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Abstract

This article aims to contribute to the understanding of shared decision making as an important aspect of user involvement in mental health care from the perspectives of service users. A thematic analysis of interviews with 25 individual service users in three different community mental health centers in Norway identified different understandings of shared decision making. Shared decision making was identified as essential in four contexts: 1) during admission, 2) in individualized treatment, 3) in different treatment contexts, and 4) in user-professional relationships. We consider shared decision making to be intertwined with treatment from the service user perspective.

This study focuses on service users' experiences being involved in decision making while admitted to community mental health centers (CMHCs) or during outpatient care organized by CMHCs. In Norway, a CMHC is an independent professional entity responsible for a significant proportion of the general psychiatric services within a defined geographic area. In recent years, the number of service users living in local communities has increased, and various forms of outpatient services have been developed in Norway. The aim of deinstitutionalization is to achieve an ideal represented by freedom and more active social involvement for service users by facilitating as much independence and self-reliance as possible (Lorem, 2006). The increase in multi-professional collaboration across services and stronger expectations of user involvement in mental health care increase the need for more knowledge about the practice of shared decision making from the service user perspective. We agree with Rise (2012), who noted that user involvement is founded on shared respect and carried out through dialogue aiming to achieve shared decision making. According to Gudde, Olsø, Antonsen, Rø, Eriksen & Vatne (2013), a deeper understanding of user experiences and preferences is important to optimize care. A precondition for user involvement is the acknowledgement of the service user's experiences and the user as an expert of his/her health, indicating a more equal status of the knowledge of users and professionals (Solbjør, Rise, Westerlund & Steinsbekk, 2011).

Decision making is one of several aspects of user involvement (Storm & Edwards, 2013). Many decisions must be made for both users and professionals about treatment and care during admission or in outpatient care. This study aims to contribute to the understanding of user involvement in mental health care. The article examines service users' experiences of being involved in shared decision making while being admitted to a CMHC or being in outpatient care organized by the CMHCs.

Shared decision making and patient rights in Norway

Shared decision making is related to service user consent. Health care can be given only with the service user's consent, unless there is a legal basis or other valid legal foundation to provide health care without consent (Norwegian Directorate of Health, 2015). The general rule on consent is associated with health legislation in Norway. A person is autonomous and has full determination rights with regard to his/her freedom, health and life. This is affirmed in international human rights and in the Norwegian Patient Rights Act (Norwegian Directorate of Health, 2015).

Decision-making competence may be considered absent only when the service user is obviously unable to understand what consent entails (Norwegian Ministry of Health and Care Services, 2011). This situation can arise for persons with physical or mental disorders, persons with dementia diseases and persons with intellectual disabilities. An assessment of decision-making competence is linked to an assessment of the person's ability to understand. Furthermore, it must be obvious that the person is unable to understand what the rationale for health care is and what consent entails. The service user should also have received sufficient information about his/her health condition, possible causes and prognosis, as well as the possible risks and side effects of health treatment (Norwegian Ministry of Health and Care Services, 2011). The information given must be used to establish a basis for discussion as required, and the service user's degree of understanding is also related to the dissemination of information. This should be adapted to the individual patient's circumstances and needs. In practice, this situation involves consideration of the background and circumstances of the service user and his/her illness, age, mental state, language, culture and experience. Furthermore, patient consent should not lapse longer than the extent necessary; failure to obtain consent in one area does not mean that consent is not required in other areas. In

Norway, it is the professional who decides whether the service user is competent to give consent (Norwegian Ministry of Health and Care Services, 2011).

The relation between user involvement and shared decision making

The degree of user involvement in mental health care ranges from mere information and consultation to real decision-making power (Tambuyzer, Pieters & Van Audenhove, 2011). However, many barriers related to inequality impede achieving high-quality care delivery, and the ways in which we organize mental health services can play a significant role in these barriers (Holum, 2012). In a study on user involvement in Norwegian mental health hospitals by Solbjør, Rise, Westerlund & Steinsbekk (2011), the service user and provider perspectives on user involvement during episodes of mental illness were investigated. The study concluded that in difficult phases of the illness, user involvement was redefined and weighed against what was perceived to be the user's best interest. In the study, both users and providers characterized user involvement as challenging when the users suffered from illness symptoms (Solbjør et al., 2011). The study raises an important question: how are users supposed to achieve real involvement if the professionals and even the users themselves see "psychiatric patients" as lacking insight during difficult phases of the illness? (Solbjør et al., 2011)

According to Thompson (2007), user involvement is co-determined by patients and professionals, and it occurs only through the reciprocal relationships of dialogue and shared decision making. Shared decision making is one of several care models that account for the service users' perspectives on their treatment and care. Shared decision making is focused on the process of treatment decisions (Storm & Edwards 2013). Shared decision making was initially suggested as an approach to medication management, but the model is also applicable to treatment in general. However, service users are frequently dissatisfied with the

level of shared decision making that occurs in mental health (Angell, Matthews, Stanhope & Rowe, 2015). A possible reason is that decisions related to mental health issues are often more complex and time consuming and involve more people than merely the doctor and service user (Beitinger, Kissling, & Hamann, 2014). Thus, several stakeholders are involved in shared decision making in mental health care. More research is needed to examine users' perspectives on factors that facilitate or hinder user involvement in treatment decisions in mental health care (Joseph-Williams, Elwyn & Edwards, 2014; McDaid &Delaney, 2011). We seek to contribute to this field of research on shared decision making in mental health care.

Methods
Personal stories as user involvement experiences

The stories that people tell about their lives represent a process of meaning making (Josselson, 2011). We consider people's stories about treatment in CMHCs and in outpatient care as valuable sources of insight about the practice of shared decision making. We follow Denzin (1989, p. 37) in his definition of a narrative: "a 'narrative' is a story that relates a sequence of events that are significant for the narrator and his or her audience. It has an internal logic that makes sense to the narrator." The stories presented in this article were constructed during interviews between the participants and the interviewer.

We present user perspectives rather than professional perspectives on this topic. We examine user involvement in terms of the opportunity to make decisions about treatment. Our research regards personal stories as topical life stories (Bertaux, 1981) because they concern a limited period in the participants' lives, namely, their stories about shared decision making while being admitted to a CMHC or being in outpatient care organized by CMHCs. Our theoretical position within narrative research is oriented toward personal stories as a social practice

(Mishler, 1999). We understand the interviews as active text—a place where meaning is co-created and performed (Denzin, 2001). A story can have different meanings in different settings. The social consequences of narratives must be understood in relation to what is at stake in the storytelling context (Gubrium, 2005). The storied events in this article relate to being admitted to a CMHC or being in outpatient care organized by CMHCs, and the article examines service users' experience or expectations of how to engage in shared decision making concerning their treatment.

Participants and recruitment

This study is based on a larger research project on insight and user involvement among 25 service users at three CMHCs in northern Norway. The 25 participants in the study (16 women and nine men) were between 18 and 87 years old. The participants were living in the two northernmost counties of Norway. The participants were recruited through a local research assistant at each CMHC. The focus on insight and user involvement in the study was reflected in the inclusion criteria: the service users should have had experienced considerable changes during their lives because of a mental illness, they had been acutely admitted to a psychiatric hospital, and they were able to provide informed consent. Information letters were distributed, and the individuals who were interested in participating in the study signed letters of consent. The participants were in different stages of treatment at the time of the interview: some had recently been admitted, and others were in outpatient care.

Interviews

Qualitative interviews aim to enable a profound understanding of the participants' opinions, beliefs, attitudes, experiences, and identities in a particular domain or domains as described by the participants (Kasper, 2015). Our study sought to understand the service users'

experiences on shared decision making. All interviews were conducted by the first author (X). Six of these 25 interviews were conducted in the participants' homes and had a different character from the interviews conducted at institutions. The interviews conducted at the CMHCs were characterized as more akin to a "therapeutic/treatment meeting" because most interviewees seemed to expect it to last 30-45 minutes (which these types of meetings often do), and it occurred at the treatment site. The interviews conducted in homes lasted longer. The duration of most interviews was 45–60 minutes, and they were digitally recorded.

The interviews began with the open question "Can you tell me what brought you to mental health services?" The open questions were designed to elicit a narrative account (Thornhill, Clare, & May, 2004), and the interviewees were invited to speak as freely as possible. The interviews varied in terms of how the participants told their stories. Some told their stories without interruptions, while others needed more assistance. Each new research interview represented new stories and a new storytelling (Authors, 2013). The interviews thematically navigated the participants' experiences of being involved or not involved in their treatment. The transcripts were translated from Norwegian to English, keeping the language as close to verbatim as possible. The excerpts presented in this article have been transformed into coherent narratives based on the interviews, a process that involves the construction of a comprehensive, condensed narration. Comments or questions from the interviewer have been omitted to maintain the coherence of the stories.

Ethics

The study was approved by the Regional Committee for Medical Research Ethics (reference no.2011/775). Participants were limited to persons capable of giving informed consent. Before each interview, the interviewer, in dialogue with the service user, ensured that the parameters of informed consent were clear. The service users could bring a companion if they

wished, and some service users brought their contact person from the center. The interviews followed a thematic guide based on feedback from a pilot interview with a service user from a mental health user organization.

At several stages in this project, we facilitated service user involvement. We cooperated with The Norwegian Center of Mental Health Service User Competence (see www.erfaringskompetanse.no). We have presented our research project to service user organizations and environments. We consider the personal stories of service users to be an important contribution that offers a broader picture of the complexity underlying user involvement within mental health services. Using personal stories as a point of departure, we hope to elucidate how the multi-storied experiences of service users can contribute to the experience-oriented knowledge necessary to ensure user involvement.

Thematic analysis

In this work, analysis is not understood as a linear process but is instead present during all stages of the project (Kvale, 1996). Analysis is a recursive process (Braun & Clarke, 2006). Thematic analysis can be used within a broad theoretical framework, and one of its benefits is flexibility (Braun & Clarke, 2006). Following Riessmann (2008), we performed an experience-oriented thematic analysis that allowed the data drive the analysis rather than attempting to fit the data into a preexisting coding frame or analytical preconceptions (Authors, 2015). We focused on the content of the stories (Riessman, 2008). The thematic analysis demonstrated the participants' complex experiences of being service users and their opportunities to engage in decision making concerning their own treatment. In the participants' stories, we were seeking relevant perspectives connected to the practice of shared decision making as aspects of user involvement. We worked with one interview at a time, isolating and ordering the relevant user involvement experiences into different contexts

(Riessmann, 2008). After performing this procedure with all 25 interviews, we sharpened the focus and identified shared decision making as essential in four contexts. Excerpts from nine interviews are included in the following section to illustrate the range and variation of experiences related to shared decision making and the complexity of practicing shared decision making in mental health services.

Results

Through the thematic analysis, we gained a better understanding of shared decision making as an ongoing and joint project between service users and professionals. It is important to develop mental health services that support community integration, involvement, and social inclusion for all persons diagnosed with mental illness (Elstad & Hellzén, 2010). However, this objective is not easy to achieve in practice. Hence, it is important to investigate those factors that service users identify as important and central when they are admitted to CMHCs or are in outpatient care organized by CMHCs. Participating in treatment decisions is a vital part of user involvement. From the service user perspective, shared decision making is intertwined with treatment and addresses *all aspects* of admission or outpatient care. We identified shared decision making as essential in four contexts: 1) during admission, 2) in individualized treatment, 3) in different treatment contexts, and 4) in user-professional relationships.

1: Shared decision making during admission

In the interviews, the participants described their first meeting with mental health services. Service users have different needs and pathways (Norwegian Ministry of Health and Care Services, 2006). For some participants, the need for mental health services emerged from an acute crisis, while for others, admission was the result of long-term thinking and planning.

However, all participants considered their need for mental health services to be caused by difficult life events. The admission was the point at which the participants transitioned from being a member of the local community to also becoming a service user within the mental health care setting.

Helene, a woman in her 50s receiving outpatient care, told about her expectations related to shared decision making during admission. At first, she felt neglected by the professionals, but this perception changed during her stay:

> I felt I had to nag to get…. [silent] … No, it is not supposed to be like that, that you feel you have to walk around and nag to get people to…[silent] But it became better. […] You ought to think about openness and honesty when working in mental health service. They decided the treatment […], and the user; it was like you could say your opinion, and you sort of…I felt, I felt it was a good treatment. I was a part of making the decisions. I LIKED THAT A LOT [silent]. No, it is very important that you are both…both seen and heard. In mental health services. That's my opinion.

Helene felt seen and heard by the professionals during her admission. Shared decision making is usually very complicated in everyday life in mental health services, both for professionals and users. Our participants emphasized the importance of the first meeting with the professionals and whether they felt that the professionals understood the difficulties they were experiencing. The service users' first admissions and their first encounters with professionals were essential in determining their experiences of being involved in shared decision making.

Marianne was in her 30s. She described her first meeting with mental health services:

> I had a breakdown; you are supposed to take care of yourself. Until one day it went no further. So I tried to kill myself. And I was in [the psychiatric hospital], and then I was admitted to day treatment at the [local] CMHC. And it ... after I was admitted, I have ... yes. Had contact with the municipal mental health services and with the [local] CMHC…yes. It is 3 years ago. My doctor wanted me to go to [the psychiatric hospital], but I was not at first admitted to the psychiatric hospital. It was in relation to the pills I had taken, so ...But I was admitted to the CMHC; it was my doctor. But there ... I accepted it right away, then. And wanted it myself. I had a need for help.... I do not know; it was a relief to those around me. I finally realized … (whispers) I needed help. Yes. It's the best thing that could happen to me (laughs). Being hospitalized there.

The first meeting with the professionals at the CMHC established the trust that Marianne felt was necessary to start the treatment process. She could participate in decisions concerning her treatment immediately through her acceptance of and willingness to receive treatment.

Aino, a woman in her early 80s, related a quite different story about her first admission. Her first encounter with mental health care services many years ago had deeply affected her.

> The first time I went to the doctor. Meds. I got some meds; I don't remember which ones. I was working in housing for elder people (coughs). I went to the doctor with one of my sisters (her voice is shivering). It was a male doctor. Yes, and when he heard, how, how, how I was – he pointed one of his fingers at my head, like this [shows with a finger on the interviewer's head]. That was my first time asking for help. FIRST time getting help. He knows himself what he did, what he meant (her voice is shivering). There was not much consolation in his behavior. On my head. On my forehead.

Aino felt violated and misunderstood by the doctor who examined her the first time. She could not participate in decisions concerning her treatment at the point of admission. Her story shows how the first meeting with the doctor served to silence her rather than to invite her to become involved as a service user. The difference between these two stories reveals some of the complexity regarding shared decision making that can arise during a patient's first admission. While Marianne accepted her diagnosis immediately, Aino's story tells us

nothing about diagnosis. She felt misunderstood and mistreated. The difference between the two women's stories can also relate to what kind of information they were given at the point of admission. While Marianne accepted her need for help immediately, Aino watched a finger being pointing at her head. Aino's story does not indicate whether she received any relevant information from the doctor whom she met about her mental health problems or why she was admitted. These excerpts demonstrate the significance of the first meeting between the service user and professionals at the mental health hospital or the CMHC. The first meeting lays the groundwork for user involvement.

Being admitted and receiving a mental health diagnosis is a significant turning point in an individual's life. Turning points are episodes in which one gains a new understanding of oneself or faces a decision about different life paths (McLean & Pratt, 2006). Life takes a different turn, and one must determine how to participate in treatment and decisions concerning treatment. To facilitate user involvement from the moment of admission to mental health care, social contexts in meetings between new service users and professionals must be created to allow space for different kinds of shared decision making.

2: Shared decision making in individualized treatment

The second context in our study relates to those participant stories that underlined how shared decision making derives from the needs and wishes of the individual. Some time often passed before the participants felt able to be involved in decisions concerning treatment. Typically, they felt that they were in need of help and care at the point of admission and were less interested in greater involvement because it felt exhausting. Sometimes, participating in an early stage of admission or in outpatient care meant allowing the professionals to take responsibility for treatment.

Ellinor, a woman in her early 50s, had chosen admission to the CMHC rather than hospitalization. She stated that the environment at the CMHC was better. Below, she explains how she felt at the CMHC:

> I feel safe and…not least because I have been a couple of times in the psychiatric hospital or immediately after the electroconvulsive therapy…and it seemed I was…I was in the emergency department for 9 days before I came here. And it was seriously tiring. Of course, it was very hectic [at the psychiatric hospital], and we were all different people and different illnesses, so when I put the bag outside the door, inside the door here [at the CMHC], I said, "Listen. Listen to the silence." There ... no, I must say that I (takes a deep breath) ... I was in a conversation ... yesterday. No, the other day and started to sort my problems, you know, and when I said, simply, "I cannot talk about it today."

Ellinor was involved in decisions regarding her own treatment through her decision not to talk on that particular day. This choice can be seen as an active decision to choose not to talk to professionals about her problems. This silence differs considerably from the silence in Aino's admission story in which she was silenced by the doctor's gesture. The participants in our study considered letting the professionals make decisions to be an integral part of their treatment. This was not expressed in their stories as *not* participating in their own treatment. To make decisions should thus be regarded as a relational phenomenon that develops between the individual user and his/her environment. This environment includes the actions and attitudes of those with whom the user relates (McDaid & Delaney, 2011).

Inger is a woman in her mid-50s who should have been discharged already. However, as a consequence of her decision to reduce her medication, her condition worsened.

> It's hard to say, the disease I have, there is a risk that one gets worse and worse every time you get sick, so right now I'm in a very bad period where I don't quite see how I...how to get

out of the situation here [at the CMHC]. So...so .... so, I – earlier it has sort of been more like a manic period, and then I got medication for it, and so I might have been a little edgy, but I've gotten a job and stuff. But this time I have – I have been manic, and so I was a little better, and then I've got like a relapse, so right now everything appears to be difficult, and it somehow... this is the worst – the worst period I have had, ever. I have been able to decide that I should cut down on drugs and stuff. But it has made...ehm. The way it looks now is that I am now in worse shape. So it's not always that this user involvement is THAT good.

Shared decision making is complex and involves more than deciding between different treatment options (Rise, 2012). These excerpts show some of the challenges in mental health concerning the individualized practice of shared decision making in mental health care. Each individual service user in our study experienced his/her illness differently and expressed different needs in terms of care. In difficult phases with strong symptoms, safe and predictable care is important. In phases with fewer symptoms, increased empowerment and responsibility can be in focus (Rise, Westerlund, Bjørgen & Steinsbekk, 2014). Many decisions must be made. Some decisions, such as Ellinor's, are of a short-term nature, while other decisions, such as Inger's, have more long-term consequences. The decision not to talk about one's problems or to reduce medication may have negative consequences for the mental health of service users in the immediate situation or in the long term, but these consequences may be difficult to foresee for both the users and professionals in the process of treatment. Ellinor's and Inger's stories make visible the need for professionals to make different kinds of user involvement available in different ways. Moreover, to facilitate service users' involvement in treatment decisions, professionals should address possible risks and side effects in ways that consider the service users' individual needs and situation (Norwegian Directorate of Health, 2015). Shared decision making must be individually adapted in mental health services and must consider that individuals are also socially

embedded in and formed by the context of their social relationships (Walter and Ross 2013). The stories of the participants in our study indicate that services must be individually adapted.

3: Shared decision making in different treatment contexts

Many of the participants in our study had planned admissions or outpatient care from their local CMHC. Several received mental health services from both their community and the local CMHC, enabling them to stay home for longer periods. Service users often commute back and forth between the hospital and their home. This necessitates new perspectives on user involvement and decisions concerning treatment. As service users navigate the services available during their mental healthcare treatment, continuity is a key component of the delivery of mental health care (Newman, O'Reilly, Lee & Kennedy, 2015).

Tom was a man in his mid-40s living in a small town. He spoke of his mental distress, and he felt that he had been treated like a "laboratory animal during his career as a mental health patient." Nevertheless, he preferred to be admitted to the CMHC. Tom became worried every time he was at home in outpatient care because he struggled with violent behavior. He would take drugs, drink, and become aggressive:

> It's sort of no SUPPORT when you come out. Among other things, when you come home and stuff, there's no support there or anything else. There is certainly nothing. That's because of all the cutbacks and the reduction of mental health services. I regret it myself [what I do when I am not admitted]; I am like a ticking time bomb. That's why I'm here.

Mental health services have changed, and decisions in this new contexts involve multiple treatment options for users. Users consider their entire life situation not through a clinical

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lens or from a medical perspective (Author, 2015). Treatment decisions for Tom are made in relation to his life as a community member, not as a "psychiatric patient." When he is in outpatient care, he seeks further help to reduce his drug-related behavior. Tom's story makes relevant the limitations related to treatment in outpatient care. User involvement in terms of making decisions about where to receive the preferred care and support is circumscribed by cutbacks and resource constraints and is thus outside of service users' control.

Ellen was a woman in her late 40s, and she had been diagnosed as bipolar. Her experiences as a community member revolved around the shame attached to her manic episodes between admissions. "Nevertheless, it is all about getting out of the CMHC," she said.

> If I only could have been admitted in X [a neighboring small town], I think that would have been PERFECT, not in my hometown. Yes. Because when you get back to yourself, you REGRET stuff. But they have been good at shielding me. We [Ellen and the mental health professionals] went for walks outside the city center, I went swimming with a woman working here, and I got to do that sort of thing…but everybody…it is a SMALL place here. Or small, it's not that small, but everybody knows the people working here…and then they know I am admitted. And I think that's TERRIBLE.

Ellen did not want her community to know about her admissions, and she found it difficult to participate in activities outside the center. If she could have chosen, she would have been admitted to another CMHC. Her story show that decisions about where to receive treatment can mean a great deal to service users struggling to manage their identities as community members and as receivers of mental health care. It also shows that professionals can be sensitive to such struggles and can adapt treatment activities to meet service users' need to keep these identities separate.

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These excerpts give us an impression of the complex oscillation between being a service user/being an inpatient/being admitted and being a service user/being an outpatient/being at home. The participants in our study were community members who were occasionally in need of mental health care. They expressed an ongoing need for continuity in care and for opportunities to separate their identities as community members and receivers of mental health care. This relates to service users' opportunities to make decisions about where to receive mental health care. Many service users feel stigma about their diagnosis, with consequences for both self- esteem and public esteem (Thesen, 2001). When involved in decisions regarding their own treatment, they obviously wanted to make choices that could *reduce* stigmatization. The service users in our study had an urgent need to avoid being perceived as "crazy" by people in their local communities. They wanted everything to be as normal as possible. Being more involved in treatment decisions while in outpatient services can be a way of normalizing everyday life.

4: Shared decision making in user-professional relationships

All of the service users in our study spoke extensively about their relations with the professionals. Relationships between service users and professionals are a key aspect of user involvement in shared decision making.

Lars, a man in his late 40s diagnosed with schizophrenia many years ago, spoke of the challenges that the professionals confronted when he was admitted last summer.

> But then I have been wobbly and unsure of what I wanted, so it has been difficult to ... I'd had an offer of aftercare housing last summer, but then I was not so ready to quit drinking, so – first I said yes, then I changed and said no, and so it was. So, you know, I've wobbled very much, even with what I wanted and what I did not. It has not been easy for them [the

professionals at the CMHC], and that's why I have been admitted for such a long time this time.

The service user-provider relationship in mental health care is longitudinal and dynamic (Eliacin, Salyers, Kukla & Matthias, 2015). These relationships and situational contexts of care play a crucial role in service users' involvement in treatment (Eliacin et al., 2015). Lars' story about his indecisiveness regarding where to receive care shows that user involvement can manifest in an unwillingness to make definite decisions about treatment and in professionals' practice of allowing for insecurity and changed decisions.

A second excerpt is from Stein, who recounted his experience during the first months of admission. At the time of the interview, Stein was a man in his 40s.

> I don't remember; I guess I was there [at the psychiatric hospital] in (clears his throat) 3 months, if I don't remember it wrongly. And, you know, you are so depressed then, that when it comes to user involvement and these things, you are not capable of…so, in a way, you know, the professionals have to take care of that in a way.

Stein's description of his first months being admitted to a psychiatric hospital makes relevant the choice to allow providers to make decisions about one's treatment. If professionals attempt to force service users to make decisions about treatment in situations such as that described by Stein, the whole idea of user involvement is undermined. Lars' and Stein's stories demonstrated that being indecisive about treatment or incapable of being involved at all necessitates flexible relationships between service users and professionals. Professionals who are patient and sensitive to changing situations in treatment may facilitate user involvement in situations of uncertainty, even if it involves a silent decision not to become actively involved at all.

Discussion: User involvement as shared decision making

This article aims to contribute to the understanding of shared decision making as an important aspect of user involvement in mental health care from the service user perspective. The participants told personal stories that related to shared decision-making processes in their everyday experiences receiving mental health services. Our study demonstrates the complexities of shared decision making in various contexts and phases of mental health treatment. We agree with Rise (2012), who noted that the aim of user involvement is to achieve shared decision making between users and providers of mental health care. Our results show that although this is a desirable goal, shared decision making must be understood in relation to different situations and social contexts. From the participants' perspective, shared decision making concerns *all parts* of admission or outpatient services; it cannot be separated as concerning only certain parts or phases of treatment. Shared decision making cannot be reduced to decisions regarding medication or participation in activities during admission. Neither can shared decision making be understood as a user's ability to act in accordance with advice from health professionals (McDaid & Delaney 2011). User involvement is facilitated in processes of shared decision making between service users, providers, other service users and significant others during admission and during outpatient care.

The capacity to make decisions has traditionally been understood as arising from the status of the individual. The psychiatric diagnosis has been a determinant of whether service users can participate in decisions concerning their own treatment (McDaid & Delaney, 2011). In a study by McDaid & Delaney (2011) based on interviews with eight persons with experiences with mental health treatment, they found that the participants described how their capacity to participate in decisions was reduced by a set of social and environmental factors. These

factors were a lack of treatment options, lack of trust in the professionals providing information, provision of information in a language they could not understand, side effects of medication, a lack of empathy from professionals, a lack of time to process information and decision making, which were also affected by the service user's social relationships and their environment (McDaid & Delaney, 2011). Moreover, as shown by the contexts presented, the stories from our participants illustrate how shared decision making in treatment is facilitated by the help and support of professionals who are sensitive to the needs and wants of individual users.

Users and professionals often regard shared decision making as professionals' responsibility to consider users' best interest during difficult phases of the illness (Solbjør et al., 2011). However, in a relational approach to shared decision making, it is important to underline shared decision making as involving *at least* two persons, both the user and the provider.

The participants in our study underlined the importance of shared decision making being relational when they sometimes delegated such decisions to professionals. This relational perspective is not in line with the Patient Rights Act (Norwegian Directorate of Health, 2015), where it is the professional who decides whether the service user is competent to participate in decisions concerning treatment. When practicing shared decision making in mental health care, professional providers of care and treatment should embrace a flexible approach in defining user involvement. According to Bee, Brooks, Fraser, & Lovell (2015), professionals use their relational skills as a core facilitator of involvement. Creating better relations between users and professionals can be a step toward developing mental health services that support community integration, involvement, and social inclusion for persons with mental health problems (Elstad & Hellzén, 2010). A study on carers' experience with mental health crises by Klevan, Davidson, Ruud and Karlsson (2016) demonstrated that

carers draw on their experiences to understand and relate to current incidents regarding both their own perspective and the perspective of the person they care for. Making shared decisions involves nonpaternalistic communication between healthcare providers and service users (Beitinger et al., 2014) in which different stakeholders have the right to be heard and to make decisions.

The participants in our study also underlined the importance of continuity of care during admission or outpatient care. While moving between services, service users must crucially to be able to negotiate shared decision making regarding care and treatment with professionals and significant others. Individually tailored high-quality services require a high degree of flexibility (Rise et al., 2014). This underlines shared decision making as an ongoing social process throughout treatment, not simply involving medication or coercion. The Norwegian Patient Rights Act emphasizes that decision making competence can be considered absent only when the service user lacks insight (Norwegian Directorate of Health, 2015). This relates to the question asked by Solbjør et al. (2013) concerning how users are supposed to achieve real involvement if they are defined as lacking insight. When decision making is practiced in terms of being relational and shared, we move the focus from "insight" as a static characteristic of the service user assessed by an expert to something that is accomplished through dialogue between parties that both have the service user's best interests in mind.

The personal stories of our participants convey a substantial degree of complexity regarding users' involvement in care and treatment as well as a need for flexibility within both inpatient and outpatient services from the CMHC. A main finding in our study was the users' descriptions of dynamic movement between shared decision making in relation to social and situational contexts in everyday life. Our study demonstrates that being involved in one's

own treatment means that one might occasionally make bad decisions. This reveals a measure of unpredictability in mental health care that may be difficult to accept for professionals who strive to provide care through controlled routines in predictable contexts. As long as these choices do not carry serious risks or danger, the providers should tolerate the possibility that the service user might have wishes other than what might seem to be in his/her best interests.

Methodological reflections

This study could be limited by the decision not to invite the interviewees to read the final transcript or to offer their opinions on the written text of the interview (through, for example, a second interview, a focus group or another method). Ideally, it is best to validate stories through all stages of analysis, but in this case, our study includes participants who are in a difficult life situation. If we, as researchers, expect too much of our participants, the threshold could become too high to participate for some, creating a dilemma. We chose to conduct one interview with each participant in our study: we believe that this made it easier to participate and allowed us to include the contributions of a wider range of service users.

Closing remarks

By using a thematic analysis, we found four shared decision-making contexts in the participants' stories. We interpret shared decision making as being intertwined with treatment from the service users' perspective. Our findings are not only relevant to mental health services but also transferable to other disciplines where user involvement is a central topic. For the service user, being involved and participating in decisions is intertwined with the entire treatment process. If stakeholders ignore this fact, the risk of violations and poor treatment increases. All stakeholders have a responsibility for shared decision making, even during difficult phases of illness. Further research addressing shared decision making from the user's perspective is needed, not only within the mental health field but also within other

disciplines. Through the implementation of shared decision making as social and dynamic processes that are individually adapted, intertwined with treatment and understood as a way of normalizing individuals' everyday lives, our participants' perspectives can have a real influence on the services provided.

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