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An Interview Study of Professional Carers’ Experiences of Supporting Patient Participation in a Maximum Security Forensic Psychiatric Setting

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ABSTRACT

Patient participation in forensic psychiatric settings seems to be complex by nature, and previous studies show that patients rate their participation as lower in this context compared to general psychiatric contexts. Studies on caregivers’ perspective could provide a clearer picture of the components and possibilities of patient participation in forensic psychiatry. The aim of the study is to describe carers’ experiences in supporting patient participation in a maximum security forensic psychiatric care setting. Twelve psychiatric caregivers were interviewed about how they support patients’ participation. The result shows that a complexity of patient participation emerges as a difficult act of balancing the paradoxical role of caring for the patient’s interests and development, while simultaneously representing and adhering to the rules and regulations of the system in which one is employed. In conclusion, it is suggested that participation is comprehended as an umbrella term and that focus is directed to conceptualising what caregivers can do in order to create positive patient-carer relationships, as well as what constitutes such a relationship.

Introduction

A common challenge for all clinicians in mental health contexts is the intrinsic difficulty in supporting and encouraging patient participation, specifically in health care settings with compulsory in-patient psychiatric care (Munthe, El-Alti, Hartvigsson, & Nijssingh, 2018). Examining this complexity from the perspectives of both carers and patients is necessary in order to enhance understanding and facilitate its implementation within forensic psychiatry. Patient participation as in shared decision making has been associated with better health outcomes as well as greater patient satisfaction (Hamann, Leucht, & Kissling, 2003). In Sweden, a conceptual analysis highlighted the following prerequisites necessary for patient participation: an established patient-carer relationship, shared knowledge and information, a surrendering of some power or control on behalf of the carer, and mutual participation in activities (Sahlsten, Larsson, Sjöström, & Plos, 2008). An additional study highlighted the necessity of shared knowledge, an emotional and interested approach to the others’ problems, a take-for-granted approach that the other has something to contribute with, as well as experiencing that one’s identity as carer is not threatened (Ashworth, Longmate, & Morrison, 1992).

Shared decision making in forensic psychiatric care has, however, an inherent setback, namely that forensic psychiatric care is rooted in a system based on restrictions and involuntary treatment (1991:1129, Forensic Psychiatric Care Act). Restrictions include aspects such as limited leave and grounds access, the right to apprehend personal belongings, and is moderated by the attitudes of staff (Tomlin, Bartlett, & Völml, 2018). This dimension of shared decision making in correctional and forensic practice has been portrayed as a dual-role problem, or dual-role dilemma, and can be described as a conflict between two sets of ethical norms, community protection (non-maleficence) and justice versus the patient’s well-being (beneficence) and autonomy (Ward, 2013). Robertson and Walter (2008) explain that this dilemma is characterised by the presence of a powerful third party, such as the community, to whom the psychiatrist has obligations. The ambiguity of both caring for patients and applying legislation constitutes a significant ethical dilemma and further highlights the complexity of forensic psychiatric care. Thus, the implementation of patient participation in an involuntary setting is imperative to examine. The purpose of the current study is to provide knowledge that can support mental health staff in the daily care of patients, and specifically in the support of their participation in their own care, in forensic psychiatric care settings.
Background

Forensic psychiatric care aims to mitigate psychiatric symptoms and prevent the occurrence of further offences. Eidhammer, Fluttert, and Bjørkly (2014) argued that a common problem within forensic psychiatric care settings is that health care staff make decisions and act without involving or informing patients. Fluttert, Meijel, Nijman, Bjørkly, and Grypdonck (2010) demonstrated a significant decrease in seclusions and violent behaviour among patients who participated in the establishment of their own risk management plans compared to those who did not, supporting the benefits of active patient participation in the care.

When forensic psychiatric patients in 25 different units rated quality of care, the participants mainly rated the quality of care as high, yet lower when compared to general psychiatric care. The lowest rating was found for the participation dimension (Schröder, Lorentzen, Riiskjaer, & Lundquist, 2016). A qualitative study from a patient perspective conducted in two Swedish forensic psychiatric clinics indicated that participation encompassed factors such as influence, confidence, and responsibility. The study emphasised the importance of being involved as a patient and that good communication between caregiver and patient is fundamental to impact care and exert influence (Selvin, Almqvist, Kjellin, & Schröder, 2016). Another study showed that patients’ needs of being accepted and belonging were critical for their ability to be themselves (Aga, Vander Laenen, Vandevelde, Vermeersch, & Vanderplasschen, 2017). Participation in forensic psychiatric care is complex due to its corrective and disciplinary nature. Hörberg and Dahlberg (2015) explored the meanings of forensic psychiatric care based on patient and caregiver reports with many experiencing power and powerlessness, and stated that this can be understood as a power balance between carers and patients.

Barnao, Ward, and Casey (2015) explored patient’s experiences of rehabilitation in forensic psychiatric care and identified two contrasting narratives. The first narrative identified experiences such as powerlessness, oppression, and despair with patients reporting violent fellow patients, bureaucratic systems, and a culture that emphasised control. Furthermore, many reported feeling insecure and not viewed as a person, and that decisions were made entirely by psychiatrists. In the other narrative, patients felt active in their own rehabilitation. This was related to supportive health care staff and a strong orientation to person-centred care. Both narratives were present in patients’ stories, but the first was much more prominent. Mason (2000) argued that patients often consider themselves as unjustly treated and therefore some episodes of objection are to be expected. Broer, Nieboer, and Bal (2014) argued that it is more constructive to admit the existence of power and authority in compulsory care and view it as something unavoidable. Moreover, they suggested that focus should be on exploring the consequences of power relations instead of whom is exerting power or assuming that power is merely a negative phenomenon that must be alleviated.

In Sweden, participation is a well-established term within the health care system and legislation outlines that patient participation is something all health care staff should work towards (Swedish Patient Act, 2014:821). The question that arises is whether forensic psychiatry can work towards the same type of patient participation as the rest of the health care system, and if the current definition of participation is employable within maximum security forensic psychiatric settings? There is a lack of research focusing on carer perspectives on patient participation and how it can be supported within forensic psychiatric care. Related research conducted from a carer perspective shows the importance of exerting dignity in relation to the patient (Gustafsson, Wigerblad, & Lindwall, 2013). Also, carers need to see patients as individuals and build trust in the relationship in order to facilitate participation (Salzmann-Erikson, Rydlo, & Wlkund Gustin, 2016). How participation is expressed within a forensic psychiatric environment, where compulsory features and correction are central components, is important to examine from both a patient and carer perspective. In doing so, an increased understanding of the phenomenon of patient participation in forensic psychiatric care can be achieved.

The aim of the current study is to describe carers’ experiences in supporting patient participation in a maximum security forensic psychiatric care setting.

Method

The study is based on a Reflective Lifeworld Research (RLR) approach founded on phenomenology (Dahlberg, Dahlberg, & Nyström, 2008) rooted in the philosophy of Edmund Husserl’s (1859–1938) lifeworld theory (Husserl, 1970) and the theory of intentionality (Husserl, 1977). In order to describe essential meanings of the phenomenon in focus for the study, the methodological principles of the RLR approach—openness, flexibility, and bridling—were used.

Settings

The study was conducted within three maximum security forensic psychiatric wards at one and the same forensic psychiatric clinic in Sweden. Patients on the wards had either been convicted to forensic psychiatric care or remitted for psychiatric treatment by the Swedish Prison and Probation Service due to severe mental illness or violent behaviour. The wards were designed from a safety perspective, including minimal stimuli, few personal possessions, and very high staff density. Most wards in this study had more than 40 carers for 12–14 patients. Most of the carers were licenced assistant mental health nurses, and five to six carers were registered nurses or registered mental health nurses. Licenced assistant mental health nurses work close to the patient in their everyday care and they have an active role in the treatment team. The wards also had behavioural pedagogues and social pedagogues employed. These staff categories have 3–4 years of higher education and are often specialised on addiction or problem behaviours.
Psychologists and psychiatrists work affiliated to the wards. The psychiatrists have the medical responsibility over the patient and work close to the licenced assistant mental health nurses and the registered nurses. Even if maximum security forensic psychiatry staff also treat patients from prison and jail, the carers are considered to be carers and not guards even though all staff working directly at the ward are responsible for both the care and the security. The care plan is developed by the patient’s treatment team consisting of carers at the ward together with a psychiatrist, a social worker, and a psychologist. The patients do take part in the development of care plan in a degree that is possible, however this is not explicitly explained in which degree more than “as far as possible”. The care plan is updated at least every sixth month.

Informants

The informants for the current study were staff who work in the patients’ daily care, that is, registered nurses, nurses specialising in psychiatric care (registered mental health nurses), licenced assistant mental health nurses, and social pedagogues. The latter work together with nurses and licenced assistant mental health nurses on the ward with an extended responsibility of social activities, and they have a higher education (at a minimum a bachelor’s degree). In this study, these professionals are all referred to as “carers”, and as such they are included disregarding their educational level.

Informants consisted of 12 carers, six women and six men. The informants varied on the following demographic variables: gender, age, length of employment (£6 months), and occupation. One informant was a registered mental health nurse, one was a registered nurse, eight were licenced assistant mental health nurses and two were social pedagogues. Their professional experience ranged from 1 year to 30 years ($M = 6.5$) and their age ranged between 20 and 63 years ($M = 37$). The managers at the wards consented to the study, and ward staff assisted with providing information and gathering informants. Written information, with contact information to the principal investigator, was displayed on each ward. Informed, written consent was provided by all informants prior to interviewing.

Data collection

Data collection consisted of interviews with open-ended questions based on a RLR approach (Dahlberg, Dahlberg, & Nyström, 2008). The following questions were employed: (1) Describe how you support patient’s participation during their time of rehabilitation on the ward?; (2) Can you describe a situation where you have supported a patient to participate?. Complementary questions were asked, such as: “Can you tell me more?”, “How did it feel then?”, and “How do you mean?” The interviews were conducted in an undisturbed room during staff working hours. The duration of interviews ranged between 30 and 50 minutes ($M = 40$). Interviews were audio recorded and transcribed verbatim.

Ethical considerations

The study was provided ethical advice (reg. number EPK 444-2017) by the Ethical Advisory Board in South East Sweden. Decisions have been made in accordance with the Declaration of Helsinki (WMA, 2013) and Swedish ethical clearance legislation (SFS 2003:460). Written and verbal informed consent was obtained from all informants and they were informed that they could withdraw from the study at any time. The principles of anonymity, confidentiality and integrity have been maintained throughout the study.

Data analysis

A phenomenological method based on a RLR approach (Dahlberg et al., 2008) was used for data analysis. In order to describe the phenomenon’s essential structure of meanings, the analysis was characterised by a movement between the whole and the parts, and towards a new whole. Firstly, meanings of the phenomenon “supporting participation in forensic psychiatric care” were searched for in the data. Meanings were grouped in clusters based on similarities and differences. The clusters were kept flexible as long as possible to avoid a too quick understanding of the meanings. In order to obtain a new structure—that is, the essential meaning of the phenomenon—a search for patterns of essential meanings between the clusters and how they related to each other was performed. The following questions were asked during the analysis process: What does it means to support patient participation? What makes it this specific phenomenon and what are the characteristics? By methodically working in terms of figure and background, whereby different meanings and clusters are understood in relation to one another, the phenomenon’s essential structural meaning could emerge.

A reflective and bridled attitude was consistent throughout the analysis process in order to restrain pre-understanding and understanding as a whole, thus allowing the phenomenon to remain indefinite for as long as possible. Bridling can be described as slowing down in the process of understanding and not taking anything for granted. It does not mean a belief that it is possible to set aside one’s pre-understanding. The idea of bridling demands a reflective and critical attitude to slow down the process of understanding in order to see and understand the phenomenon in a new way (Dahlberg et al., 2008). There was a determination to keep the analysis open and flexible as long as possible to prevent assigning definite meaning to the phenomenon too quickly. By investigating the phenomenon’s patterns of essential meanings, a new whole could emerge on an essential level and is presented as an essential structure of meanings. The more contextual nuances of meanings were presented in the following constituents: The ambiguous range of participation, the balancing act in the roles as carer and “guard”, a good relationship: not participation but the next best thing, and caring interventions with which one aims to create participation. During the analysis process, the authors worked both individually and together with critical, questioning, and bridled attitudes.
Results

The meaning of the phenomenon “supporting participation in forensic psychiatric care” emerges in the contrast between the role of supporting patient participation and the custodial role. There is a clear discrepancy between the meaning of the concept of participation and how it can be applied in forensic psychiatric care. Support for participation is limited and needs to be included within the framework of compulsory care and forensic psychiatry. Supporting participation as involvement in minor matters within this framework and the range of activities therein can be understood as a substitute for participation in a broader sense. The quality of the carer-patient relationship is crucial for whether or not participation can be supported as this is essentially the foundation for this phenomenon.

Communication and shared information are the underpinnings for building a caring relationship and in the establishment of trust. Moreover, by reinforcing a mutual patient-carer relationship the patient can be strengthened and participation can be supported by providing the right tools, learning to manage setbacks, highlighting progress, and increasing motivation. In order to support participation, an approach as a communication partner is taken where the relationship is characterised by honesty and where the patient is not deprived of more power than necessary. This entails striving to create coherence by sharing knowledge with the goal that the patient should better understand himself and his place in the forensic psychiatric system.

In the almost impossible task of supporting participation, the carer is in a precarious position between the system and the patient. This ultimately entails a difficult act of balancing the paradoxical role of caring for the patient’s interests and development, while simultaneously representing and adhering to the rules and regulations of the system in which the carer is employed. Supporting participation in forensic psychiatric care appears to be complex as it involves supporting the patient to follow the structures, rules, and frameworks of the institution while concurrently supporting the patient to do so for their own sake, by their own willing.

The ambiguous range of participation

To support patient participation is complex and gives rise to questions about what participation means in forensic psychiatric care. The phenomenon “patient participation” within a forensic psychiatric care context is elusive. The range of participation in compulsory care is ambiguous, but its importance is still advocated by carers. The carers’ reflection about the meanings of participation show that the concept is experienced as a label, a collective concept of something that appears much broader, and in practice difficult to grasp.

It is a subjective experience of... like, one perceives their own participation subjectively. It is nothing that can be measured in objective terms really. Because one perceives their own participation differently. (interview 11)

Supporting participation is described as an opportunity to allow patients to make choices and decisions, even though decisions in themselves are limited. Due to the fact that the care is compulsory, carers are unable to allow patients to decide over certain things, such as cessation of care. Thus, carers can merely offer patients a limited participation in their care. Nonetheless, carers give the patients the opportunity to make minor decisions whereby the carer’s aim is not to minimise the patient’s space for decision-making any more than necessary. This can include, for example, allowing the patient to decide the order in which they are offered certain care interventions, such as addiction treatment. To support participation can also include allowing the patient to make small everyday decisions, such as what time to get up in the morning.

Allowing the patient to be involved in making decisions in minor matters such as the layout of the ward environment, for example, assisting in decorating during holiday festivities can be described as a way to support patient participation. Furthermore, it can include granting patients the opportunity to choose between different activities. However, carers express that such an example does not increase participation, yet can give patients a feeling of participation.

but if you look at the things that they actually can decide then I think that several patients would say that they are participating in things that they can anyway... though if you would just straight off ask then I do not think there is particularly many that would say that they are involved. (interview 2)

The balancing act in the roles as carer and “guard”

Support for participation is found to be limited and dependent on rules and safety regulations. It is a balancing act where, on the one hand, the carer should support participation, and, on the other hand, needs to work along the path that the patient constitutes a high risk and needs to be limited in its freedom. This often entails a degree of frustration amongst carers in not being able to work in a way that supports patient participation.

I am aware that you need to assess in the right way to not expose society to danger. But if you cannot structure and plan and try, then you don’t get anywhere. (interview 7)

To support participation, despite the presence of barriers, can mean that carers express that rules and limitations are unfortunate but that these policies at the same time must be followed. Thus, the viewpoint of the individual and the psychiatric system come to diverge. In the role of a carer this entails being able to take responsibility for rules regardless of one’s personal attitudes towards them, while concurrently being able to empathise with the patient. To share one’s own feeling could be a way to support participation.

if there is one rule that I think is wrong then I say that I too think that it is a really stupid rule but unfortunately we have to follow it... it’s just as tedious for you as it is for me. (interview 10)

To provide compulsory care is challenging. There is a determination among carers to try to be something other than a guard. This can be demonstrated in carers’ ambitions to act in a way so that patients see them as human beings,
and not only view carers as a “function” of the system. In doing so, an effort is made to try to minimise the power exertion. The carer experiences double roles; they in part act as a support for patients and take responsibility for their best interests and try to support their participation, and at the same time need to respect the rules and structures in place. One carer explains how patients can express this.

That you come and knock on the door, you don’t really want anything you just open the door “how’s it going today”. What the hell you are no prison guards, you mean us well. You want something with us. So then you have then gained something with this … (interview 1)

This shows that the relationship between the carer and the patient is an important foundation for supporting participation. However, sometimes it is difficult to get a patient involved, which can cause feelings of failure and be difficult to handle. In this way, the care becomes incapacitating and the carer becomes frustrated.

It is clear that patients generally do not want to be involved in the care here and do not even want a care team meeting… yes then we have a patient who is far from participating in the care. (interview 9)

A good relationship: Not participation but the next best thing

Participation is a complex phenomenon for carers as they try to efficiently balance their duties as a carer and a “guard”, while also attending to the most central aspect: the carer-patient relationship. Building a relationship through trust, security, communication, and how you treat others is essential to create the conditions for participation. Although full participation cannot be achieved, the carers mean that through good relations with the patients, they can make the patients understand that they are doing their best.

It is not me that should say that now we are going to do this because it is written in their care plan, it is that they want something themselves. Then I think, in order for me to want something, then I have to have some sort of relationship to the patient anyway. If I come and order and give a load of suggestions on things, then there will be nothing… like, it is a lot easier, partly it is easier too when you get to know someone because you know a little about the goals they have for themselves. (interview 2)

Treating others well is the basis for creating and maintaining a patient relationship, to win trust and understanding. To create a relationship where participation exists is done through building a carer-patient relationship whereby the patient gradually regains responsibility during the care period.

Despite the power advantage it entails to care for someone in compulsory care, there is a determination to get patients to trust the carer. At the same time the carer, in attempting to create a trustworthy relationship, must be careful and take responsibility for the power they possess in order to achieve participation at some level.

I am already in a situation where I have the power… I have the key, I have the card, I am the staff. There comes a stranger that has never been to visit us. It is like completely new… there it is really important that we are very careful in our approach and the way we talk and converse and so forth, do not condemn and all of that. (interview 9)

Caring interventions with which one aims to create participation

In striving for patient participation, carers can take advantage of the already established relationship with the patient and thereby attempt to work for experienced participation with the patient. By aiming for good relationships there is an opportunity for carers to help the patient cultivate acceptance, understand his or her illness, develop an attachment to society, and, in several ways, help the patient towards a meaningful sense of coherence. In the context of such a relationship, the carer is always present in an attempt to listen and be of assistance. In many ways, the carer role is a reflective one that aims to support the patient to view situations from different perspectives. Sometimes, it is the small things that carers can do to support patient participation, like listening to and talking to the patient.

The patient is not … He has a resistance already when he arrives within care and to us. He does not want to partake, participate in what we offer him and in this way when we start to talk about the care and his needs and that and create that trust then there is a participation in this that the patient understands. (interview 1)

The fact that the patient is under compulsory care means that he or she requires help with overcoming the resistance for the care being offered by being supported in seeing the care as care and not merely as “punishment”. One tool to be implemented by the carer is holding the patient accountable for their own behaviour, not viewing him or her as a helpless individual but rather as a human being capable of accepting responsibility. However, the challenge for the carer is to balance the level of confrontation in a conversation of this kind. Yet again, it is a balancing act that demands the carer’s courage to be able to challenge the patient to accept responsibility for their own actions despite the risk for the development of friction. One particular carer extends an example of how a patient can be challenged.

The patient: ‘I don’t want to go to the physiotherapist today’ … The carer: ‘No, why not?’. The patient: ‘No, I can’t be bothered, I don’t have the energy’. The carer: ‘Oh no, really why not? What is the difficult part? Why don’t you have the energy? (interview 6)

To inform and provide expertise on the forensic psychiatric services is described as helpful for the patient. Informing about the care and about the limitations of the care can facilitate the patients’ understanding of the carers and help the carers motivate the patients to work on their own development as well as maintain progress in their own care process in the long term.

Discussion

The findings reflect carers’ experiences in supporting patient participation in a maximum security forensic psychiatric care setting.
The results in this study show, from the carers’ perspective, how challenging it is to support patient participation in forensic psychiatric care, something that can be explained by the unavoidable power relations present in compulsory care. This can be further explained in relation to Hörberg and Dahlberg’s (2015) postulation that the duty of forensic psychiatry is double-sided with an inherent risk that the caring potential is overshadowed by involuntary actions and disciplinary measures. More specifically, there seems to exist a contra-productive pattern of power, discipline, and involuntariness in forensic psychiatric care. Participation within forensic psychiatry can therefore be argued as limited, and the duty to support participation as complex. Nonetheless, this is a balancing act whereby carers have to take responsibility for the forensic psychiatric care institution, support regulations, and maintain a working order.

This study illustrates how carers, from a power perspective, describe the facilitation and support of patient participation. Their expectations of supporting participation sometimes resulted in negative emotions when they failed. Our results give example of presence of power in the caring relationship and, that not being able to support patient participation, can yield feelings of powerlessness among carers. Holmes (2005) suggest that carers and patients share the same fate in being in a state institution where they are equal parts subject and object, and where the institution shapes and decides their behaviour. Therefore, they exist within a potent network of power relations. Both are prisoners in a law-enforcing “ carceral” organisation. Additionally, Hörberg, Sjögren and Dahlberg (2012) argued that patients in forensic psychiatry learn what is expected of them and which behaviour pays off; in other words, find strategies that provide benefits. Carers within forensic psychiatry have the power to punish, reward, or simply wait out the patient. Patients can, in turn, use their power to not conform, to conform, or to withhold information from carers. Our study demonstrates how complicated this power relation is in the context of supporting participation in forensic psychiatry. Carers describe the importance of participation, but at the same time emphasise that the implementation of participation is not possible when based on a narrow definition. To support participation in a maximum security forensic psychiatric setting is instead described as something that entails not using more of your own power than necessary while at the same time maintaining the patients’ right to decide as far as possible.

The carers describe a desire to be something more than a “ guarding function”, and how they try to instil an understanding for this with their patients. The guard metaphor is employed by carers to illustrate what participation is not. This can be understood as a part of the dual-role dilemma between these two roles or sets of tasks, promoting public safety on the one hand and the wellbeing of individual patients on the other hand (Robertson & Walter, 2008; Ward, 2013).

Askola et al. (2018) argued that patients in forensic psychiatry often begin their time in psychiatric treatment feeling a sense of alienation. Sometimes patients start fighting against the forensic psychiatric institution, while at the same time being very vulnerable. The authors suggested that patients need different methods of approaching at the different stages of the treatment. As the psychiatric treatment continues the patients, in most cases, experience how nurses transition from being “villains” to becoming helpers. Likewise, the results from the present study indicate that cultivating a more power neutral patient-carer relationship is a process which occurs over a longer stretch of time and wherein the carers try to achieve increased levels of trust during the patients’ time in care.

This study implies that participation is a complex concept in high security forensic psychiatric settings, and that it is difficult for caregivers to comprehend and take responsibility for the concept as it seems difficult to know what is expected, thus, participation has an ambiguous range in this context. In fact, caregivers use an arsenal of other concepts in their strive to understand and explain participation in forensic psychiatry. It seems more accomplishable to describe how to build a good relationship with patients or how to treat patients in a respectable manner. Nilsson, From, and Lindwall (2019) suggested that participation as a concept is vague but that patients’ participation can be understood from three concepts: learning, caring relationship, and reciprocity. They suggested that the concept can be clarified if the science of caring manages to introduce these attributes in clinical practice. According to Olsson and Schön (2016), patient participation within forensic psychiatry can function as a protective factor in the avoidance of violence. It is, however, described as a challenge to instil understanding of the importance of participation in patients convicted to compulsory care. The mentioned study concluded that a good patient-carer relationship, wherein the patient can feel trust and safety, is a prerequisite for further supporting patient participation. The current study shows that carers attempt to make the forensic psychiatric care comprehensible by explaining the ways in which it operates, why it is devised as it is, as well as why rules and regulations are in place. The carers also try, through establishing a caring relationship, to support the patients’ participation.

The current results show how the carers attempt to gain the patients’ trust and to establish a caring relation. This is described as a process where the carer strives to maintain a caring approach in attempting to create a trustworthy relationship whereby the patient regains more responsibility during the care period. According to Hörberg (2018), maintaining a caring approach and striving to understand should not be seen as a method but rather as a tool for carers to remain open and sensitive in interactions with patients. The importance of understanding is relevant not only for nurses but provides a foundation for a caring attitude for all categories of caregivers (Hörberg, 2018). It requires courage from the carer to engage in in-depth conversations with patients, and to share their suffering (Rydenlund, Lindström, & Rehnfeldt, 2019). Hörberg (2015) suggests an implementation of a caring science perspective based on a lifeworld approach within forensic psychiatric care, but concurrently argues that caregivers are in need of assistance in
the transfer of care science theory into practice within the context of patient contact. This argument can also be understood in relation to one of the findings from the present study, namely the struggle of supporting patient participation while simultaneously balancing a caring role and the role as a representative of the institution within which the caregiver operates and within which the structures and frameworks need to be maintained. This is a process that takes time and with which the carers need to be patient. In other words, they must maintain their footing under shaky conditions and constantly be prepared to take responsibility for the patient-carer relationship.

Conceptualising participation as the opportunity to take part in decision making and having access to choices means that participation is limited in the context of forensic psychiatric care. In the results of the present study, participation is defined as abstaining from making decisions that the patients themselves can make or to offer several different options. Supporting participation can, from this perspective, be understood as encouraging the patient to make decisions regarding certain aspects of their own care. These are decisions that the patient practically, legally, and organisationally has the opportunity to make. To exemplify, partaking in addiction treatment is not voluntary for patients if they want to progress in their care, however nothing prohibits patients from making decisions about the speed of succession in such an addiction treatment programme. This viewpoint centres around providing the patient with an opportunity for decision making. If participation is to be understood as a joint decision-making process and the will to listen to the patient in this process, facilitation of participation can then be further discussed from a more modern person-centred care concept. Person-centred care is a broad notion that, in the inpatient psychiatric environment, is defined as cultural, relational, and recovery-oriented (Gabrielson, Sävenstedt, & Zingmark, 2015). According to the Swedish Nurses’ Association (2016), person-centred care is a term that successively has gained more attention in the public discourse. The concept of person-centred care has also been included in international policy documents from the WHO, as well as in National Guidelines in Sweden, the United States, United Kingdom, Australia, New Zealand, and Norway. Ekman et al. (2011) noted that a paradigm shift to a more person-centred care is occurring slowly but that the progression has begun with many sectors of the care system already operating in a more person-centred manner. However, organisations are still in need of guidance as to how they are going to function in a systematic and consistent manner in line with the person-centred approach. Thus, three key concepts have been formulated: shared decision making in the partnership, the patient narrative, and documentation.

In this study, working towards offering patients opportunities for decision making is equal to supporting patient participation. In this case, the possibility to make small choices, even if they seem simple, is referred to as a way to support participation. Therefore, we want to discuss participation from the perspective of person-centred care and shared decision making.

Shared decision making is also a leading aspect to the person-centred care paradigm. In a review article, the results indicated that shared decision making can enhance patients’ experience of the care and boost treatment adherence (Patel, Bakken, & Ruland, 2008). By employing shared decision making, patients can feel strengthened and valued, their attitudes towards medication improve, along with their adherence to treatment (Nott, McIntosh, Taube, & Taylor, 2018). Caregivers wish to involve their patients in their care, while simultaneously being aware of the obstacles that stand in the way of this, e.g., the lack of competence to participate (Patel et al., 2008). In order for patients to fully experience shared decision making, power and knowledge are necessary components. Studies have highlighted that patients do not partake in shared decision making simply because they cannot due to various structural, predisposing, interactional, and preparatory factors rather than an unwillingness to participate; the latter being a rather common misconception among caregivers within different care settings (Joseph-Williams, Elwyn, & Edwards, 2014). This perspective can also be employed to understand the results from the current study. These results are illustrative of how carers describe participation as an opportunity to choose between different types of food to include in your daily meals; merely this opportunity to make decisions provides a sense of autonomy. Caregivers strive to increase patient participation by providing clear information, as well as attempting to motivate and educate the patient. However, they are unable to offer a platform for shared decision making if the patient’s own will and needs are not congruent with those of the care plan. In turn, this means that participation is contingent on the patient taking part in the own care process.

Shared decision making within forensic psychiatry appears to be a challenging venture and calls for the clarification of how person-centred care and shared decision making could be implemented in such a context with a significant amount of restrictions and where safety regulations pose obstacles. In a study on shared decision making, paternalism, and patient choice the authors argued that shared decision making is described as a norm for person-centred care, however there exists no clear distinction between shared decision making and other models such as paternalism and patient choice. The authors reasoned that shared decision making is of interest only if it acts to reduce the polarised relation between paternalism and patient choice (Sandman & Munthe, 2010). In another study, Sandman and Munthe (2009) described the concept of shared decision making in relation to autonomy, where they portrayed shared decision making on a continuum with paternalism on one end and full patient choice on the opposite end. The authors argued for nine distinct types of shared decision making where the degree of autonomy varies. In their view, autonomy should be valued as a property of a person’s life, and self-realisation, from an ethical perspective, as an imperative part of the autonomy construct. Accepting the argument that paternalism and free
patient choice are indeed two polar opposites on one spectrum clarifies the findings of the current study. In contrast, if participation is considered to be part of a more fluent scale, the results of the present work indicate that caregivers’ attempts to foster motivation and understanding and information sharing with their patients can be comprehended as means of facilitating participation. In this way one can avoid the realisation of participation and non-participation as a dichotomy, and instead recognise the concept based on levels of participation and the process of supporting participation.

Methodological considerations

The fact that the study is done solely within one forensic psychiatric setting is a limitation. It involves, however, informants from three different wards, which nevertheless gives a variation of meanings of the phenomenon. The transferability is possibly restricted to maximum security forensic psychiatric units, but by presenting the result in a general abstract level, the results may apply to other contexts with lower security as long as it is an environment that entails compulsory care. In support of van Wijngaarden, Meide, and Dahlberg (2017), we argue that a strength of RLR is that the analysis results in a description of the phenomenon on an essential level in an essential structure of meanings, and thus creates possibilities for transferability of the results.

Through the analysis process, a bridling approach was used. This means that openness and flexibility, as well as a reflective attitude towards the phenomenon, was employed, which according to Dahlberg et al. (2008) enhances validity. However, the first author who conducted the interviews has long experience of working within forensic psychiatric care, both as licenced assistant mental health nurse and as registered mental health nurse. Thus, the first author has own lived experiences of supporting patient participation. The methodological principle of a bridling attitude during the analysis process has been supporting both in the interview situation and during the analysis to not let the own understanding obscure the understanding of the phenomenon in focus. The discussions in the research team have been characterised by a reflective attitude. The phenomenon supporting participation was hard to capture due to the concept’s range which seems to include wide variations. It is important to point out the obstacles to an increased understanding of the possibilities of supporting patient participation. The phenomenon is hard to capture in this context, but that does not make it less important. This is, however, presented in the results and in the discussion.

Conclusion

The term participation can be interpreted from a variety of philosophical perspectives, and this has been done in different conceptual analyses. From an intellectual and philosophical standpoint, the term participation can be somewhat clarified by the science of care, however, the translation of this term into practice within a maximum security forensic psychiatric setting appears to be altogether complex.

In conclusion, based on the analyses conducted in this study, participation in a maximum security forensic psychiatric setting is a desired and sought-after ambition. In order to reach this goal, the adoption of a relational and humane approach is necessary. However, this is something that should not be accepted as a substitute for the wider term participation. Further, the current study elucidates that participation is difficult to conceptualise in the context of forensic psychiatry. Nevertheless, caregivers within this sector try to understand the phenomenon of participation mainly by describing what they perceive as the opposite construct. Thus, it is simple to perceive participation and non-participation as a dichotomy rather than existing on a continuum; with the second perspective possibly making the term participation easier to grasp. Based on the aforementioned results it is further suggested that participation is comprehended as an umbrella term and that focus is directed to conceptualising what caregivers can do in order to create positive patient-carer relationships, as well as what constitutes such a relationship. Conclusively, patient participation is a secondary outcome and something to continuously strive for.

Clinical relevance

If supporting participation means building positive and good relationships, then the clinical implication of this finding means that more effort needs to be placed on supporting caregivers within the forensic psychiatric sector in the creation and development of their caring relationships to patients. Likewise, caregivers must also be helped in balancing and mitigating the consequences of their conflicting work roles; that is, concurrently being responsible for the caring function and the protective function inherent to their position. Participation needs to be understood as a contextual concept in order to prevent it from becoming merely a word—and ultimately, an obstacle for caregivers in their daily practice. We thus suggest that staff get guidance in how patient participation can be understood and applied in the development of care plans, and that efforts are undertaken to assure that patient and staff have a common understanding of patient participation in these contexts.

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