

User Participation and Insight among Mentally Ill Individuals: Stories from District Psychiatry Centres in Northern Norway

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Link to the Research Output

- Klausen, R. K., Haugsgjerd, S., & Lorem, G. F. (2013). *'The Lady in the Coffin' – Delusions and hearing voices: A narrative performance of insight*. *Qualitative Inquiry*, 19, 431–440. doi: <http://dx.doi.org/10.1177/1077800413482096>

The purpose of this text is to describe the beginning of a qualitative study related to user participation and insight among mentally ill individuals. The term 'user' describes a patient who is not a passive recipient, but an active user of services. The study uses a narrative methodology and includes 30 in-depth interviews with consenting participants who have experienced serious changes in their lives because of their disease and who have experienced one (or more) hospitalization because of their disorder. Through a pilot interview with a user patient, who became a co-researcher and consultant for a very short period of time, the interview guide changed. During the interviews, I realized that the results would be different than first expected. Unexpected challenges arose in relation to the interviews as three of the participants were refugees who had been denied their applications for asylum. I had prepared myself for interviews with patients who were well acquainted with the Norwegian treatment culture. Telephone interpreters were needed, and the interview situation changed. Dilemmas related to the role of the researcher emerged. It was difficult to be a researcher, and exclude the therapist role. Reflexivity proved necessary throughout the research process; by exploring what happened during each interview, I came closer to see what shaped my research results. A reflexive approach proved to be fruitful in the process of constructing of knowledge.

Learning Outcomes

After reading this case, students will know more about

- Research design and data collection
- Question formation: 'What brought you to psychiatric services'?
- Meeting the participant you don't 'need' in your study: feeling ashamed
- Being a researcher, not a therapist: the complex nature of emotion work
- Research ethics and reflexivity: How did I construct my knowledge? How do we construct knowledge?

Topic of the Research

The main purpose of this study is to examine how seriously mentally ill individuals understand their illness and treatment. This study aims to help provide a language that describes insight and how it can be related to the way the patient describes himself or herself in conjunction with psychiatric treatment. The project will emphasize communication that relates to the patient's knowledge of himself or herself and his or her health in relation to health professionals and treatment services. The goal is to expand the ways in which user expertise among the mentally ill can be utilized. The second purpose of the study is to focus on user participation as a right and a duty in psychiatry; how do the patients experience user participation in their daily lives at the institution? Do the patients feel that they have a real impact on their treatment at the individual level, the system level and the political level? By interviewing 30 patients, I hoped to gain a better understanding of the concept of user participation as a dynamic and complex matter that constantly needs to be discussed in district psychiatric centres. The third purpose of the study is to examine the meaning of the place where the patients receive their treatment; in a changing therapeutic landscape, new health reforms are challenging patients to receive psychiatric treatment closer to home to avoid hospitalization. The project was approved by the Ethics Committee of the Fifth Region in Norway in 2011.

Background Overview of the Topic

Insight is closely related to the concept of consent among psychiatric patients and often focuses on topics such as risk or danger, prognosis and outcomes of treatment. Lack of knowledge is often regarded as a diagnostic feature, and the majority of the practitioners in this research tradition focus on clinical factors. This study seeks another approach to insight.

In accordance with Norwegian Health and Social Affairs, *user participation* is conceptualized at three different levels:

- the individual level – the user gains influence in relation to a specific service (i.e. it is possible to participate in the selection, design and application of the offerings)
- the system level – the user is included in an equal partnership with public services and actively participates in the planning and decision-making about treatment
- the political level – user groups and user organizations are involved in political processes

The study focuses specifically on user participation on the individual level. The *meaning of place* is connected to where the patients receive their treatment.

Contemporary psychiatry has undergone major changes in recent years in Norway, and as a result, we now encounter a new psychiatric landscape. Health reforms are bringing changes into the field, and more patients should receive the help they need from their own municipal services.

Development of Research Questions

Based on the purposes of the study, the following research questions were developed:

- How does the user understand his or her life situation? What aspects of his or her life situation does the user think is important that others understand?

- What experiences does the user have with interaction and participation? How did he or she interpret the situations in which he or she did or did not participate?
- How does the local treatment place affect the way the user perceives his or her health and copes with the situation?

Using these research questions, I developed the interview guide.

Interview Guide and Question Formation

I prepared some words as an introduction before the interviews, so I had something to 'hold on to'. This was sent in advance to the participants:

This interview is about your perception of your everyday life and the treatment you get here at (name of place). I would like to hear your thoughts about why you came here. I would also like to hear some of your thoughts about how this stay (or the experience at this place) will affect your life in the future.

This project focuses on what is referred to as user competence (i.e., how to influence what happens to you when you need help).

We want to hear about your experiences using the district psychiatric centre. In doing so, we hope that the users' voices are clearly reflected in the research.

Participation in the study is voluntary, and you can always withdraw from the project. You do not need to explain why. We want you to participate voluntarily because you think that you have something to say about your own experience as a user of a district psychiatric centre.

(Figure 1)

Figure 1. Caption: Interview guide.

Topic	Possible questions
<p>1. <i>Thoughts on personal life situation</i></p>	<ul style="list-style-type: none"> • Can you tell me how you got to (the name of the district psychiatric centre)? Or something about the decision that was made before you came here? Was it your desire or need? If others were involved, who? How did you react to the provision that you come here? Happy, relieved, confused? What did your family and friends say? • Do you think you needed to be admitted? • What do you need help with? <p>(Have you ever experienced losing control over your own situation? Have you been hospitalised? What do you think of that?)</p> <ul style="list-style-type: none"> • Do you think that your diagnosis is accurate and describes how you actually feel? • What do you think about the help you get here? • Do you think you can influence the help you get here? • Do you feel that you are being heard? Tell me about a situation in which you felt that you were listened to. Why were you listened to? • Can you tell me about a situation in which you were not listened to? • Are there any aspects of your life you feel should be better taken into account while you are here?
<p>2. <i>User participation</i></p>	<ul style="list-style-type: none"> • Tell me about a situation in which you took part in an important decision about your treatment. • Who was present during this decision? • Why do you think you got to influence the decision? • Tell me about a situation in which you could not be part of an important decision about your treatment. • Who was present during this decision? • Why do you think you did not get to influence the decision? • What would it take to change the situation? What could have been done differently? • Can you tell me about the medical treatment you receive?
<p>3. <i>Importance of context</i></p>	<ul style="list-style-type: none"> • What do you think about the place you live now? (Is it better to stay here than other places you have lived?) • Who do you have contact with in your everyday life (other patients, friends, family, network)? • Do you have family/relatives/networks nearby? • Is this your hometown? Do you know many people who live here? • Do you like it here? Do you feel at home? • Do you participate in any community activities? • Who is closest to you? Family, friends? What role do they play in your daily life? • What do you think of your everyday life?
<p>Users Resources: What could have been done</p>	

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The interview guide was thoroughly reviewed at this time, but I decided to contact a patient representative from an organization of users of psychiatric services. Because I was conducting a study about user participation, I felt that it was appropriate to include a user at this stage of the study and that it would be interesting to test whether the questions were sufficient enough to achieve the study's purpose. I made contact with a user, and she agreed to participate in the development of the interview guide. I conducted a pilot interview with her, and she served as a consultant during the pilot interview. I sent her an information sheet about the study and the questions in advance so that she could read through them and offer feedback. She thought that the interview guide was far too detailed and that the study participants would have too little space to talk about their concerns. She advised me to create an interview guide that was more open and less detailed to give the study participants more space to talk during the interview. She suggested that I open the interview by asking, 'Can you tell me how you first came into contact with psychiatry?' This question provided a broader opening for the participants' stories. She also advised me to ask more about medication and experiences of coercion, but those questions would move the conversation further away from the study's purpose. I decided to follow her advice about the opening question and making the interview more open to the participants' stories. I kept the interview guide as a reference during the interviews, but I was more concerned with what the individuals said and used the guide to address the study's themes. The three topics of the study (insight, user participation and the meaning of the place) were all addressed during the interviews, but not necessarily in the same way as in the guide.

Data Collection

I contacted the managers at three district psychiatric centres after the interview guide was complete, presented the study and asked whether they were interested in participating. They all immediately reacted positively to the study and asked for information in writing so that they could inform patients and staff about the study and elicit their opinions about participating. We agreed to get in touch again in 2 months and to start the data collection immediately if there was interest in participating. Information sheets about the study were sent to all of the centres, and one of the employees at each location was selected as a contact person who was responsible for the practical

issues involved in the study. The contact person was well informed about the project and the procedures for recruitment so that information could be clarified and questions could be answered orally. It was important for the participants to receive adequate information about the study's purpose, the right to withdraw from the study and the anonymous and confidential nature of the data. It was also important to give the potential participants time to think before they responded and to ensure that the project only received feedback about those who wanted to participate. The invited participants were unknown to the project staff until their responses were received directly. After 2 months, I began the data collection. Many participants wanted to contribute to the study. The inclusion criteria for participation in the study were informed consent and one (or more) admission(s) to a psychiatric hospital. The final inclusion criterion was that their disease had led to significant changes in their lives. The contact person at each centre ensured that all participants met these criteria. If the participant chose, he or she could bring one person from the centre (or someone else) with her or him to the interview. Before each interview started, I was supposed to re-confirm the participant's informed consent and ensure that the participant understood what he or she was participating in. How can we fully understand what we are involved in before the interview has even started?

The Challenge of Ethical Mindfulness

Ethical mindfulness within qualitative research can be said to fill five functions (Guillemin & Heggen, 2008). The first function is to recognize the role of ethically important moments in everyday research, and second, as scientists, to be prepared to accommodate not feeling comfortable in a situation. There may be something wrong during the interview, and it is important to reflect on what this might be. Sometimes, this feeling tells about ethical dilemmas in research. In certain cases, it may be stressful to talk about matters affecting one's own illness and treatment, including difficult and/or abusive experiences. This possibility required special ethical consideration in the interviews. I was capable of providing assistance, supervision or other necessary measures that were needed. It was important for the participants to understand that the interview was part of a research project and not a therapy session. Third, ethical mindfulness requires that I articulate what is ethically important in the research process

(Guillemin & Heggen, 2008, p. 295). To be able to do so, one must be familiar with the basic principles of health research, that is, the procedural dimension of research ethics (Guillemin & Gillam, 2004). The fourth feature concerns reflexivity. I must be aware of my own role in research, particularly in relation to my study participants. Being mindful ethically, I would reflect on my role in the entire process of undertaking the research, carefully scrutinizing what I say and do, and reflecting on the possible interpretations and consequences of my actions (Guillemin & Heggen, 2008, p. 296). The last feature is courage. Ethical mindfulness requires courage from the researcher; I must dare to take everyday ethics seriously within my project, even when I meet the participant I don't 'need'.

The Unpredicted Fieldwork

At the first centre, several participants had not been admitted in time for the interview, and the contact person made the appointments in the participants' homes or at a nearby office. The contact person drove me around the large district centre, which covers several municipalities. The distances were large and gave me an impression of the area that I would not otherwise have had. Conducting the interviews at the participants' homes created a different atmosphere; I was a guest coming to their homes. Coffee was served; I greeted family and relatives. Pictures and the places where the patients lived became a central component of this fieldwork. A total of 12 individuals were interviewed in this area. I stayed in the area for 3 days at a hotel, conducting the interviews during daytime and writing notes in the evenings. It was exhausting but very exciting and professionally rewarding. Each interview (except one) lasted at least 30 min. One interview lasted only 12–13 min before concluding. In that case, the contact person had been unsure about whether the woman was capable of providing consent. The contact person and I decided that she would attend the interview. It soon became clear that the participant did not understand what she was agreeing to do, although she did confirm her consent, and we stopped the interview. This process took several minutes because the participant spoke very indistinctly and said she was lonely and had been waiting for us. We had to stop the interview in an appropriate manner.

At the second centre, I conducted all of the interviews with people who were admitted. The contact person at this centre had not made any appointments with the participants,

and we had to 'take it as it came'. A total of 10 interviews were completed, and 3 of them were conducted with refugees whose applications for asylum had been denied. When the contact person at the centre asked me whether they were interesting to talk to, I could not say 'no'. The interviews with these people were difficult, and I felt that I could not connect with them as well as with the other participants. An important reason for this disconnect was the lack of a common language, which required the use of a telephone interpreter. I was not prepared to use an interpreter and found these interviews exhausting and overwhelming. The three refugees discussed traumatic experiences from known war zones in the world and did not seem very interested in their user rights in psychiatry. The informed consent process was conducted with all three participants in advance, but I asked myself afterwards whether they really understood what they were participating in. All three participants were concerned that their applications had been denied and feared that they would be forcibly returned to their homelands upon release from the psychiatry centre. *Did I represent a hope of help?*

I stayed at the centre for 5 days and lived in an apartment that belonged to the centre and was intended for the patients' relatives. Being at the centre all day felt like a burden, and I felt tired after each day with two interviews.

At the last district psychiatric centre, I conducted seven interviews, including five with admitted patients. The last two participants came to the centre for the interviews. The contact person at this centre had planned everything, and all of the participants were ready when I came. I stayed for 3 days. I stayed at a hotel not far from the centre but because of the experience at the second centre, I knew that I needed the afternoons 'off' while gathering the data. This centre had more participants who talked about suicide attempts, and I thus felt the need to talk on the phone several times with one of my supervisors. He is a psychiatrist with many years of experience in the field. I heard so many painful stories, and I felt a lot of pressure because I was not working as a therapist in this setting but 'only' as a researcher. The stories from the people I met during data collection made a deep impression on me, and there were days I felt physically sick. How could they cope with all the suffering? How could the professionals provide them with the help and support they needed?

Analysing the Data

After completing the interviews, the transcription began. I transcribed all the interviews verbatim, but I left out the interviews with the woman who had to stop after a short time, with a young man affected by illegal drugs and the three refugees. Why did I leave the refugees? All of the sighs, coffee cup noises and dogs barking were transcribed within the other interviews. Transcription was a large task; at times, I felt I spent all my time with the computer and did not see any progress. However, something happened with the interviews during this time. I heard the dialogues in a different way, and I was glad that I had not delegated the work to someone else. Transcribing all of the interviews was an important part of the analysis; I could listen to them in a different way, read through them and find new themes emerging from the papers in front of me. I spent 2–3 months on the transcription. I had to stop the tape recorder many times and listen repeatedly to ensure that the transcription was correct. After the first transcription of an interview was completed, I had to review it several times to ensure that it was entirely correct. In projects such as this, it is difficult to pinpoint the analysis as a single point. On the contrary, the analysis begins before the interviews. You choose topics and questions that you hope will help you find a way ‘through the jungle’. But I could not ignore the fact that I had left the refugees ‘out in the cold’. I felt ashamed of myself, and I had doubts about my researcher qualities. According to research, a narrator experiencing shame during the telling of a tale is likely to feel exposed, lacking, wrong, bad or inadequate (Heller, 2003; Lewis, 2003; Owens, 2006; Scheff, 1988). I had all those feelings, struggling to convince myself that I did the right thing leaving them out of my data. The main reason for not including them was their ‘otherness’ compared to the rest of the interviews. Was that reason good enough? The fact that I was not prepared and was afraid that I had not conducted them in a good manner, what about that? According to Bellas (1999), ‘scientists are trained to suppress emotions’ (p. 104). I had to investigate what this was.

Meeting the Participant You Don't 'Need' in Your Study: Feeling Ashamed

The first participant I met at the second centre was Faizah, a Yemeni woman, 30 years old and a refugee. Her application for asylum was rejected twice by the Norwegian authorities. An Arabic woman was the telephone interpreter, translating our conversation.

I asked Faizah what she thought about the psychiatric treatment at the centre.

Faizah talks in Arabic to the interpreter.

Interpreter: What I'm thinking, the first time I came here, I had mixed feelings and I was scared. Anxious, did not know what was going to happen. What people she should contact. But already the second week, you [the staff at the center] have erased those thoughts away completely. She is so well taken care of, that it wiped away completely, the anxiety.

Rita: Hm. Do you think that you are getting too much or too little help?

Faizah talks in Arabic to the interpreter.

Interpreter: I get too much help, she says. More than what she needs. For example, if one day she did not get up, they come into the room after a few hours, and wonder why she has not come out – so they care about her.

Further into the conversation, I ask Faizah about how important it is for her that she is in this place. The interpreter translates

to Faizah, and the interpreter says Faizah answers:

She says that at first, she was very excited at the same time she did not know how it was – but from the second day she felt like she was at HOME with her family.

Rita: Is it better to stay here than elsewhere?

The interpreter translates to Faizah and they laugh.

Interpreter: Yes (laughing still).

There are several things in this excerpt that is worth taking a closer look at. The interpreter changes between using first and second person; she says 'I' and 'she' when she refers to Faizah's statements. I remember getting confused by this, not being sure how to ask the questions. Should I say ask them directly to Faizah or ask the interpreter what Faizah thought? What impression would this give Faizah, being talked about (and to) in third person? Another issue is that the interpreter (or is it Faizah?) talks about the staff at the centre as if I was a part of them: 'But already the second week, you [the staff at the centre] have erased those thoughts away completely'. Do Faizah and/or the interpreter *really* know that I am not working as an employee at the centre? Instead of trying to stop and examine this, I just continue with my questions. I can hear myself on the tape recorder, not knowing what to do. The situation becomes even more apparent when I ask Faizah whether it is better to be at the centre than elsewhere. What do I mean by 'elsewhere'? Do I mean her home country, Yemen, where she and her family were politically persecuted? Or do I mean the Reception Centre in Northern Norway? Or do I mean Norway? Faizah and the interpreter both laugh at the absurd question. To me, the situation becomes even more absurd when the interpreter asks Faizah if she would say something before the end of the interview. Faizah then thanks the Health Ministry. She also thanks me for all the help I have given her, and every person who works at the centre – from the doctors to nurses. I do not know what help I have given her. And what the Health Ministry had done for her? The interpreter ends the interview by saying to me, 'I just hope she gets well soon'. I am left with the thoughts that if and

when Faizah gets well, she will probably be placed on the first plane back to her entry point in Europe by the Norwegian authorities.

Being a Researcher, Not a Therapist: The Complex Nature of Emotion Work

According to Molly Andrews (2007)

stories are never told in a vacuum, and nor do we as researchers simply tabulate information which we gather. Rather, we feed into the process on every level, and our subjectivity is always a part of that which we are documenting. (p. 3)

I had the feeling, during the interviews, that they had a need that was not properly addressed through the routines of the centre. The interview became an opportunity for the participants to talk about their agenda, and was experienced (at least by me) as 'therapeutic' to some extent (Peel, Parry, Douglas, & Lawton, 2006). As a researcher, I must undertake the impact of the research on both the participants and myself (Dickson-Swift, James, Kippen, & Liamputtong, 2009). The emotional nature of qualitative research (Rager, 2005) must be made transparent in my project. Reflecting on emotions as they operate in a research context can enrich our knowledge (Evans, 2012). I agree with Owens (2006) that shame is a reflexive emotion and when it occurs during an interview 'the participant cannot both continue with the shame-producing thread and avoid the experience of shame' (p. 1168). I felt ashamed of not being able to understand Faizah's story as a very important story in the context we were in. I was ashamed for not really listening to Faizah, but more to the interpreter. The conversational space created during the interview was confusing. If we consider the conversational space as 'the arena of topics, gestures, and language safely available to individuals in a given verbal interaction' (Owens, 2006, p. 1161), I would not feel safe in the situation. Did Faizah feel safe? I did not know how to ask about the refusal of her asylum application, what she thought about it. I was afraid that I would break into tears.

Research Ethics and Reflexivity: How Did I Construct My Knowledge?

Being a reflexive researcher means to understand one's own values and attitudes in relation to the research process, and it begins prior to entering the field (Hesse-Biber & Leavy, 2007). It is a process whereby I am aware of the situational dynamics that may occur between the participant and me. I was not prepared for Faizah and the interpreter. I was not prepared for their stories. I had an overwhelming feeling of guilt, guilt for being a part of the nation which had refused Faizah protection in a traumatic and difficult situation. I was ashamed of not being able to help. I was ashamed for trying to hide their interviews in a drawer because their stories revealed my shortcomings. By looking at myself and the research process through lenses of reflexivity, 'subjectivity in research can be transformed from a problem to an opportunity' (Finlay, 2002, p. 531). The need to explore what happened during the interview with Faizah helped me see what shaped my research results. The construction of knowledge in my project happens when I am having an ongoing conversation about the research experience.

Research Inputs – Or Outputs?

I have chosen to focus more on research inputs in this text. The reason for this choice is that the emotional nature of research work is often undervalued within university culture (Dickson-Swift, James, Kippen, & Liamputtong, 2007). Conducting qualitative research can have a powerful impact on the researcher, and self-care strategies may be needed (Rager, 2005). Through a reflexive meta-glance at my own research process, I found that my feelings of shame can be understood as a useful tool in the construction of knowledge.

Reflecting on the research process, I have asked myself whether I could have kept the user as a consultant throughout the study. It would have been a different study, and I would have needed new approval from the regional ethics committee. However, it might have been more closely related to the study topic of user participation to actually conduct the study *together*. It may also have affected the interview setting if a user

of psychiatric services was present as a co-researcher. Maybe he or she could have asked the questions to Faizah, which I felt too ashamed to do.

Exercises and Discussion Questions

- Challenges exist in ensuring that the research questions are covered in the interview guide; how do you turn abstract concepts into concrete questions?
- What are the advantages and disadvantages of conducting a pilot interview?
- How can we better engage users of psychiatric services in research about them?
- How can we prepare for unforeseeable events during the interviews?
- What are the challenges in distinguishing between the role of a therapist and the role of a researcher?
- How can we use our reflexivity and subjectivity as a tool for constructing knowledge during research processes?

Further Reading

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Web Resources

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