How patient participation is constructed in mental healthcare

A grounded theory study

Jørgensen, Kim; Rendtorff, Jacob Dahl; Holen, Mari

How patient participation is constructed in mental health care: a grounded theory study

Kim Jørgensen RN, MNSc (PhD Student, Senior Lecturer)[1] (iD), **Jacob Dahl Rendtorff** PhD, Diplom Pol (Senior Associate Professor)[2] and **Mari Holen** RN, MNSc, PhD Health[3]

[1]Department of Nursing, University College Copenhagen, Hillerod, Denmark, [2]Department of Social Sciences and Business, Roskilde University, Roskilde, Denmark and [3]Department of People and Technology, Research Centre in Health Promotion, Roskilde University, Roskilde, Denmark

Scand J Caring Sci; 2018

How patient participation is constructed in mental health care: a grounded theory study

Aim: The aim of the study was to explore how patient participation is constructed in social interaction processes between nurses, other health professionals and service users, and which structures provide a framework for the participation of service users in a psychiatric context?

Methodological design: Ten tape-recorded interviews of nurses and observations of interactions between nurses, other health professionals and service users reflected differing constructed views of patient participation. Charmaz's interpretation of the grounded theory method was used, and the data were analysed using constant comparative analysis.

Ethical issues and approval: The study was designed in accordance with the ethical principles of the Helsinki Declaration (1) and Danish law (2). Each study participant in the two psychiatric departments gave informed consent after verbal and written information.

Findings: The articulation of patient participation emphasises the challenge between, on the one side, orientations of ethical care, and, on the other, paternalism and biomedicine. The core category was generated from four inter-related categories: (i) taking care of the individual needs; (ii) the service user as expert; and (iii) biomedicine, and (iv) paternalism, and their 13 subcategories.

Conclusions: This study illuminates the meaning of patient participation in a psychiatric context based on social interaction between nurses, other health professionals and service users. This can contribute to dealing with the challenges of incorporating patient participation as an ideology in all service users in a psychiatric context and is therefore important knowledge for health professionals.

Keywords: patient participation, mental health, psychosocial nursing, holistic care, communication, compliance.

Submitted 17 February 2018, Accepted 20 March 2018

Introduction

In recent decades, the participation of service users (patient participation) has been a milestone in the health sector (3–6). The Health Act requires patient participation, and the demand is followed by recent policy strategies and objectives in the recognition that patient participation is not adequately implemented in Danish psychiatry (3). The introduction of patient participation has given service users a new identity as active and decision-making participants in the treatment process (6–8). The ideal service users are considered to be responsible, strong, able to act, controlled, and acknowledge and accept responsibility for playing an important role in managing their health problems (8–10). Expectations for the patient's active role are also written into the health policy strategies: 'The citizens must actively participate and play the leading part in their course of the disease' (11:11). The professionals are expected to promote patient participation in order to enhance the patient's self-responsibility, ownership and self-management of his or her symptoms, and the patients are expected to actively comply through rational choices, regardless of their mental diagnosis and symptoms (3).

In the literature, it is not clear what is meant by 'patient participation', and several discourses on patient participation exist simultaneously (6, 12). Terms including 'patient participation', 'mental health consumer',

Correspondence to:
Kim Joergensen, The Department of Nursing, University College Copenhagen, Carlsbergvej 14, 3400 Hillerod, Denmark. E-mail: Jorgensen.k@outlook.dk

'partnership', 'collaboration', 'user involvement', 'recovery', 'compliance', 'mental health services', 'person-centred care' and 'shared decision-making' are used, in combination with terms such as 'patients', 'citizens', 'clients' and 'service users' (13–19).

However, if we look at the concepts of recovery or compliance, they can be perceived as a continuum between two competing recognition directions, as the success of personal recovery is based on the service user's subjective perception of his or her problems (20, 21), while the success of compliance is based on an objective medical perception of whether the prescribed treatment is followed (22). Both poles coexist as extremes of the continuum and the contradiction between them entails a dynamic tension.

The concept lacks clarity, and affiliations to a theoretical framework have led to poor understanding and communication among researchers, health practitioners and policymakers, along with problems in measurement and comparison between studies across different hospitals (5, 23–25).

However, we do not yet know much about the consequences of patient participation and what it means to nurses and service users in a mental health context. The Danish Health Policy uses a rhetoric in which the service user is to be activated and take responsibility for his or her health and treatment (11, 26, 27), but how does patient participation develop in social interaction processes where the health professionals are taking care of the service users' lives?

Our efforts to construct the concept of patient participation as a concept and how it is underpinned by institutional power and communication structures can help illuminate some of the potential challenges associated with the concept in a psychiatric context (28). Moreover, identifying the meanings of the term 'patient participation' can highlight some of the challenges that may be associated with implementing it in a psychiatric context, which legitimises the relevance of this study.

In this study, a psychiatric context and a nursing perspective on patient participation are taken, in the recognition that this is partly due to the realisation that people with mental illnesses constitute a marginalised and neglected group in healthcare policy, management and society (29, 30). The reason for choosing nurses is that nurses are employed to follow the service users' course from start to end. This provides a good basis for insight into whether patient participation varies over time as a category. There is seemingly very little research showing how nurses construct patient participation as a concept within a psychiatric context (28), and, for this reason, this study will contribute to knowledge about patient participation from the nurses' perspective and highlights the challenges in achieving the service users' expectations during the course of treatment.

The study

Aim

How is patient participation constructed in social interaction processes between nurses, other health professionals and service users, and which structures provide a framework for participation in a psychiatric context?

Design

Charmaz's social constructivist interpretation of grounded theory was selected (31–33) as an approach to the interactive nature of gathering data and analysing and evolving theories (Fig. 1). Grounded theory originates from sociology and symbolic interactionism, whereby meaning is negotiated and understood through interactions with others in social processes (34, 35). Symbolic interactionism is a constructionist perspective and builds on three relatively simple assumptions: (i) people strive and act towards what represents meaning for them, (ii) meaning arises out of social interaction and (iii) meaning is being dealt with and modified through interpretive processes. This constructivist approach places priority on the phenomena of study and understands both data and analysis as being created from shared experiences and relationships with participants and others (36, 37). From a constructivist perspective, we use the grounded theory method to pursue varied emergent analytic goals and foci instead of pursuing *a priori* goals and foci such as a single basic social process. We assume that both data and analyses are social constructions that reflect what their production entails. These social processes are subject to structures and procedures that affect how interactions unfold and are shaped in different contexts. The purpose of grounded theory is to explore the social processes (causes, contexts, contingencies, consequences, covariances and conditions) and the creation of this knowledge of social realities is achieved through careful observation of behaviour and speech practices in order to understand patterns and relationships between these elements in a psychiatric context (31, 33, 38, 39).

Researchers have suggested a grounded theory approach with interviews and observations to obtain descriptions of experiences or the meaning of a phenomenon (31, 40), which is used in this study.

Grounded theory is a situation-specific approach that deals with a smaller part of a given specific area. Unlike, for example, hermeneutic and phenomenological analyses, data collection, data analysis and the inclusion of participants take place simultaneously. It is through the identification of the basic processes systematically related to categories and properties through theoretical sampling and a constant comparative method on which the theory is based.
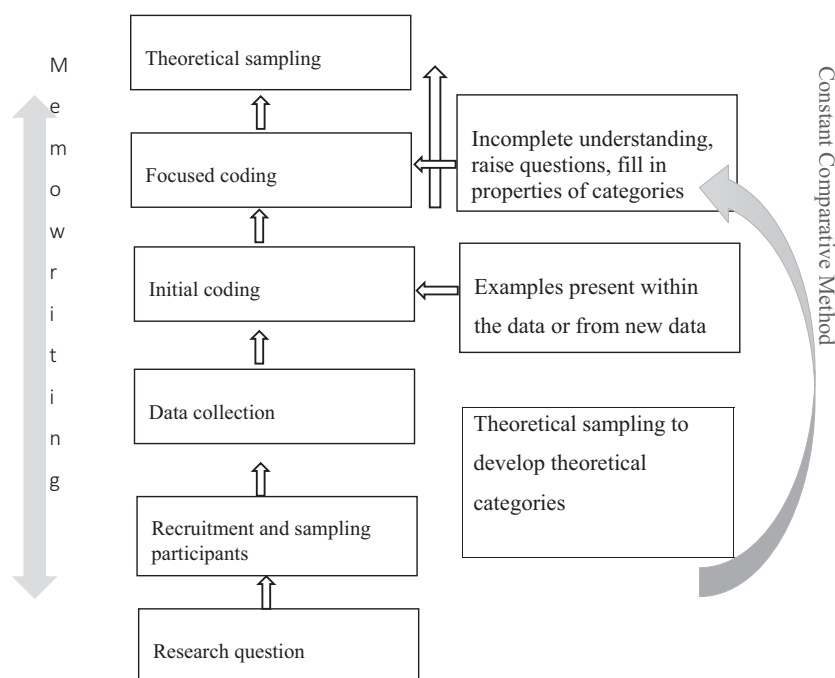
Figure 1 Visual representation of grounded theory.

Data collection

The informants were recruited from an open psychiatric ward and outpatient clinic in a mental health hospital in Copenhagen. The main group of service users had different psychiatric disorders, including schizophrenia, affective disorders, personality disorders, abuse-related trauma and anxiety. The hospital is subject to regional goals, including it transpired, that treatment should be based on a recovery-oriented framework where service users are involved throughout the course of treatment (41).

Participants

Participants (Table 1) included nurses between the ages of 29 and 52 who were interviewed and observed interacting with other health professionals and service users in an open ward and ambulatory. The other health professionals were physicians, psychologists, social workers, social and health assistants and physiotherapists.

Interview

Interview data were collected to situate participants' meanings and actions within larger social structures and discourses of which they may be unaware. The intention was to uncover the assumptions on which participants construct their meanings and actions.

The interviews were semi-structured in nature and were conducted by the first author after having

Table 1 Participating nurses

	Age	Employment	Experience (years)
1 Sylvia	37	Open wards	12
2 Maria (middle manager)	29	Open wards	2
3 Mille	48	Open wards	18
4 Marianne	35	Open wards	9
5 Jette (ward manager)	38	Open wards	11
6 Katja	43	Ambulatory	17
7 Birgit (middle manager)	35	Ambulatory	5
8 Kirsten	42	Ambulatory	15
9 Henny	32	Ambulatory	7
10 Connie	52	Ambulatory	22

received training and instruction in the use of open-ended questions and in probing responses. Each interview lasted from 45 to 75 minutes. An interview guide was created, and the interviews were conducted in accordance with Charmaz's approach to commencing the work (31). The interview guide (Table 2) was discussed with the research team as well as service users in a mental healthcare setting, alongside existing interview guides, and was tested in a pilot study (31). The pilot study gave rise to formulating more specific individual questions.

The interview guide focused on the research question, and I used active listening to encourage the participants to expand upon specific experiences, ideas and incidents that highlighted their experiences (42). All interviews were tape-recorded and transcribed verbatim.

Table 2 Interview guide

What do you think of when I say patient participation?
(Detailed description: What is patient participation? How do you understand it?)
When you say xx, what do you mean by that?
Can you give a concrete example of that?
How do you see patient participation in your daily work?
Is there anything else you would like to add or supplement your comments with?
Can you come up with some (more) examples from your daily life where you have experienced patient participation?
Can there be challenges involving service users? (Elaborate on the answer: where, when, why)
How do you find out what the service user has in terms of needs and preferences?
What are the success criteria for patient participation?
Can you devise a status report on how your department is doing in relation to the involvement of service user? (For example, physical environment, intersectional collaboration, procedures/guidelines, time, knowledge of methods/tools, etc.)
Do you find that the management at your department sets out objectives for the participation of service users? (Elaborate on the answer: where, when, why, agree/disagree)
Any other comments or remarks? Anything you think is missing, something you want to elaborate upon?

Table 3 Observations guide

The following open questions served as a means of sharpening my observational focus:
Do the service users participate at interdisciplinary conferences and ward rounds?
Who sets the agenda at interdisciplinary conferences and ward rounds?
How do the nurses talk about the service users and which words do they use regarding the service users' perspectives on interdisciplinary conferences, ward rounds and report situations?
Do the nurses involve the social, psychological and existential aspects of the conversation with the service users? If yes, how?
How do they involve the service users' perspectives in the service users' treatment and formulation of goals?
Do nurses discuss whether service users expect to be involved in treatment?
Do the nurses invite the service users to share their thoughts, hopes and goals for the future?
How is the service users' role articulated in decision-making?
How do the nurses act in communication with the service users and other health professionals – for example, body language, modality, the participatory relationship, objective/distancing, subjective/empathetic, positive/negative?

Observations

With the purpose of gaining access to social processes, where meaning is negotiated and understood through interactions between nurses and service users, observations were made of interdisciplinary conferences, report meetings and ward rounds in a mental health hospital (31). These forums were selected because nurses discussed the service users' treatment and made continuous progress there. The observations were concentrated on participants' language, actions, structures for communication and how the service users' perspectives were articulated in conversations between the health professionals (Table 3).

Ethical considerations

Close adherence was paid to the ethics of scientific work. According to the Helsinki Declaration (1) and Danish law (2), no formal permit from an ethics committee was required, as the purpose of the research was not to influence the informants, either physically or psychologically. The study participants gave their informed consent after receiving verbal and written information. The participants were informed that participation could be halted at any time and that all data would be treated in such a way that no unauthorised person could have access to the material.

Data analysis

This study uses Charmaz's construction of grounded theory by traversing basic grounded theory phases. The initial coding was performed by closely studying fragments of data, words, lines, segments and incidents for their analytical importance. The preliminary phase was followed by a focused selective phase that used the most significant or frequent initial codes to sort, synthesise, integrate and organise large amounts of data (31). The focused coding involved an insight into different perceptions, motives, negotiations and procedures reported by the nurses and their communication with other health professionals and service users. The categories were constantly compared in the data and made a 'point of departure' from which to organise and interpret the qualitative data (31). The final analysis phase was theoretical sampling, which means seeking pertinent data to develop the emerging theory. We conducted theoretical sampling by sampling to develop the properties of our categories as a basis for the theory until no new properties emerged. The categories were considered to be 'saturated' when gathering fresh data no longer sparked new theoretical insights or revealed new properties to the theoretical categories (31). Memo writing helped in facilitating a deeper consideration of the codes early on in the research process.

In accordance with Charmaz's approach to grounded theory, the first author conducted interviews and observations, and, throughout the analysis process, the

researcher's team were invited to discuss the generated coding and categorisation (31, 39). Following Charmaz's interpretation of grounded theory, a critical assessment of the study's credibility, originality, resonance and usefulness was made. The pragmatic conceptions of validity require extended dialogue, deep reflection and considerations about the research consequences (31). This was achieved by a discussion of the findings with other researchers and practitioners to clarify various interpretations of the data.

Findings

Patient participation as a challenge between ethical care and a biomedical/paternalistic approach emerged as a core category. This core category was generated from our inter-related categories: (i) 'Taking care of the individual needs'; (ii) 'The service user as expert'; and (iii) 'Biomedicine', and (iv) 'Paternalism', and their subcategories (Table 4).

The core category constitutes different values between a humanistic approach to meeting the service user as an individual with his or her lived experiences and expectations, and, on the other hand, despite an increased willingness for engaging and involving culture, some structural power and a biomedical approach offer challenges to the anchoring of a humanistic recovery-oriented culture.

The informants speak for an ethical care which involves the service users' abilities and expert knowledge as an important contribution to recovering from illness and actively managing their responsible self-care. The informants emphasised ethical care: 'It is not enough we focus on diagnosis and symptoms, we need to share knowledge and lead service users so that they can live a good life despite their symptoms. The participation of service users is to listen and to give them the opportunity and space to express their thoughts and feelings, but also that they are suitably addressed in making the right choices for them. We do not think that they will live healthily unless motivated to do so. To see humans as more than a disease, and to meet them wherever they are, also involves the psychological, social and existential aspects of their lives'.

In ethical care, the nurses argue for involving the patients' perspectives, for instance life experiences and life conditions, to jointly reach the best solution for the patient. In ethical care, the diagnoses and symptoms should not set the agenda for treatment, but instead personal recovery, where nurses encourage hope and motivation to help the patient as best as possible through his or her recovery process.

The biomedical/paternalistic approach overshadows the ethical care, as the communication centres around diagnoses, symptoms, medications and decisions regarding the treatment generally taken by nurses. Interdisciplinary conferences, ward rounds and report situations form a landscape for the health professional discussion of service users' treatment. The service user is subsequently informed of decisions regarding treatment. The informants emphasised the biomedical/paternalistic approach: 'We have the best intentions about involving the service users' perspectives, but too few resources to solve the tasks and vacancies, which makes it difficult to live up to'. Therefore, there exists an understanding that ethical care would require more time and additional resources.

Table 4 Constructed categories based on social interactions between nurses, health professionals and patients and how they are associated with organisational procedures, paradigms, structures and communicative relationships at a microlevel in a psychiatric context

Core category	Categories	Subcategories
Patient participation as a challenge between ethical care and biomedical/paternalistic culture	(i) Taking care of individual needs (ii) The service users as expert (iii) Biomedicine (iv) Paternalism	Ethical care as a situational approach Recovery orientation perspective Shared decision-making The service users have personal experience and knowledge Confidence Empowerment The service users' problems were discussed, interpreted and resolved within an objective biomedical conceptual world Compliance The service user's own thoughts about his or her illnesses or problems were not mentioned or requested Evidence-based knowledge as a starting point Standardisation Consent to treatment Hierarchical control

This core category ethical care was generated from: 'Taking care of the individual needs'. This category emerged from the informants' articulation of patient participation. Patient participation is transformed into incorporating the service users' perspectives and giving the service users' expectations and needs a voice in the course of treatment. Every situation is unique and the nurses are subject to ethical guidelines of care, which means being respectful to the service users' self-determination, integrity and individuality.

In continuation of the core category, the subcategory 'ethical care as a situational approach' means an ethical claim to help the service users without expecting something in return. The ethical perspective relates to communicating with the service user about his or her individual perceptions of their suffering and clarifying goals and hopes for the future. There is a perception that this approach to treatment could motivate more service users to be active and responsible for their recovery. The informants perceived this approach as a contrast to the existing approaches in the two psychiatric units, where treatment is subject to efficiency and productivity requirements, which results in a more distant relationship between the nurse and service users: 'As nurses, we are schooled in a human view, where it is about meeting the service users, where they are, how they perceive their situation, and what they need help with. It is an ethical way to meet with service users and an ethical culture which does not quite agree with government policies with fewer beds and more efficiency in the system'. The nurses advocate for a humanistic approach and try to promote this approach in the treatment in coexistence with new public management control mechanisms. The nurses see an emergence of the health professionals' expertise, where the patient's situation is understood and solved from general and evidence-based knowledge, rather than focusing on the individual patient's experiences and wishes for help.

'A recovery-oriented perspective' means helping the service users identify and prioritise their personal goals for recovery, and recognising the service users' experiences and resources to focus on a lifestyle and not just the disease, promoting empowerment and helping them regain the opportunity for self-care. Recovery is not a rejection of biomedicine, as this knowledge also constitutes an important contribution to recovery. Thus, most service users rely on medicine to ameliorate severe psychological symptoms. The informants emphasised that 'Participation and recovery are connected, since participation of service users is about nursing to help the service users in the direction they want. We cannot expect inpatients to make big decisions when they are both psychotic and everything's possible. Then we take it quietly, and, in my opinion, it is no problem. If the service user is much weakened, we take over a little'. The nurses thus experience an ethical obligation to take over when the patient is not deemed to be able to make decisions about their treatment. Because of the severity of the symptoms, the patient cannot always be involved. This assessment seems to be up to the nurses to decide.

'Shared decision-making' was articulated as a model for involving the service users actively and organising individual treatment. It is a collaboration whereby the patient gains knowledge about his or her illness and treatment, and the benefits and disadvantages of the offered treatment. 'The nurses articulate shared decision-making as a dialogue with the service users concerning expectations about their treatment. The nurses inform the service users of illness and treatment, and they discuss the pros and cons of a given treatment'. The dialogue is coupled to active listening, which concerns listening to the verbal and nonverbal languages and encouraging the service user to take responsibility for his or her recovery process.

'The service user as expert' also emerged from interviews with nurses to describe patient participation. The service user is considered as being resourceful and able to articulate his or her expectations and needs for treatment. 'The service user as expert' is characterised by 'the service users have personal experience and knowledge', 'confidence' and 'empowerment'.

'The service user has personal experience and knowledge' was explained by the fact that it is the service users who feel the disorders. In this case, the service user knows best which treatment will be the most beneficial for his or her recovery process. According to the nurses, 'Patient participation means meeting the person behind the illness and involving his or her individual knowledge and experiences in life with their illness and building a course of recovery together with the service users'.

The nurses felt committed to implementing a recovery-oriented culture, where the service user is considered to be an expert. Many service users in the two units have been in the system for many years and have personal experience and knowledge, and it is necessary to use this to make individual plans. The service users' resources frequently vary depending on whether they have been hospitalised for a period or if they follow an outpatient course of treatment. Service users in outpatient care were often more resourceful, as the symptoms of the disease are less debilitating. Some service users do not consider themselves as being experts and have difficulties in relating to their diagnosis and do not recognise their disease. The service users' background was often a challenge if they had had bad experiences with, for example, medicine, and would not accept the course of treatment that the nurses considered would best help them.

'Confidence' means that the nurse listens to the service users' preferences and acknowledges their expert knowledge, which a nurse explains as confidence and

relationships are important when talking about participation, because the service user is blotting out his or her problems and the trust for which we must show respect by meeting them. We always try to build a relationship and we have known some of our service users for a long time. It may take time to create a good relationship and, because of paranoia, it may be even harder. By involving them, we show confidence that we believe in them and it helps to create a good relationship. 'All service users have knowledge and experience that we need to listen to and know, because of what works for them, they know where the shoe fits and can help us in how we can help them'. It is only appropriate to talk about expert knowledge if the nurse is confident that this knowledge is important. Confidence is perceived as an attitude towards another human being and the will to believe in them. Confidence is required for the patient feel motivated to open up and share thoughts and experiences which is important knowledge for the nurse when he or she involves the patient.

'Empowerment' means beliefs and involving behaviours, which has a positively impact on one's life. It is about strengthening the service users' coping abilities where they are insufficient to live an independent and controlled life: 'Apparently, it seems that it is in the relationship when we listen to their thoughts and wishes. We try to meet them wherever they are. I also see it as empowerment that we strengthen their empowerment so they become more independent. If the service user is anxious, he can completely isolate himself, and it can have major consequences for his everyday life. Here we can learn about the fear and how to control it so that eventually they can live a good life with anxiety'. Patient participation is the key to empowerment and living a good life independent of professional help, which appears to be a health ideology.

'Biomedicine' appeared in the way in which the nurses spoke about the service users' perspectives at interviews, interdisciplinary conferences, report meetings and ward rounds. The biomedical approach became a culture, which was a dominant approach as a framework for what treatments could be considered, and thus the ways in which service users could be involved. Biomedicine is characterised by the subthemes 'The service users' problems were discussed, interpreted and resolved within an objective biomedical conceptual world', 'Compliance', 'The service users' own thoughts about his or her illness or problems were not mentioned or requested', and 'Evidence-based knowledge as a starting point'.

'The service users' problems were discussed, interpreted and resolved within an objective biomedical conceptual world' at the interdisciplinary conferences, report meetings and ward rounds. This means that the biomedical knowledge reflected a theoretical frame for what was important to assist in treating the service users' illnesses.

A nurse observes: 'Many of our service users cannot manage to relate to many questions, and, when we simultaneously have limited resources, we are focused on the diagnoses, symptoms and medical treatment. The treatment is based on a cognitive approach, but it requires service users to reflect on their illness and life, which many do not manage. Service users are more aware of the constraints caused by the anxiety or the voices in their lives'. The discussion of each service user's case reflected factual elements such as residential and economic factors, education and occupation, but, overall, the biomedical approach dominated the discussion among the health professionals, but also in reporting situations and in the ward rounds with service users. The focus was on treating the disease and the symptoms rather than how the service users themselves experienced their problems.

'Compliance' means whether the service users adhere to the treatment. This aspect appeared from observations of the social interaction at interdisciplinary conferences, report meetings and ward rounds: 'Compliance' *was significant for patient participation, that the success of patient participation was measured on whether the patient followed the prescribed treatment and avoided readmission. There was an understanding that patient participation referred to helping the patient to achieve compliance, since it would facilitate his or her treatment and quality of life.* Compliance is referred to as one of the parameters for the service users' behaviour in terms of medication, diet and lifestyle, and the medical advice received by the service user. Compliance was found to be a key factor for the success of treatment.

The service user's own thoughts about his or her illness or problems were not mentioned or solicited at interdisciplinary conferences, report meetings and ward rounds: 'Observations of healthcare professionals' discussions on service users' treatment plans reflect how the success of the treatment is measured according to whether the service users take the prescribed medicine and follows the treatment plan'. This means that we do not, through observations, hear how the service user perceives his or her illness and situation, what goals and hopes they have for the future, or whether they have expectations for treatment.

'Evidence-based knowledge as a starting point' means the treatment was planned in a biomedical frame, where evidence was sought to support decisions. There seemed to be greater confidence in the evidence rather than a belief that a recovery-oriented approach would be best for the service users. Health professionals had the most knowledge and were the best placed to decide which course of treatment was most appropriate. Evidence was used as a term with an implicit meaning and was not challenged, for example: Chief Physician: 'How is Bettina doing?' Nurse: 'It is the same, a little improvement last week. She has had six electro-convulsive treatments, but

only the three of them have been of use, the rest have not worked'. Chief Physician: 'I think there is good evidence for an increase in power and strength, has she been prescribed Oxaxepam or what?' The example identifies evidence as an argument and knowledge base for decisions that are difficult to argue against.

'Paternalism' was here characterised by 'Standardisation', 'Consent to treatment' and 'Hierarchical control'.

'Standardisation', such as instructions, guidelines and package processes and treatment methods formed a framework for patient participation. Nurses identified standards and methods as evidence of their professionalism and did not want to override this. 'The idea is, too – that is, if it is the cognitive one, like choosing to say that it is the line we follow – then the service users will also be involved in the method, what it is for a method, and why it works. This is why we think it would be good to use in relation to the problems faced by the service users. Therefore, it is like an introduction to the method, for me to see that there is a lot of focus upon. So, they have some tools to use when they are having a hard time'. The participating wards used cognitive therapy, environmental therapy, motivational interviewing and psychoeducation as standard approaches to the service users' treatment. These methods were highlighted as evidence-based and therefore also for the benefit of the service users. Despite the fact that, for example, psychoeducation had a defined content and purpose for teaching service users about diseases, medicine and treatment, the nurses' conception was that the methods cater for the individual needs of all service users.

'Consent to treatment' means the service users were informed about the plans for treatment on ward rounds or by individual conversations. The focus was on explaining the treatment and ensuring the service users' consent to be treated, securing their agreement and cooperation, and ensuring that the service users understood the meaning of the treatment. Nurses considered patient participation as being that the service users received adequate information about treatment options and possible results, including the possibility of no treatment, so the service users can make decisions on an informed basis. The conversation in ward rounds opened up for the service users' questions and the service users asked for information about medicine and accepted the treatment plans. They did not discuss the treatment and were not critical and the nurses did not necessarily expect much input from the service users. 'The service users are often cognitively and emotionally disturbed and need to leave responsibility to us. Many service users do not understand their diagnosis and therefore do not follow their treatment'.

'Hierarchical control' means the health professionals' discussions at the conferences reflected a hierarchy where the chief physician sets the agenda, then the physician, psychologists, the chief nurse and nurses. Observations showed 'that the physicians and psychologists were predominantly focused on diagnosis, tests and symptoms. The nurses used the same language'. Decisions about service users' treatment were taken on this theoretical basis and subsequently reported on ward rounds or individual conversations.

Discussion

This study illuminates the meaning of how patient participation is constructed and what structures form a framework for participation in a psychiatric context. This can contribute to dealing with the challenges in incorporating patient participation as an ideology in all psychiatric contexts and is therefore important knowledge for nurses. The consequence of the lack of precision in patient participation means that nurses and other professionals often act in ways that relate to how they each individually want to involve service users (43–45).

The analytical findings reveal patient participations were articulated and practised at two ends of a continuum between an *ethical care*, in which the nurses attempted constant adjustment to the service users' condition, and a *biomedical- and paternalistic-oriented framework*. The nurses advocated for an ethical care where nursing involves meeting the service user with openness, trust and the encouragement for the user to take responsibility for his or her recovery process. Implementation of this ideology was challenged by organisational structures where treatment was predominantly based on a biomedical- and paternalistic-oriented framework, and where the service user's opinions and expectations could not be a measure of the theoretical approach to treatment. Other studies show that it will require a new culture in psychiatric treatment if the service user's own goals and hopes are to direct the formulation of their treatment plan (21, 46). Patient participation and recovery were perceived in a dialectical relationship, where the service user's perspectives formed the starting point for making a plan for the service user's recovery process. Recovery means taking the small steps, which help the service users to live fulfilling lives with or without symptoms. The prerequisite for organising this process is that the service users must be involved throughout the process with their experiences and expectations to ensure the service users feel that they have ownership over their recovery process.

The recovery-orientated approach supports the possibility of the service users being involved in the process with their own knowledge, skills, hopes and goals. According to another study, this approach requires a shift from staff members, who are seen as remote and in a position of expertise and 'authority', to being people who behave more akin to personal coaches or trainers, offering their

professional skills and knowledge, while learning from and valuing the service users, who is an expert by experience (47). Also in this study, the nurses endorsed the ideology of recovery and a nonpaternalistic culture as something that was required for an open and trusting relationship, where the service user's perspective could be involved throughout their treatment.

Nevertheless, the healthcare professionals decided the plans and goals for the service users' treatment, for example in conferences, which the service users do not attend. It is not an individual recovery-orientated approach, and the service users were described as weak and unable to participate in the conferences where the treatment plans were formulated. Personal recovery was one of the hospital's goals for the treatment (41), and the nurses found this approach an important one to meet. Nevertheless, the consequence is that people with mental illnesses are deprived of their opportunity to be an active party in their course of treatment, that is to participate in decisions and perform them in everyday life (28).

Observations of social interaction processes between nurses, other health professionals and service users reflected a practice where the starting point was focused on diagnoses and symptoms rather than how the service users themselves experienced their problems and need for help. The nurses considered the lack of resources, the rapid flow of service users and severely ill service users and that the service users could not live up to the ideology of active participation in a recovery-oriented perspective, to be barriers. Wright et al. demonstrate that, due to the lack of resources (inpatient beds and community care follow-up), the part played by patient participation was diminished. In their narratives, health professionals associated the person with the process and used language which dehumanised the individual (19). In our study, we saw challenges to implementing an ethical care where the service user was actively involved with his or her own perspectives as being a result of a dominant paternalistic and biomedical culture defined by the physicians and who set the agenda for the nurses' and service users' roles in practising a recovery-orientated approach.

Blinded with anonymity reveals how the Danish policy strategies and objectives indirectly define a paternalistic and biomedical discourse of care which defines the service users' and health professionals' roles. Patient participation is subject to an overarching political governance that is linked to a neoliberal approach, in which a service user's freedom of choice and self-determination is subject to the basis of administrative and economy management tools (3).

According to Holen, Oute and Glasdam, neoliberal management technologies will indirectly define consumer roles, where service users are no longer passive recipients, but rather consumers, and thus, evidence-based services must be provided. In a neoliberal approach, management technologies and efficiency are signifiers where, among other aspects, there are national goals, health agreements, etc. The neoliberal management technologies have made their contribution, which deprives the health professional of an influence on how they organise the treatment (4–6). The health professionals must accommodate the neoliberalist approach and technologies and the path to recovery within a medical treatment on an evidence-based basis.

Paternalism can be interpreted in the light of policy-makers' goals to base the treatment on standardised methods for the least possible costs (3). In our study, we did not know the service users' own thoughts about their situations and what expectations they might have, as the nurses did not ask for that information.

This study confirms that a paternalistic culture dominates in psychiatric hospitals, which can be an explanation of why the service user is not invited to, for example interdisciplinary conferences where the service user's treatment plan is made, and his or her expectations for participating are not discussed. Other studies have shown that paternalism still dominates, and it is one of the reasons why patient participation is not yet properly implemented (45, 48, 49).

'Compliance' was significant for patient participation: the success of patient participation was measured by whether the service users followed the prescribed treatment and avoided readmission. There was an understanding that patient participation referred to helping the service users to achieve compliance, as it would facilitate their treatment and quality of life.

Evidence-based practice was part of the working culture of nurses – especially where medical treatment is a central activity. The observations of conferences showed that the treatment was planned in a biomedical frame, where evidence was sought to support decisions. There seemed to be greater confidence in the evidence rather than a belief that a recovery-oriented approach would be best for the service users. Health professionals had the most knowledge and were the best placed to decide the most effective form of treatment. Evidence was used as a term with an implicit meaning and was not challenged.

The grounded theory study created a construction of a reality as it appeared through data processing. The theory generation shows a construction of a reality as it appears in the selected data material. The social constructivist realisation is entirely entangled within sociality and subjectivity. It is not possible to achieve clear objectives and unmediated access to nature and the natural world. In other words, there is not one truth, but many. There is no question of pure relativism, the validity of knowledge claims is generated through recognised methods and theories (39, 50). As we constructivists develop our analyses, we know that we offer an interpretation contingent upon our knowledge of our participants and their situations.

We view data as being constructed rather than discovered, and we see our analyses as interpretive renderings not as objective reports or the sole viewpoint on the topic (33).

The study's validity was continuously assessed based on critical attention paid to every step through data collection and the three stages of analysis (31, 32, 51). All coding, memos and critical reflections were systematised to ensure rigour and transparency. To maintain the preliminary categories through the analysis process, a continuous comparison of each analysis step was performed and also between the steps (31).

Clinical implications – how can clinicians encourage patient participation in health care in a hospital?

Consistent with the existing literature (5, 19, 45, 49, 52), this analysis, in a mental health context, reveals the challenges of implementing patient participation as a framework for nursing care. The concept of patient participation is based on a humanistic framework where the service users meet a situational approach while, at the same time, the basic knowledge of the treatment is based on a biomedical-oriented framework. Patient participation can therefore be understood as a new paradigm, where participation and personal recovery must coexist with an evidence-based biomedicine approach.

This study can inspire further discussion on how this concept should be understood, and it must be discussed whether it should be offered to the service users or instead something they can request.

Conclusions

This study shows how patient participation is constructed in social interaction processes between nurses and service users and which structures provide a framework for participation in a psychiatric context. Patient participation is articulated in the two ends of a continuum between an ethical care and a paternalistic and biomedical approach. On the one hand, this means participation is based on the service user's perspective, a person who needs help to promote his or her own recovery process, including building empowerment, self-care, self-determination and self-confidence. Within this meaning, patient participation also means shared decision-making as a model for involving the service users actively and organising individual treatment. It is a collaboration where the patient gains knowledge about his or her illness and treatment, and the benefits and disadvantages of offered treatment. However, on the other hand, participation here simply means informed consent and the compliance of the service users in following the health professional's recommendations. The study found that nurses on an open

psychiatric ward and outpatient ward committed themselves to a biomedical- and evidence-based approach. The service users did not participate at interdisciplinary conferences where decisions about their treatment were taken, and the service users were subsequently informed about the treatment offered.

This calls for more studies in a psychiatric context with a view to gaining an insight into the concept of patient participation, for instance in the areas of psychiatry, which are termed general, closed and forensic psychiatric departments. Under these institutional conditions, the service user's freedom is significantly reduced, which involves participation in a particular perspective. More research is needed on how the most ill service users can be individually involved in their treatment course.

Acknowledgements

Conflict of interest

None declared.

Author contributions

KJ was responsible for the study conception and design, performed the data collection, performed the data analysis, was responsible for the drafting of the manuscript, and provided administrative, technical or material support. JDR og MH made critical revisions to the paper for important intellectual content. JDR & MH supervised the study.

Ethical approval

The ethics of scientific work were adhered to. According to the Helsinki Declaration (1) and Danish law (2), no formal permit from an ethics committee was required, as the purpose of the research was not to influence the informants either physically or psychologically. The study participants gave their informed consent after receiving verbal and written information. The participants were informed that participation could be halted at any time and that all data would be treated in such a way that no unauthorised person could have access to the material.

Funding

References

1 World Medical Association. Declaration of Helsinki – Ethical principles for medical research involving human subjects. World Medical Association 2013; (June 1964): 1–8.

2 Sundheds og Ældreministeriet. Lov om videnskabsetisk behandling af sundhedsvidenskabelige forskningsprojekter [Law on science ethics of health science]. *Sundheds og Ældreministeriet* 2014; 2011: 1–10.

3 Blinded with Anonymity. Patient participation as discursive practice – a critical discourse analysis of Danish mental healthcare. *Nurs Inq* 2017; 25: e12218.

4 Oute J, Huniche L, Nielsen CT, Petersen A. The politics of mental illness and involvement – a discourse analysis of Danish anti-stigma and social inclusion campaigns. *Adv Appl Sociol* 2015; 5: 273–85.

5 Glasdam S, Oeye C, Thrysoee L. Patients' participation in decision-making in the medical field – "projectification" of patients in a neoliberal framed healthcare system. *Nurs Philos* 2015; 16: 226–38.

6 Holen M. Sundhed og sundhedspolitikker i velfærdsstaten [Health & health policies in the welfare state]. *VIA Univ Coll Gjallerhorn* 2015; 20: 37–47.

7 Castro EM, Van Regenmortel T, Vanhaecht K, Sermeus W, Van Hecke A. Patient empowerment, patient participation and patient-centeredness in hospital care: a concept analysis based on a literature review. *Patient Educ Couns* 2016; 99: 1923–39.

8 Holen M. *Medinddragelse og lighed -en god idé [Patient Participation and Equality – A Good Idea?]*, Vol. 7. 2011, Institut for Psykologi og Uddannelsesforskning, Roskilde University, Denmark.

9 Mik-Meyer N, Villadsen K. *Magtens Former [Power Forms]*. 2007, Hans Reitzels Forlag, København, 189.

10 Rose N. *Livets politik. Biomedicin, magt og subjektivitet i det 21. århundrede.* 2009, Dansk Psykologisk Forlag, Virum.

11 The Ministry of Health. Mere borger, mindre patient – Et stærkt fælles sundhedsvæsen [More citizen less patient – A strong public health care system]. Minist Heal Minist Sundh og Forebygg 2013; 1–48.

12 Oute J, Petersen A, Huniche L. Who & what does involvement involve? A multi-sited field study of involvement of relatives in Danish psychiatry. *Issues Ment Health Nurs* 2015; 36: 953–62.

13 Elstad TA, Eide AH. User participation in community mental health services: exploring the experiences of users and professionals. *Scand J Caring Sci* 2009; 23: 674–81.

14 McCloughen A, Gillies D, O'Brien L. Collaboration between mental health consumers and nurses: shared understandings, dissimilar experiences. *Int J Ment Health Nurs* 2011; 20: 47–55.

15 Porter M. Service user involvement in care planning: the mental health nurse's perspective. *J Psychiatr Ment Health Nurs* 2001; 65: 43–59.

16 Solbjør M, Rise MB, Westerlund H, Steinsbekk A. Patient participation in mental healthcare: when is it difficult? A qualitative study of users and providers in a mental health hospital in Norway. *Int J Soc Psychiatry* 2013; 59: 107–13.

17 Storm M, Davidson L. Inpatients' and providers' experiences with user involvement in inpatient care. *Psychiatr Q* 2010; 81: 111–25.

18 Tee S, Lathlean J, Herbert L, Coldham T, East B, Johnson TJ. User participation in mental health nurse decision-making: a co-operative enquiry. *J Adv Nurs* 2007; 60: 135–45.

19 Wright N, Rowley E, Chopra A, Gregoriou K, Waring J. From admission to discharge in mental health services: a qualitative analysis of service user involvement. *Health Expect* 2016; 19: 367–76.

20 Anthony WA. Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. *Psychosoc Rehabil J* 1993; 16: 11–23.

21 Karlsson B, Borg M. Recovery Traditioner, fornyelser og praksiser. Gyldendal Akademisk; 2017.

22 Jacobsen C, Pedersen V, Albeck K. Patient participation between ideal and reality – An empirical study of shared decision making and everyday meetings between patient and health professionals. Sundhedsstyrelsen, Monitorering & Medicinsk Teknologivurdering og Dansk Sundhedsinstitut. 2008, 1–126.

23 Castro EM, Van Regenmortel T, Vanhaecht K, Sermeus W, Van Hecke A. Patient empowerment, patient participation and patient-centeredness in hospital care: a concept analysis based on a literature review. *Patient Educ Couns* 2016; 99: 1924–33.

24 Sahlsten MJM, Larsson IE, Sjöström B, Plos KAE. An analysis of the concept of patient participation. *Nurs Forum* 2008; 43: 2–11.

25 Larsson IE, Sahlsten MJM. The staff nurse clinical leader at the bedside: Swedish registered nurses' perceptions. *Nurs Res Pract* 2016; 2016: 1–8.

26 The Ministry of Health. *Ligeværd – nyt fokus for indsatsen for mennesker med psykiske lidelser. [Equality – A New Focus for Action for People with Mental Disorders]*, Vol. 16. 2014, The Ministry of Health, København, 1–16.

27 Regeringen DR og K. Nationale mål for sundheds- væsenet. Regeringen, Danske Reg og KL. 2013; 24.

28 Jørgensen K, Rendtorff JD. Patient participation in mental health care - perspectives of healthcare professionals: an integrative review. *Scand J Caring Sci* 2017; https://doi.org/10.1111/scs.12531.

29 Jacobsen CB, Martin HM, Andersen SL, Christensen RN, Bengtsson S. *Stigma og psykiske lidelser: som det opleves og opfattes af mennesker med psykiske lidelser og borgere i Danmark [Stigma & Mental Illness: As Experienced and Perceived by People with Mental Illnesses and Citizens in Denmark]*. 2010, Danish Health Institute DSI and the National Center for Social Research, Copenhagen Denmark, 1–106.

30 Ringer A, Holen M. "Hell no, they'll think you're mad as a hatter": illness discourses & their implications for patients in mental health practice. *Health (London)* 2016; 20: 161–75.

31 Charmaz K. *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. 2014, SAGE Publications, London, Thausand Oaks, New Delhi.

32 Charmaz K. Grounded theory in the 21st century: applications for

advancing social justice studies. In *The SAGE Handbook of Qualitative Research*. (Denzin N, Lincoln Y eds), 2005, Sage, Thousand Oaks, CA, 507–36.

33 Charmaz K. Shifting the grounds: constructivist grounded theory. In *Developing Grounded Theory: The Second Generation*. (Morse JM, Stern PN, Corbin J, Bowers B, Charmaz K, Clarke AE eds), 2009, Left Coast Press Inc, Walnut Creek, CA, 127–93.

34 Bruce S. Symbolic interactionism (book). *Br J Sociol* 1988; 39: 292–5.

35 Handberg C, Thorne S, Midtgaard J, Nielsen CV, Lomborg K. Revisiting symbolic interactionism as a theoretical framework beyond the grounded theory tradition. *Qual Health Res* 2015; 25: 1023–32.

36 Charmaz K. "Discovering" chronic illness: using theory. *Soc Sci Med* 1990; 30: 1161–72.

37 Charmaz K. Grounded theory. In *Rethinking Methods in Psychology* (Smith J, Harre R, Langenhove L eds), 1995, Sage, London, 27–49.

38 Charmaz K. Constructionnism and the grounded theory. In *Handbook of Constructionist Research*. (Holstein JA, Gubrium JF eds), 2008, The Guilford Press, New York, NY, 397–412.

39 Charmaz K. Grounded theory as an emergent method. In *Handbook of Emergent Methods*. (Hesse-Biber SN, Leavy P eds), 2008, The Guilford Press, New York, NY, 155–72.

40 Strauss CJ. *Basics of Qualitative Research Techniques and Procedures for Developing Grounded Theory*, Vol. 3. 2008, SAGE Publications, California, US, 379.

41 Region Hovedstadens Psykiatri. *Virksomhedsplan 2014 (Values)*. 2014, Region Hovedstadens Psykiatri, København.

42 Jørgensen K (RED). *Kommunikation for Sundhedsprofessionelle [Communication for Health Professional]*, 4th edn. 2017, Gads Forlag, London.

43 Jönsson ABR, Nyborg MJG, Pedersen VH, Pedersen LH, Wandel A, Freil M. Sundhedsprofessionelles forståelser af patientinddragelse [Health Professional's perceptions of patient involvement]. Videncenter brugerind dragelse [A Cent Sci about user Involv]. 2013.

44 Freil M, Wandel A, Pedersen L, Jönsson ABR, Nyborg M. Læger og sygeplejerskers forståelse af patientinddragelse [Doctors and nurses' understanding of patient involvement]. Videncenter brugerinddragelse [Scientific Cent patient Particip] 2014; 5–60.

45 Pedersen L, Wandel A, Freil M, Jönsson ABR. Patientinddragelse er endnu ikke fuldt implementeret i sundhedsvæsenet [Patient involvement is not yet fully implemented in health care]. *Ugeskr Laeger* [weekly J Dr] 2015; 177: 2–5.

46 Hobbs M, Baker M. Hope for recovery – how clinicians may facilitate this in their work. *J Ment Health* 2012; 21: 144–53.

47 Shepherd G, Boardman J, Slade M. Making Recovery a Reality. Sainsbury Cent Ment Heal 2008; 1–23.

48 Taylor K. Paternalism, participation and partnership – the evolution of patient centeredness in the consultation. *Patient Educ Couns* 2009; 74: 150–5.

49 Holen M, Ahrenkiel A. "After all, you should rather want to be at home". Responsibility as a means to patient involvement in the Danish health system. *J Soc Work Pract* 2011; 25: 297–310.

50 Wenneberg SB. Socialkonstruktivisme – positioner, problemer og perspektiver [Social Constructivism – positions, problems and prospects]. 1. udgave. Samfundslitteratur; 2010.

51 Kvale S. *Doing Interviews (Qualitative Research Kit)*. 2008, Sage Publications Ltd, London.

52 Ringer A. *Listening to Patients. A Study og Illness Discourses, Patient Identities, and User Involvement in Contemporary Psychiatric Practice*. 2013, Roskilde University, Denmark.