Rogers, 2012). One of the core elements in providing a propitious environment is good user–provider interaction, where providers permit power distribution. Episodes described by our respondents when they were not being heard or refused a possibility to participate in decision making suggest that the absence of a favorable environment could have intervened with their further growth. This situation can be viewed as an example of objectification of users as reported by Thesen (2001). Our findings about the lack of needed attention from professionals agree with the results of several other authors who observed that users within the mental health system felt that staff neglected in listening to their requests (Rise et al. 2011; Ross & Goldner 2009; Storm & Davidson 2010).

Choice

From the perspective of the World Health Organization's definition, empowerment for mental health service users is linked to the level of choice they have over their life (World Health Organization 2010). This agrees with the consumerist model of empowerment that puts the choice as a central prerequisite for a power redistribution between users and providers with a shift of responsibility for health to users (Masterson & Owen, 2009; Winkler, 1987). Our respondents were in some cases denied a choice, even when they were in a possession of enough competence and a wish to decide. This suggests that professionals had a power to impose the users' decisions.

Mental health service user's ability to choose was introduced in 2015, but this is a controversial issue in Norway. In 2006 Vrangbæk and Østergren (2006) compared the introduction of a patient's entitlement freely to choose a hospital in the Norwegian and Danish health systems. Such choice was widely supported by politicians and patients' organizations in Norway, but psychiatric associations and the regional health enterprises in consultative comments regarding this new patient right argued that choice was not appropriate for these patients. Because of their often very complex and unresolved conditions, they could lose insight during critical periods of their illness. The divergence in opinions and a debate on choice is likely to be conditioned by the different worldviews of professionals in two countries, with a tendency of Norwegian professionals to be more focused on the medical model (or treatment) model in mental health care (Diseth & Høglend, 2014). Additionally, Norwegian psychiatric specialists have dominated policy in the field of mental health services and political bodies were reluctant to challenge this (Ramsdal, Hansen, Hengesen & Feiring 2008). Hence, the politics of users' choice in the field of the mental health care in Norway was influenced by these circumstances, and this, in turn, might have had an influence on users' empowering process.

Other issues that can influence a choice are related to provisions of the health system. The current reality, regarding choice in the mental health service field as we have mentioned before, is represented by the lack of staff, long waiting lists for treatments and insufficient information. These findings provide evidence of the gaps in management and governance of Norwegian mental health services, but at the same time point to the reluctance of actors possessing power in its redistribution.

Information provision was shown to be the factor that has the greatest influence on exercising choice (Damman, Spreeuwenberg, Rademakers, & Hendriks 2011). However, empirical studies reveal gaps or absent information provision to mental health system users (Happell, Manias, & Roper 2004). In our case, users reported shortcomings in information provision even about medicines' incompatibilities, which sometimes had serious consequences.

The underlying conditions for user choice require a wide selection of competing service providers, combined with the ability of the user to choose from among the providers on offer (Hickey & Kipping, 1998). Political efforts were made in Norway to support users' choice in health care. One of the attempts in this direction was introduced by putting into focus users' choice as a part of the market-based model to modernize the public sector (Hansen, 2007; Storgaard & Askheim, 2014). By making a choice, a user becomes the judge of the quality of service and this is supposed to increase competition between providers and result in better service.

Coming back to our results, empowerment principles appear to guide users in Norway during their experiences in mental health care. These principles are translated into a desire to understand their illness, along with a wish and efforts to influence treatment decisions. While free choice is crucial for empowerment, there were limitations to the degree of choice. One aspect of such limitations was linked to information and insufficient offers of specialized wards, procedures, and treatments. Another aspect was defined by attitudes of staff who were not disposed to take into consideration users' opinions. The challenge here is that while users are empowered from a psychological empowerment perspective (with the exclusion of temporary episodes), and their rights to participate in treatment decisions are guaranteed by law, their empowerment is overruled by an authority exerted by medical professionals. However, our respondents had regained a trust in themselves and optimism for the future and this shows their sufficient level of empowerment. While this optimistic approach can be explained by the youthfulness of our respondents, one should project the situation of users' lack of power in the future.

The eventual solution to power redistribution can be supported by more direct mechanisms of users' influence via the adoption of schemes by which professionals are salaried based on user evaluations. We realize that developing such mechanisms needs more research to support it. It will be advisable to develop system quality indicators that would include users' evaluations of their information provision, a spectrum of treatment choices and extent to which users could use them. Experience from overseas might provide insights how this can be achieved. In the UK for example, so-called Patient-Reported Outcome Measures (PROMs) were introduced as a tool to promote empowerment. A White Paper on the issue published by the UK government (WP 2010) contained new health strategies and highlighted the introduction of greater patient choice and control over health care services, including the use of PROMs as quality indicators that could be used as a basis for hospital funding.

The study's limitations

We are aware that the small size of the group of respondents used in our study restricts the extent to which our findings can be generalized. However, the data were acquired over a 12-month period and the user feedback was extensive. Our findings might have been different if an older age group had been included. Younger respondents are usually more active than older ones with respect to participation in health decisions, and this might also be the case for empowerment.

Conclusions and relevance to clinical practice

Our analysis reveals that from a psychological perspective, our respondents' expressions of personal strength provide evidence of having an adequate level of empowerment. This should not be dismissed, even when users sometimes experience feelings of self-devaluation, which may be linked to the character of their illness or by the stigmatizing attitudes of professional providers. Respondents wanted to take their own responsibility for their illness and tried in several ways to do that. They could make clear choices in terms of their preferences, for example for certain professional specialists, medications and treatment institutions. However, opportunities to act on their choices were limited by the attitudes of professionals, lack of staff, places at institutions, and the unavailability of alternative treatments and medications.

Our study suggests that the young service users' empowerment as mental health patients were restricted by environmental factors, most of all the skewed power distribution between themselves and the Norwegian mental health care professionals. While structural factors like better provision of information or employing more staff can be changed more easily, the professionals' attitudes represent a complicated problem that deserves more attention. The clinical relevance of our findings lies in the fact that the provision of greater power to health service users may improve treatment outcomes and promote greater control of their life situation and future. There seems to be a complex interplay between users' openness and initiative to be empowered, and their dependence on relationships with professionals and traditional routines inside the mental health system. A clear answer about how empowerment of Norwegian users of the mental health service is manifested during their contact with the health system has not been given, and therefore there is a need to understand better what influences it. and care. The interviews were carried out by one of the authors and transcribed verbatim. To observe any changes and avoid retrospective data collection, each informant was interviewed four times during a 12-month period. Thus, a total of 32 interviews were conducted, each lasting 30–90 minutes. Two participants dropped out after one and three interviews, respectively.

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