

“The patient’s voice-empowerment in a psychiatric context”

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ABSTRACT

The aim of the study was to gain knowledge of the patients’ views and experiences of the principles of empowerment in a psychiatric context. Qualitative content analysis was used to interpret the meaning of the patients’ views and experiences based on focus group interviews. The findings and interpretations revealed three main themes; possibilities and presuppositions for participation, the system influences the empowerment process and collaboration along a continuum of power between empowerment and powerlessness. The findings and interpretations give voice to the patients and allow their concerns to be raised. The need for further research regarding the system’s influence on empowerment, power and cooperation is apparent both from the patients’ and the professionals’ perspective.

Introduction and background

Empowerment and advocacy are important mechanisms to address challenges in mental health (1). Empowerment in healthcare is based on a philosophy of seeing the patient as an equal, autonomous member of the healthcare team. Gibson (2) claims that empowerment at the individual level can be defined as a social process of recognizing, promoting and enhancing people’s abilities to meet their own needs, solve their own problems and mobilize the necessary resources to feel in control of their own lives. The three main principles of empowerment are patient participation, acknowledging the patients’ competency regarding themselves, and redistribution of power (3). Empowerment can be described in various ways, depending on the level of analysis: individual, organizational or community. All levels are interrelated (4).

Advocacy is about empowerment, a process of supporting and enabling people that seeks to ensure they can express their own views and defend their rights (5). Empowerment and advocacy have been shown to reduce the duration of inpatient treatment and the number of visits to the health service, building self-esteem and feelings of well-being, enhancing coping skills, strengthening social support networks, and improving family relationships (6). Moreover, the Action Plan endorsed in the Mental Health Declaration for Europe in the WHO European Region proposes to empower service users to take responsibility for their care in partnership with providers (1).

Research on empowerment as a process or outcome of interventions within the mental health field is scarce (7).

A review of the literature of user participation in mental healthcare revealed that even though much work is being done by the government and within health and social services to encourage user participation, there is still criticism of its effectiveness, and of government and psychiatric professions for not having fully embraced the concept. However, there is research showing that user participation is both effective and evaluated positively by professionals (8).

Truman and Raine (9) explored users’ meanings and experiences of successful user participation and conclude that from a user perspective, successful and meaningful user involvement should enable and support users to recognize their existing skills, and develop new ones, at a pace that suits the users’ particular circumstances and personal resources. This process may require adaptation by organizations, service providers, and non-involved users.

Lammers and Happel (10) conclude that there is a need to view consumers (service users) as heterogenous and to respond to individual needs and interests regarding consumer participation in mental health service. The authors further argue that despite variations in experience, there is a clear need to develop mechanisms to support consumer involvement and to influence the attitudes of health professionals to become more valuing of a consumer perspective.

Further, Connor and Wilson (11) explored the views of a sample of

users of mental health services regarding user involvement. The authors conclude that while user involvement is frequently mentioned in policy documents, in practice the aims are not yet being fully achieved.

According to Stickley (12), psychiatry is an archetypical arena in terms of power and control. The traditional view is that the patient is at the bottom of the hierarchy. Patient involvement, however, allows transcendence of the power hierarchy. The author thus suggests that a critical realism perspective representing an alternative approach to understanding these complex relationships, offering a model that does not kowtow to the dominant discourse, but recognizes that service users possess power in terms of being able to provide services that statutory services providers now require. Masterson and Owen (13) argue that empowerment is particularly important for mental health service users, given the often extremely disempowering psychological effects of mental health problems. Despite widespread use of the term empowerment, conceptual ambiguity undermines efforts to put mental health service user empowerment into practice, and any discussion of empowerment will be superficial without an examination of power itself.

Developing service users’ influence through participation is important, not only at the political and organizational level, but also in those contexts where users and professionals meet and collaborate (14).

A study aimed at exploring patients’ strategies for coping (defined as individual struggles on the path toward achieving recovery) with mental ill health showed that the main areas of concern for inpatients were: information, communication, relationships, activities, self-help, patient involvement in care treatment plans, and the physical environment. The study further underlines the importance of partnership between health professionals and psychiatric patients (15).

Norwegian white papers emphasize the need to include patient participation in treatment and organizing psychiatric care. However, an overview of Norwegian research literature showed that psychiatric inpatients’ voices are relatively absent in psychiatric research (16). Knowledge of the patients’ experiences concerning participation may be gained only by asking patients themselves.

Aim and research question

The aim of this study was to gain knowledge of the patients’ views and experiences of the principles of empowerment in a psychiatric context..

The research question was: What are the patients’ views and experiences of the principles of empowerment: participation; being viewed as experts regarding themselves; and redistribution of power?

Design and method

The design of the study is qualitative with explorative, descriptive and interpretative aspects. The research venue was two units of a psychiatric inpatient centre in Norway. The first unit represented patients with

more acute needs than the second unit, however, there was some degree of cooperation in the activities offered. All the patients were voluntary users of the service. The diagnoses of the patients were unknown to the researchers. A diagnosis may represent stigma and stigma may represent a barrier to empowerment (17).

Data were gathered by means of two focus groups, interviewed twice during autumn 2008 and spring 2009. The data from both interviews were analysed when the second interviews were finished.

Focus group interviews were chosen because this research method is ideal for exploring experiences, opinions, wishes and concerns, allowing the participants to propose their own questions, frames and concepts, as well as providing the participants with the opportunity to pursue issues on their own terms and in their own words (18). The discussion in the focus groups aims to stimulate the group process and the interaction between the participants, and thus generate different data from individual interviews (19).

The subjects in the focus groups were 14 adult patients. Purposeful sampling was used (20). The inclusion criteria were that: 1) the patients were chosen and asked to participate in the study by the physician or the psychologist in collaboration with the other professionals; 2) the participation was voluntary; 3) the patients were at least 18 years old.

The first group consisted of four male and two female patients representing both units and the second group consisted of three male patients and five female patients representing both units. The focus groups were interviewed by the first author (the moderator), while the second author (the assistant moderator) administered the tape recorder and summarized the items in the discussion. The participants were then invited to comment on the summary. Their comments thus represented respondent validation.

An interview guide was used consisting of items that specified the research question: experiences with participation, being viewed as an expert, power and redistribution of power and collaboration with the health professionals. Both interviews in both groups dealt with the items in general after having stimulated the participants to some small talk in order to create a secure atmosphere. The second interviews contributed to widening and to some extent deepening the items. Each interview lasted approximately 60 minutes and took place in a conference room in the centre. The interviews were tape-recorded, and the taped interviews were transcribed verbatim by the second author.

Qualitative content analysis

The transcribed text was analysed by qualitative content analysis (21). The starting point of the analysis process was a repeated reading of all the text by all three authors in order to gain an overall impression of the text. This overall impression was that the patients needed to understand the rationale behind the therapy, the organization and the collaboration. Next, all three authors searched for meaningful units in the text: words, sentences or paragraphs related to the research question. Thirdly, the meaningful units were condensed into 7 sub-themes which were abstracted into three main themes. The analysis process was conducted by all three authors in parallel, and the findings and interpretations were discussed until a common agreement was reached.

Ethical considerations

The study was performed in accordance with the Declaration of Helsinki and approved in 2007 by the Regional Ethics Committee of the Southern Region in Norway and the Norwegian Social Science Data Services. Permission to conduct the focus group interviews was obtained from the director of the centre. The chosen patients were asked to participate in the study by the physician or the psychologist in the centre, and were then informed about the study and their participation by a nurse, orally and in writing. The patients were guaranteed confidentiality and that they would not be identifiable in publications. They were further informed that participation was voluntary and that they could withdraw from the study at any time without giving a reason. In addition they were informed that they could contact the researchers after the interviews if necessary (one of the researchers is a psychiatric nurse). The patients who wanted to participate in the study gave their informed consent to the researchers.

Findings and interpretations

The content analysis revealed three main themes:

1. Possibilities and presuppositions for participation
2. Influence of the system on the empowerment process
3. Collaboration along a continuum of power between empowerment and powerlessness

Main theme 1: Possibilities and presuppositions for participation.

The analyses revealed that *understanding* represented possibilities as well as presuppositions for participation. The participants expressed that they had to understand when and how to participate in personal care and also in common daily activities:

“You need to have insight to be able to participate...”

“Sometimes the door is locked, and I believe they have their reasons...”

They had further experienced that their initiative was not in line with the service, and they therefore expressed a need for explanation from the professionals. One participant related that once she had asked for her family to visit her, but the professionals would not allow it. The participant stated that she did not understand the reason why her family was not allowed to visit her.

The participants also discussed their experiences on being viewed as experts. Being viewed as an expert might lead to trust, they argued. They underlined the importance of real acknowledgement, not acknowledgement as a formal claim. If they experienced being acknowledged as experts on their own life and feelings, then their self-confidence increased and made participation easier, as the following quote shows:

“..that the professionals are honest and not only acknowledge me because I am a patient...”

Learning about own problems, own diagnosis and own reactions represented possibilities and presuppositions for participation. One participant argued that group discussions represented a possibility for learning:

“We could discuss actual items and then learn from each other...”

The participants further argued that they wanted more group activities and opportunities to exchange experiences. The group activities and the discussion thus represented presuppositions for participation.

Care represented possibilities and presuppositions for participation as well. The participants discussed the importance of being acknowledged, supported and helped. Some participants argued that they needed to be pushed to participate. They further argued that they often felt too little was going on and that passivity reduced their initiative to participate. The following quotes are examples thereof:

“We are bored stiff...”

“We are left alone too much ...”

Main theme 2: The system influences the empowerment process.

The analyses revealed that *available time, organization, and the service offered* (individual plans and common norms and regulations) influenced participation, experiences regarding being an expert on oneself, and power balance.

Some participants argued that the estimated duration as an inpatient represented a hindrance to participation in the treatment process. They needed to be strong to participate, and sometimes they found that they needed more time to become strong enough. They also reported that insufficient time available led to stress, and this stress reduced their possibility to participate. Sometimes they found that insufficient time available reduced their experience of being viewed as experts on themselves, as the following quotes show:

“I am afraid of not reaching my goal...”

“I need to be here longer...”

The analysis showed that the organization of the centre influenced the empowerment process. The participants argued that they wanted more activities during the day, both individual and in groups.

They further argued that they needed some kind of follow-up therapy after the inpatient period. To understand their own need for follow-up therapy implied being an expert regarding their own life and situation, they argued. One participant expressed:

“I asked for two more weeks, and I got it...”

The analyses showed that the service offered influenced the empowerment process. The service included, for example, individual treatment, common activities and milieu therapy. It also included opportunities for participation in the treatment plan and in the decision-making process. However, the analyses revealed that the participants did not always fully understand what they could participate in. Thus, lack of understanding of the rules of the system probably reduced their participation and their feeling of being acknowledged as experts, as the following quotes show:

“We are not allowed to lay the breakfast table...”

“I did what I would have done at home, when I laid the table for dinner, but that was wrong...and I did not understand why...”

“Some rules decrease our initiative...”

Main theme 3: Collaboration along a continuum of power between empowerment and powerlessness.

The analysis revealed that the collaboration between the patients and the health professionals had contrasting aspects: cooperation versus rules; equality versus inferiority; and fellowship versus loneliness.

Power and redistribution of power represented an item in the discussion, in addition to what characterized the collaboration.

Some participants experienced cooperation with the health professionals, as well as acknowledgement and possibilities to influence their own treatment plan, as these quotes show:

“I experienced being listened to and taken seriously...”

However, some participants experienced the contrary, that the cooperation was largely dominated by rules and regulations, as this quote shows:

“You have to go to bed at eleven o’clock, if you disobey, they stand in front of you waiting for you to obey the order...”

The analyses revealed that being acknowledged represents equality. Some participants experienced being respected and accepted as equal members of the healthcare team, as these quotes show:

“I am an expert regarding my own body, but not regarding the therapy...”

“You decide for yourself, you are not at all pressed...”

Some participants experienced being treated as inferiors. One participant argued:

“If I don’t do what they want me to, then I am forced to take pills...this threat is always hanging over me...”

Fellowship versus loneliness represented another sub-theme. Some participants experienced fellowship with the health professionals when being acknowledged and participating in the treatment process. One participant argued:

“When I am sad and the professionals become aware of it, then they grasp it and help me to find my way out.”

However, fellowship with other patients represented an important aspect of the milieu in the centre and an opportunity for participation, as the following quote shows:

“When being together you feel that it is not only you having trouble, you share...and do not feel lonely”

The participants further commented that they appreciated group activities as a means of experiencing fellowship.

The analyses revealed that loneliness represented the opposite of fellowship. Loneliness occurred when the participants experienced being left alone when there was no organized activity during the day.

Discussion

Two focus groups were interviewed twice. A larger sample (more groups) might have given a greater breadth of data, however, after the second interviews in both groups no new views and experiences seemed to appear. The essential purpose of focus group interviews is to generate data through interaction between the participants (21). However, this interaction is hard to identify, describe and understand. In addition, during focus group interviews individual experiences and views are not focused upon, since the data are generated from the group discussion and interaction. One may further argue that non-verbal communication is poorly explored in focus group interviews. The participants in both focus groups had prior acquaintance with each other, as fellow inpatients, but not with the researchers. This may have caused feelings of insecurity and thus influenced their contributions to the discussion. Furthermore, it was difficult to initiate the discussion in both groups and the moderator therefore asked one of them to start it off, which may have made them feel inhibited. On the other hand, the participants said that they enjoyed the structure of the interview, and being led through the different items. The two authors were present during all four focus group interviews, analysed the text by means of parallel analyses and discussed the findings and interpretations. Further, respondent validation was conducted by summarizing each interview and giving the participants the possibility to correct or comment on the issues, which probably increased the credibility.

Possibilities and presuppositions for participation

The participants reported their need to understand when and how to participate in daily activities. Thus understanding probably represents a presupposition in the empowerment process. This seems to be in line with the findings of a study of the therapeutic milieu conducted by Thomas, Shattell and Martin (22). This study argues that patients need deeper contact with health professionals and insight-oriented therapy in order to obtain deeper understanding. This underlines the importance of how information is given, as there might be a contradiction between the information given and received. The health professionals probably inform the patients, however, the patients do not necessarily understand the information given. The health professionals have the main responsibility to ensure that the patients understand the information given. However, Walsh and Boyle (15) underline the importance of partnership between health professionals and psychiatric patients with regard to coping.

The participants wanted more group activities. When sharing experiences with others in the same situation, the patients help each other to increased insight through recognizing problems and reactions, which probably represents a resource in the knowledge process (patient education) (23, 24). To be a model for others’ learning, it is not necessary to be a professional; the patients may as well be models to each other (25, 26).

The participants reported that being acknowledged as experts on themselves contributed to increased self confidence, which in turn enabled participation. This is in line with the central principles of empowerment (27). Empowerment values redistribution of power from the health professional to the patient, and represents a certain change from a paternalistic to a democratic perspective. However, in the empowerment process, the patient is not a receiver of therapy, but a participant in it. Participation includes acknowledgement and participating in the decision process regarding the patient’s own life and health represents presuppositions to empowerment (28, 29).

The participants reported that care per se represented possibilities or presuppositions for participation. They underlined the importance of being acknowledged, supported and helped. This points to the importance of the quality of the relationship between the patient and the health professional. According to Vatne (30), acknowledgement is important in psychiatric nursing. A presupposition to a therapeutic relationship is that the patient should participate and experience a positive change in conditions.

Johansson and Eklund (31) underline the importance of the relationship between the patient and the health professionals. Empathy, interest and understanding, in addition to a secure therapeutic milieu,

are the most important factors. Røssberg (32) found that non-psychotic patients' well-being increases in a milieu characterized by a high level of autonomy and professionals' engagement in the patients' conditions and individually oriented care.

Influence of the system on the empowerment process

The findings and interpretations of our study show that the system influenced the empowerment process. The system, or the way the centre is organized, may well represent a barrier to empowerment due to limited time available for participation and collaboration between the patients and the professionals. This seems to be in line with the findings of Minett (8), concluding that even though much work is done within health and social services to encourage user participation, there is still a need for further development.

The participants wanted more group activities. This can be related to the organization of the service and is in line with the growing recognition of the capacity of people with mental illness to provide support to one another (33). However, the quantity and quality of group activities depend on the chosen model of the care and treatment offered (11).

Norms and regulations imposed by external funding agencies are included in the organizational system. In a psychiatric centre there are more patients with different needs which may be contrasting. Rules and regulations can therefore be experienced as inhibiting participation and redistribution of power and thus represent a barrier to empowerment for one patient, but represent a necessary aspect of care for another. The importance of bearing in mind the distinction between the individual and the collective is underlined by Hickey and Kipping (34).

The system influences the individual's empowerment process. This argument underlines the importance of including all levels of empowerment when describing and exploring empowerment, and is in line with the findings of Elstad and Eide (14), arguing that processes on the micro and macro-level can be viewed as both separate and intertwined.

The participants' need for understanding may be linked to the participation continuum described by Hickey and Kipping (34). Understanding the rationale for the system's rules and regulations is important in relation to empowerment. Thus how the information is given and received represents an important aspect of the collaboration process between patients and professionals and may in turn be linked to the values and ideas of the service offered or the system *per se* (35).

Collaboration along a continuum of power between empowerment and powerlessness

Further, for the health professionals to act as an acknowledging cooperation partner in the empowerment process probably assumes that they have competence and that the culture of the organization allows the principles of empowerment to be put into practice. Lack of commitment from the organization is one of the most important constraints to user participation (34).

The caring and therapeutic aspects of the rules and regulations of the system may contrast with the core of empowerment. The patients may perceive the rules and regulations as paternalistic, and some participants in our study expressed that they were sometimes made to feel like children. Empowerment is the redistribution of power and the opposite of paternalism.

Some participants reported that the concept of power was irrelevant, while some said that the health professionals had great power. One may assume that some participants were uncomfortable with the term "power", perhaps because they had a negative attitude to the term. This underlines the importance of redistribution of power in the empowerment process (3).

The professionals' power as professionals is legitimate and accepted even by patients in general. When some patients in our study argue that "power is irrelevant in our context", this may be interpreted as referring to legitimate power. However, since not all the participants share this view, this legitimate power is probably not total. According to Flyvbjerg (36), legitimacy is contextual. Further, Foucault's perspective on pastoral power seems relevant; the patients may have adopted the professionals' values and views regarding their need of change (37). The patients are voluntary inpatients; however, they may

not want to be patients, but understand the necessity of being cared for. In this situation, the patients probably accept that they have to submit to the professionals' decisions, rules and regulations. This is in line with the findings of Kennedy (38).

The participants reported that when viewing the limited self-regulation retrospectively, they better understood the necessity for it. This retrospectively obtained insight may represent contextual understanding. When in the situation, one understands it in one way, and when reflecting retrospectively, the understanding changes. This also demonstrates being on a continuum of power.

Legitimacy related to power can be linked to the trusting relationship between patient and professional. Hewitt and Coeffey (39) argue that if there is a trusting relationship between patients with severe psychiatric illness and professionals, the patients' compliance appears to increase. Compliance is linked to empowerment (40).

Conclusion

The findings and interpretations show that in a psychiatric context understanding, learning and care represent possibilities as well as pre-suppositions for participation. Further, the system influences the empowerment process and collaboration between the patients and the health professionals goes along a continuum of power.

While acknowledging the stated limitations of the study, the findings and interpretations give voice to the patients and allow their concerns regarding empowerment to be raised. However, further research regarding the system's influence on empowerment, power and cooperation is needed both from the patients' and the professionals' perspective.

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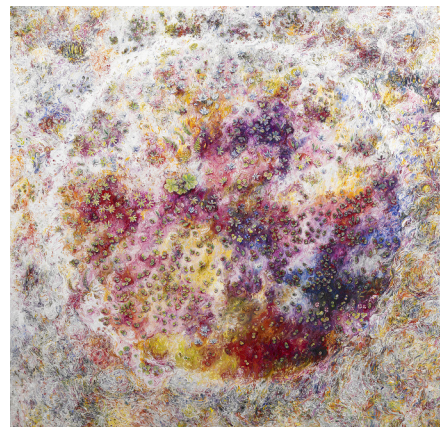
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A NEW RELEASE

FAMILY NURSING IN ACTION

EDITORS
ERLA KOLBRUN SVAVARSDOTTIR
and HELGA JONSDOTTIR



The book *Family Nursing in Action*, published by the University of Iceland Press in July 2011, has three core bases where practice models in family nursing are displayed; results of family nursing research and intervention are presented; and innovations in programs of nursing research within a variety of health care settings and systems are introduced. In multifaceted societies, individuals with acute or chronic illnesses need their family support systems to deal with difficult health situations. Our wish is that the content of this book will empower nurses around the world to practice evidence-based nursing with families. We hope the book will encourage nurses to continue to watch over and care for families in need of support and assistance from health care professionals, enabling these families to stand alongside and to care for their loved ones.

Edited by: Erla Kolbrun Svavarsdottir and Helga Jonsdottir, professors at the University of Iceland, Faculty of Nursing.

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