Patients' Experiences of Participating Actively in Shared Decision-Making in Mental Care

Lise Sæstad Beyene, PhD(c)[1,2,3], Elisabeth Severinsson, DrPH[4], Britt Sætre Hansen, PhD[2,3,4], and Kristine Rørtveit, PhD[1,2,3]

Abstract

Background: Patients in mental care express a wish for more active participation. Shared decision-making is a way of increasing patient participation. There is lack of research into what the shared decision-making process means and how the patients can participate in and experience it in the context of mental care. **Objective:** To describe patient participation in shared decision-making in the context of indoor mental care. **Method:** A qualitative content analysis of data from in-depth interviews with 16 patients was performed. **Results:** One main theme was revealed: *thriving in relation to participating actively in a complementary ensemble of care*, which represented the red thread between 2 themes: *having mental space to discover my way forward* and *being in a position to express my case*. **Conclusion:** Patients can participate actively in shared decision-making when the patients' and the mental health-care professionals' joint expertise is applied throughout their mental care. The patients experience thriving when participating actively in a complementary ensemble of care.

Keywords

mental care, patient experiences, patient participation, qualitative research, shared decision-making

Introduction

Patient participation relates to the patients' role and involvement in decision-making regarding their treatment and care (1) with the intention of increasing patients' influence on safeguarding that the care is in accordance with their requests (2). When hospitalized in a mental health ward, the patients' daily life and activities are lived in close contact with the mental health-care professionals (MHCPs) in a therapeutic interpersonal relationship (3,4). In Norway, MHCPs are the frontline workers on the ward. Most of them have a bachelor degree in nursing or are social educators, some have a specialized education in mental care, and some are high school educated health-care workers or unskilled assistants. The MHCPs working on the wards where this study took place are aged between 20 and 65. They have various professional backgrounds and experience of mental care—ranging from more than 20 years' experience to none. This context of mental care provides a setting for the patients to work through their mental problems, contributing to restored mental health (5,6). During mental ill-health, some patients may lack insight and may not always choose what is in their best interests. They may sometimes have difficulty in describing what they want, which influences their ability to participate (7). Participating in care also means that patients sometimes can make inexpedient and unpredictable decisions (8), and in severe mental ill-health, they may not always be able to take responsibility for their own choices and actions (7). In order to empower the patients in their process of restoring their mental health, they should work together with the MHCPs to explore their experiences of health and ill-health (9). In spite of much attention on patient

[1] Stavanger Community Mental Health Centre, Stavanger University Hospital, Stavanger, Norway
[2] Department of Research, Stavanger University Hospital, Stavanger, Norway
[3] Department of Health Studies, University of Stavanger, Stavanger, Norway
[4] Department of Nursing and Health Sciences, Faculty of Health and Social Sciences, Centre for Women's, Family and Child Health, University of South-Eastern, Kongsberg, Norway

Corresponding Author:
Lise Sæstad Beyene, Stavanger Community Mental Health Centre, Stavanger University Hospital, P.O. Box 8100, N-4068 Stavanger, Norway.
Email: lise.sestad.beyene@sus.no

Table 1. Description of the Participants.

Pseudonym	Age	Gender	Length of This Hospitalization	Number of Hospitalizations	Patient's Own Description of Hospitalization Cause
Anna	57	F	3 months	38	Emotional unstable personality disorder
Ben	33	M	4 months	3	Psychoses
Christian	59	M	2 months	10	Depression
Daniela	39	F	5 weeks	3	Depression
Eric	66	M	2 months	2	Depression
Febe	53	F	3 months	3	Obsessive-compulsive disorder
Gabriella	68	F	2 months	28	Depression
Harriet	37	F	1 month	2	Suicidal attempt and trauma
Ina	68	F	5 months	1	Anxiety and depression
John	63	M	5 days	30	Relief stay
Ken	30	M	3 months	15	Depression
Laura	48	F	4 months	2	Posttraumatic stress disorder
Mary	54	F	24 days	2	Suicidal
Ned	55	M	4 months	1	Depression
Oscar	48	M	6 weeks	1	Life crisis
Paula	77	F	2 months	2	Life crisis, panic attacks

participation, patients express a wish for more active participation and the tension between patients' and MHCPs' perspectives on care remains a challenge in mental health wards (2,10,11).

A strategy for patient participation is to implement shared decision-making (SDM), which considers both the patients and the MHCPs as experts who should share information, and to cooperate and agree on a choice of intervention (2,12,13). Shared decision-making focuses on the process of decisions, with the intention of increasing the patients' knowledge and control over decisions that affect their mental health (1). Shared decision-making highlights the balancing of power and responsibility, which is a dynamic process requiring a continuous assessment of the patient's resources, limitations, and necessity for assistance. Both the MHCPs and patients have power and responsibility for SDM which should be balanced in a way that secures the patients' best interests throughout the process of their mental care (14). Therefore, there is a need to consider the patients' ability to participate actively and to define their role in SDM (8). In order to achieve active patient participation, we should also consider how the patients can participate in SDM throughout the process of their care (7,8). The objective of this study was to describe patient participation in SDM in the context of indoor mental care. The research question was "What are patients' experiences of participating in SDM?"

Methods

Design

A qualitative inductive design was used in order to illuminate the patients' lived experiences (15).

Participants

The 16 participants had differing reasons for their hospitalization and various magnitudes of experience from different mental health institutions and differing lengths and numbers of hospital stays (Table 1). They were recruited from 3 different wards in a community mental health center in the western part of Norway. The MHCPs on the wards, who knew the patients well, were asked to recruit patients willing to participate. The inclusion criteria were experience of being an in-patient for at least one month, aged >20 years, and having the ability to speak Norwegian.

Data Collection

Individual interviews were conducted between March and August 2016 by the first author (L.S.B.), all at the community mental health center where the participants had their current connection. In order to achieve an in-depth understanding of patient participation in SDM, it was necessary that the participants shed light on various elements and aspects of their experiences (15,16). The participants were asked to share only the experiences that felt comfortable and right for them to share. A social interaction with a trusting communication between the interviewer and the participants was important in order to make them feel free to share their experiences for providing rich data (17). The flexible nature of the qualitative interview made it possible to follow up understandings, interpretations, and subjective experiences (18). The interviews took the form of a dialogue from open-ended questions about the participants' experiences of being involved in SDM during indoor mental care (15). They responded with their experiences of participation in SDM while being hospitalized in a mental health ward.

Table 2. Description of the Qualitative Content Analysis According to Graneheim and Lundman. (19, 20).

1 The audio-recorded data material was transcribed verbatim by the first author (L.S.B.), and the transcribed text was further repetitively read in order to grasp a sense of the whole.
2 The inductive analytic approach involved dividing the content into meaning units that were condensed and labeled with a code, which formed the basis of the categorization.
3 The codes were compared and sorted into subthemes, which all comprised a manifest content.
4 The subthemes were organized and abstracted into 2 themes by the first (L.S.B.) and last (K.R.) authors.
5 The 4 authors discussed the meaning of the 2 themes. Further analysis of the themes and subthemes were discovered and integrated in one main theme.
6 The data were compared across points in time and the themes and main theme validated through reflections and conversations by the 4 authors and qualitative research group.

Analysis

A qualitative content analysis (19,20) was performed to systematically unveil a deeper understanding in the collected data (Table 2). The authors' preunderstanding was related to their experience as researchers and clinical nurses. Three of the authors (L.S.B., K.R., and E.S.) are authorized mental health nurses and have several years of clinical experience from mental care.

Ethical Considerations

This study was carried out in accordance with the Declaration of Helsinki (21) and has been approved by the regional ethics committee of Western Norway (2015/1721). The invited patients were informed verbally and in writing about the study and a guarantee of anonymity and confidentiality was given. Confirmation of the fact that participation was voluntary and that the participants could withdraw at any time with no consequences for their further treatment at the hospital was provided prior to the start of the study. The patients who agreed to participate in this study were able to give their informed consent and signed the consent form. The participants are referred to by pseudonyms (21,22).

Results

One main theme was revealed: thriving in relation to participating actively in a complementary ensemble of care, which represented the red thread between 2 themes: having mental space to discover my way forward and being in a position to express my case. The first of the 2 themes was based on the 3 subthemes: learning from life experiences, feeling encouraged by supportive MHCPs, and making use of flexible frames. The second theme was based on the 3 subthemes: participating by using own current resources, feeling trustingly included, and sensing an empowering ward atmosphere (Table 3).

Thriving in Relation to Participating Actively in a Complementary Ensemble of Care

This main theme described patients' experiences of SDM relating to their care. The participants in this study described that they wanted all those involved in their care to work together in companionship, which was interpreted as the complementary ensemble of care. Patient participation in SDM was associated with feeling important and included, regardless of mental ill-health. The participants conveyed that the process of restoring their mental health depended on their possibility to participate and to what extent they were respected. Participating actively was considered to give them the motivation, willpower, and courage to move forward.

The participants highlighted that they felt safe when the MHCPs were companions and were complementary to their own participation in SDM. Their feeling of safety was described as necessary for thriving. It helped them try new interventions and work with themselves. In situations where the participants had reduced insight and rationality, they communicated that they felt safe knowing that the MHCPs would take care of them by safeguarding their values and treating them according to their best interests without feeling violated. When the participants were in better mental health, they wanted to participate by sharing their experiences, knowledge, and observations with the MHCPs in order to collaborate to find suitable solutions and to make appropriate decisions. They experienced that their contribution of participating actively was necessary for making a complementary ensemble of their care.

Some participants described the lack of opportunity to participate as being held back, controlled, and restricted, which resulted in feelings of irritation, humiliation, and violation. Not being allowed to participate was experienced as destructive. In contrast, the participants experienced thriving through positive development, growth, and restored mental health when they participated actively, which reflects a maturation in the process of care.

Having mental space to discover my way forward. This theme referred to the participants' wish to discover what worked or not in their process of restoring their mental health, the meaning of feeling encouraged by supportive MHCPs, and the use of flexible frames in this process.

Some participants highlighted the importance of *learning from life experiences* without the MHCPs controlling them in order to find something on which to build their own processes of restoring mental health. Several participants highlighted that they had experienced through their life what was necessary for restoring their mental health. They conveyed that support for practicing what they already knew was important, and if the MHCPs told them that they could not do it in that way without any further reflection, they found it destructive.

Table 3. Main Theme, Themes, Subthemes, and Condensed Meaning Units.

Main theme	Thriving in relation to participating actively in a complementary ensemble of care					
Theme	Having mental space to discover my way forward			Being in a position to express my case		
Subtheme	Learning from life experiences	Feeling encouraged by supportive mental health-care professionals	Making use of flexible frames	Participating by using own current resources	Feeling trustingly included	Sensing an empowering ward atmosphere
Condensed meaning unit	My self-esteem is very low and I'm very unsecure concerned how to live my life and how to take care of myself . . . I think I'm in the "trial and error-phase." I know that there should be a balance in life, but where is my balance? I'm struggling with that.	When I arrived I talked to T who told me about experiences with quitting addictive medicine and how well another person succeeded and that I could succeed as well. I didn't believe in it, but now I've managed to quit completely.	I asked for a talk at night and she refused me like I was a little kid by saying: "It's not allowed to talk at night. Take this magazine and go to your room!" I felt bad and dishonoured. I just needed to talk a little . . .	When I'm very ill I have to trust them. They always ask me and they give me advice. Then it's up to me if I want to listen to them or not. I am treated with respect.	He never gave me up. He included me and was always there for me. He did everything to help me (. . .) he listened to me and gave me advise.	They say I need to do it in that way but I don't know why . . . It's like kindergarten; I don't need to sleep but I must go to bed anyway . . . It makes me very annoyed, grudging and reluctant. I try to avoid having contact with them.

Feeling encouraged by supportive MHCPs was emphasized both for the participants trying to discover a new way forward and for the participants who already knew what was necessary for moving forward. The participants described that they felt encouraged when MHCPs were supportive by listening to them and reflecting together with them. They experienced the MHCPs having faith in and responding to their wishes, cooperating, and kindly pushing them as supportive. *Feeling encouraged by supportive MHCPs* was enhancing for *having mental space to discover the way forward*. Some participants described that the poorer they felt, the more they wanted their supporters to be engaged, closer, and more compassionate. In better phases, the participants still wanted their supporters, but less engaged and with greater distance.

Making use of flexible frames was described by the participants to be essential in order to achieve the *mental space to discover the way forward*. Some of them had experiences of being cared for by MHCPs saying "that's the way it is," which gave no space for finding a solution more suitable for them. The participants experienced that *making use of flexible frames* created more creativity, courage, and enthusiasm for care, which made them feel that their participation in decision-making was important.

Being in a position to express my case. This theme described the participants' experiences of wanting the opportunity to express what was important to them, their wishes, and how they found their situation in circumstances where decisions were to be taken. The participants required that the MHCPs listened to them and responded to what they expressed in order to influence the decision-making.

The participants conveyed that their capacity for participating in decision-making when being hospitalized varied according to their mental health. They wanted *to participate by using their own current resources*. Sometimes, when they were in poor mental health, they found it hard to know what was for their own best and to be responsible for their own decisions. They imparted that during such circumstances, they found it supportive when the MHCPs helped them by sharing experiences, giving advice, or conducting the decision-making. If the MHCPs deemed it necessary to take charge in a situation, the participants wanted to participate by getting information and being invited to a dialogue about their thoughts and opinions in order to feel present in their care.

The participants revealed that *feeling trustingly included* was important for participating actively. They desired to experience that the MHCPs listened to them, respected them, and that they were taken seriously. Some of the participants had experience of MHCPs who signalized that they already knew the situation from their own perceptions, which gave little or no opening for the patients' voice and patient participation became difficult. The participants wanted the MHCPs to be present and to take the initiative to include them in their care. They conveyed that they felt *trustingly included* when they experienced the MHCPs to be supportive with positive attitudes.

Some participants believed that an exchange of information, thoughts, and views were important to make them feel trustingly included and in a position to express their case.

They shared that when they were in poor health, it was easier to participate if the MHCPs informed them of what they thought was for the best, simultaneously asking them for feedback on the issues that had been raised.

Sensing an empowering ward atmosphere was highlighted as an important issue when *being in a position to express one's case*. Some participants had experienced that routines on the ward were a hindrance for them to participate in decision-making and it gave them a sense of powerlessness. They wanted a ward atmosphere which could serve them in achieving autonomy and value.

Discussion

This study aimed to describe patient participation in SDM in the context of indoor mental care. Patients' experiences of participating in SDM revealed the main theme *thriving in relation to participating actively in a complementary ensemble of care*. This represented the red thread between 2 themes: *having mental space to discover my way forward* and *being in a position to express my case.*

The first theme describes the importance of patients *having mental space to discover their way forward*. The MHCPs can give patients mental space by accepting unpredictability and letting them make decisions with uncertain outcomes as long as they are not put in danger. The patients might have wishes which do not seem to be for their best, but they want space to find their way (8). In line with this study, Barker and Buchanan-Barker (9) highlight that patients *learning from life experiences* without MHCPs controlling them is of great importance in their process of discovering their way forward. No one is fully able to understand the experiences of others. We can only know our own experiences and only by learning from life experiences can the patients become wiser about the events in life. By discovering what is suitable for themselves, the patients can develop confidence, independence, and become able to make decisions on their own and take responsibility (2,13), which is important for thriving in the process of restoring their mental health (9).

This study reveals the importance of *feeling encouraged by supportive MHCPs* to discover their way forward. Sufficient support is necessary for being able to work on restoring their mental health (9), but how much support and what kind of support the individual patient requires varies with their mental ill-health, which must be continually assessed (14). The supporters should focus on empowering the patients by exploring with them how they understand their problems and by helping them to recognize how to increase their control of their lives. The best supporters are those who let the patients "own" their experience without trying to control the situation completely. In this way, the supporters should guide the patients toward making appropriate choices by intervening, not interfering (9). Patients want to work in companionship with the MHCPs to explore together their experiences of health and ill-health. This is considered to empower the

patients in their process of restoring their mental health (9,10) and promoting thriving.

In order to have mental space to discover the way forward, it is necessary to *make use of flexible frames* which are designed on the basis of the patients' prerequisites. Routines of the ward are frames in which many patients feel safe and secure in times of mental ill-health. These frames may at the next turn serve as a hindrance in letting the patients learn from life experiences because they protect them too much from real life (9).

This study reveals the importance of patients *being in a position to express their case*. In mental care, it is the MHCPs' duty to determine whether the patients have insight or not. The assessment of patients' insight builds on the MHCPs' understanding of rationality, and if patients lack insight, their views are seen as invalid (7). As the patients do not always define and prioritize the dimensions of their care in the same way as MHCPs (23), the MHCPs may take a dominating position in order to practice their understanding of safe care (7). In order to participate in SDM, the patients must *be in a position to express their case* throughout their mental care. The onus should be on the patients, their experience of ill-health, and their appreciation of what they want in order to handle the current problems (9). Montori et al (24) claim that the MHCPs should empower their patients by informing about their own preferences and state the reason for these so that the patients can judge for themselves whether this view makes sense for them in this situation or not. The MHCPs should also listen to their patients' point of view. An equal dialogue between the patients and the MHCPs is of importance in order to put the patients in a position where they can participate actively (8).

This study finds that the patients must *feel trustingly included* by experiencing that the MHCPs are interested in them as people and available for them. Without feeling trustingly included, the patients will be on their own (3). The MHCPs should be close to their patients in order to get the companionship required for SDM when exchanging information, cooperating, and for finding the optimal choice together (9,12).

Sensing an empowering ward atmosphere is of great importance for the patients in order to be in a position to express their case. The MHCPs who are strongly committed to general guidelines seem to be less involved with the patients as individuals (23,25). This can form a ward atmosphere of powerlessness where the patients' *position to express their case* is reduced (14).

Limitations

The data in this study had high information richness which gave a deep insight into patients' experiences of participating in SDM (17). However, the results might have been different if we had selected participants who were discharged from hospital or who had a specific diagnosis.

One limitation may be with regard to the selection procedure of participants. Carlson et al (26) argue that trustworthiness regarding sampling procedures in qualitative studies involving persons with severe mental health issues needs to be thoroughly discussed as these procedures may influence the results. In our study, MHCPs selected the participants and thereby were given power to decide who should be given a voice and who should not (27). Such a procedure may be influenced by stigmas about mental illness as people with severe mental illness may be considered unable to participate in research studies. Therefore, we considered that the thorough ethical procedure, the description of recruitment procedures, and the fact that the data analysis was carried out by more than one author were important in order to attain trustworthiness in the reported findings of our study (26).

The findings are not to be generalized but hopefully the knowledge presented will be transferable to similar contexts (15). Further research might investigate how the patients' lack of opportunity to participate actively in their care can be improved.

Conclusion

Patients can participate actively in SDM when the patients' and the MHCPs' joint expertise is applied throughout their mental care. How the patients participate and how much support they desire vary according to their mental ill-health and should be continually assessed. The patients experience thriving when participating actively in a complementary ensemble of care in a ward which is conducive to allowing them the mental space to find their way forward and to be in a position to express their case in order to restore their mental health.

Authors' Note

The study was designed by L.S.B., K.R., and E.S. L.S.B. coordinated the research. The data were collected and transcribed by L.S.B. L.S.B. made the categorization in the analyses of the data, while L.S.B. and K.R. discussed the underlying meaning of the findings. The themes and main theme were validated through reflections and conversations by the 4 authors (L.S.B., K.R., E.S., and B.S.H.). The report was written by L.S.B. with supervision from K.R., E.S., and B.S.H. All authors provided feedback on the draft manuscript and approved the final version. They all adhered to the criteria pertaining to roles and responsibilities in the research process recommended by the ICMJE (http://www.icmje.org/recommendations).

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Author Biographies

Lise Beyene is a clinical nurse and PhD student at the Stavanger University Hospital. She is an expert on mental health nursing.

Elisabeth Severinsson is a professor at the University of South-Eastern Norway. She is an expert on mental health and clinical supervision.

Britt Sætre Hansen is a professor at the University of Stavanger. She is an expert on nursing and leadership.

Kristine Rørtveit is an associate professor at the University of Stavanger and is an expert on clinical mental health nursing.