Narrative performances of user involvement among service users in mental health care

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This article deals with user involvement in mental health care and emerges from interviews with four service users at a community mental health center in northern Norway. The stories told by the participants were related to an impending closure of the center following a new health care reform. The aim of this article is to take a closer look at how user involvement was performed by the participants in the storytelling context. We explore the stories told using narrative contextualization analysis. Through our analysis, we find that narrative environments demands our attention to turn to storytelling as stories play out in the here and now of everyday life in mental health care.

Keywords: narrative research, narrative contextualization analysis, narrative performances, mental health care, user involvement, stories of user involvement

Introduction

To gain an understanding of how the service users make sense of their experiences of user involvement in a community mental health center (CMHC) we treat their stories as performances of user involvement in the local and global interview context (Helsig, 2010). User involvement is a legal right and a means to ensure the protection of users’ needs for care and treatment. A key target for improvement is to strengthen the user’s rights to participate in the design and execution of services (Norwegian Ministry of Health and Care Services, 2006).

Narratives can tell us about social and political critiques of social structures by taking into account marginal experience narratives (Stone-Mediatore, 2003) from people in marginalized social positions. In line with Andrews (2004) we see stories as constructed within a larger social context. Stories are social creations,
and people compose them by adopting and combining narrative types that culture makes available to them (Frank, 1995). When people tell their stories, they relate them to master or dominant narratives. According to Bruner (1987, p. 15) all of us create our stories from the ‘toolkit’ which is culturally available to us.

Consistent with Denzin (2001, p. 28) we understand the interview as the method by which the personal is made public, and the stories are always directed towards an audience. By looking at the interview contexts as transferable to narrative environments, we see the interview as a performance in a transitional space between the storyteller and the listener (Horsdal, 2012). By analyzing and understanding the stories told in the interviews as a doing of user involvement we understand the interviews as an active text, a place where meaning is created and performed (Denzin, 2001). Service users in mental health care can easily be described as a voiceless community, and listening to their stories can thus be seen as a political act in itself. This narrative study aims to contribute to the understanding of user involvement in mental health care. We focus on service users’ performances of user involvement in the interview context. The understanding of the interview context as a narrative environment is transferable to not only mental health practice, but also other disciplines where user involvement is a central topic.

We first provide an outline of user involvement in Norwegian community mental health care. The narrative approach is presented, followed by description of the method and setting of the study. The analysis focuses on the stories of user involvement as performances in the local and the global interview contexts. By analyzing four stories as contextualized performances, we also participate in an ongoing process of expressing user involvement as a dynamical and relational concept. We subsequently present concluding remarks, with recommendations for a narrative environment within mental health care.

User involvement in Norwegian community mental health care

User involvement makes great demands on service users, service providers, and communities. The definition of user involvement includes a range of concepts from active participation at the micro-level to service planning and participation in research arenas at the macro-level (Tait & Lester, 2005). With the political processes and organizational changes towards more local community services in Norway, there has been a change in the service user role. From being in a passive role as a mental health service user, one is now expected to be an active participant in the treatment. The new role requires service users to practice their experience competence, and it requires the professionals to let users participate (Klausen, 2016). In line with Rise (2012) we take our point of departure from a definition of user
involvement as a means to strive for shared decision making between users and providers through mutual respect and dialogue. As the new health reform promoting decentralization of mental health care and treatment is in the process of implementation, service users face changes that affect the conditions for user involvement in ways we know little about. Participation is regarded as a key feature of the new health reform, the aim of which is to shape health policy and ensure a patient-focused health care system (Pizzo, Doyle, Matthews & Barlow, 2014). The Norwegian context is transferable to other Western countries where decentralization has played an important role within mental health services (Klausen, 2016). User involvement has been ‘a key aspect of policy making for mental health services globally for the past two decades’ (Storm & Davidson, 2010, p. 111).

In Norwegian communities user involvement is currently not systematically organized. Nor is it an integral part of mental health services in terms of individual treatment or organizational decisions (Klausen, 2016). In this light our study aims to make a contribution by broadening our understanding of user involvement in mental health care through an analysis of user involvement as performed in the context of research interviews.

**Narratives as performances in context**

We follow Denzin (1989, p. 37) in his definition of a narrative: A ‘narrative’ is a story that tells a sequence of events that are significant for the narrator and his or her audience. A narrative as a story has a plot, a beginning, a middle and an end. It has an internal logic that makes sense to the narrator. Moreover, each story told and lived is situated and understood within larger cultural, social, and institutional narratives (Clandinin & Caine, 2008). In this study we analyse four stories told by the participants during the interviews. The narrative contextualization analysis relate these stories to cultural, social, and institutional narratives in the wider context. The stories told by the four participants in this study all relate to changes

1. The new health reform strengthens municipal responsibility for disease prevention and promotion of health in all sectors of Norwegian society. The aim is to achieve equality in service provision for service users nationwide, i.e., it is “an offer based on the vision of presence, accessibility and user involvement” (Norwegian Ministry of Health and Care Services, 2006). This reform was implemented in the healthcare sector, outside of mental health care, in January 2012. At the time of the interviews, municipalities were preparing for the introduction of the reform in mental health care and the budget cuts in rural areas were beginning to affect this user group. One of the alleged repercussions of the reform was that several smaller CMHCs would reduce the service provision because politicians wanted to give more responsibility to municipalities. This was an important context in the participants’ stories.
in mental health care brought on by the new health reform. The CMHC they were admitted to at the time of the interviews were facing an impending closure, and the users’ experiences or expectations of how this may or may not affect their abilities to enact what they perceive to be user involvement. We understand the reform and an impending closure of the CMHC as an important part of the context in which the stories are told by our participants.

Stories are being produced, distributed and circulated in society (Gubrium, 2005). How stories relate to particular social contexts requires an understanding of what those contexts do with words. The social consequences of stories must be understood in relation of ‘what is at stake in the everyday contexts of storytelling’ (Gubrium, 2005, p. 525). The meaning individuals make through storytelling is not only personal or idiosyncratic but rather political in nature (Hammack, 2011).

When the service users in this paper are co-constructing stories together with the researcher, they are co-constructing stories of personal experiences and expectations that can be explored by the researchers through contextualization analysis. Following the turn to performance within narrative research, we approach the question of contextualization from a perspective of a narrative as a making and a doing (Peterson & Langellier, 2006), which means that stories are viewed as emergent situated practices through which, for example, personal experience is both re-produced and transformed into something new. We argue that the emergence of transition in the act of storytelling makes it possible for the story to break through meanings, normative traditions and dominant narratives (Langellier & Peterson, 2005) and become a performance.

There has been attention directed towards the concept of context within narrative research for years (Peterson & Langellier, 1997, 2006). Some pay close attention to the immediate narrative interaction between interlocutors i.e. the local interview context (Bamberg, 2004), whereas others also emphasize the pre-interview communication between interviewer and interviewees, i.e., the global interview context, as an important context for the stories told in the upcoming interview (Lucius-Hoene & Deppermann, 2000; Helsig, 2010; Karlsson & Prieto, 2012). Social settings are important in relation to stories. Social settings represent different narrative environments that affirm or refuse certain stories. Narratives are being constructed, reproduced and privileged for several purposes (Gubrium, 2005). From a performance perspective on narrative, the interview as context actualizes the performance of interview-talk (Petersen & Langellier, 2006), storytelling or being a service user interviewee. A contextualization analysis of stories that targets both the local and global context (Lucius-Hoene & Deppermann, 2000) of the interview in terms of what bodies participate, where, when and for what purposes can help
us to politicize a narrative account. According to Andrews (2007), the stories that our research participants tell and the stories that we as researchers hear are heavily influenced by the norms of the community.

Project, data and method

Participants and recruitment

This article is based on a larger research project on user involvement among 25 mental health service users at three different CMHCs in Northern Norway. The 16 women and 9 men were between 18 and 87 years old. They had been acutely admitted to a mental hospital, and experienced major changes in life caused by mental distress. The participants represented a heterogeneous group with different stories related to their experiences as service users. The mental distress had manifested at different stages of life, and the participants expressed diverse and individual needs for assistance related to their everyday lives. An important background for the study was the focus on user involvement as a right and a duty in mental health care. The participants were recruited through a local research assistant at each institution. Information letters were distributed, and individuals who were interested in participating in the study signed letters of consent. Each service user could bring along someone if they wanted to, either a professional from the CMHC or somebody they felt safe with. Before each interview, the interviewer and the user discussed the letter of consent to make the informed consent clear and to ensure that the service users felt that they knew what they were participating in.

Data collection

All of the interviews began with the open question “Can you tell me what brought you to mental health services?” A thematic interview guide was used, based on feedback from a pilot interview with a service user from a mental health user organization. User involvement was the main issue. The interviews lasted from 35 to 60 minutes. The interviewees were invited to talk as freely as possible. The interviews varied in terms of how the participants told their stories. Some spoke uninterruptedly, while others needed more assistance (Klausen, Blix, Karlsson, Haugsgjerd & Lorem, 2017). Interviews were digitally recorded and the sound
files were transcribed verbatim. The transcripts were translated from Norwegian to English following the Norwegian as close to verbatim as possible.

The four participants in this article were all admitted at the same CMHC at the time they were interviewed. The CMHC was a general non-hospital unit with 15 beds and an outpatient clinic. Psychiatric nurses, occupational therapists and social workers worked in teams around the individual service user. The four participants’ excerpts were chosen for a closer analysis because they related their stories to the narrative of the new health reform, performing different stories of user involvement. All the interviewees in the study performed user involvement from their individual perspectives in the storytelling context, but the relation to the health reform was most clear among the four participants presented in this article. In particular, the relation to the reform was evident through the participants’ concern for the impending closure of the CMHC.

**Analyzing performances in the interview contexts**

In the following section of the paper we present a model for contextualization analysis of the four participants’ stories. By making an analytical distinction between the global and the local interview contexts, we are able to analytically operationalize the performance perspective of the stories told. The contextualization analysis draws on work by Lucius-Hoene and Deppermann (2000), Helsig (2010) and Karlsson & Prieto (2012).

The **global interview context** focuses on the aim of the study and the surroundings connected to each interview. It describes the research trajectory that led to the actual interview (Helsig, 2010). The point of departure for the analysis is not the actual story or the storytelling but rather the interactional embedding of the story that grows out of the dynamics between the interviewer and the interviewee, as related to both the global and the local interview context (Helsig, 2010). As mentioned, the interviewee had been in touch with a research assistant before arriving for the interviews. The research assistant had given the service users information about the study and obtained informed consent. The users were told that there was a researcher coming, and she was going to ask them about user involvement. When we designed the study, it was decided that there were three inclusion criteria that

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2. The participants are presented under pseudonyms to protect their identity.

3. The transcription of the recordings followed these principles: … indicates a pause of two-three seconds; ( ) indicates an explanation from the interviewer; (…) indicates that some text in the interview is excluded; – indicates a cut-off. […] indicates a clarifying comment from the author.
had to be met by the participants: (1) Experience of being admitted to a mental hospital, (2) Mental distress that had caused serious changes in the service user’s life, and (3) Consent to and an understanding of the risks, benefits, and possible drawbacks of involvement in the project. By identifying research participants that met these criteria, the global interview context “becomes part of the stories told in the interview encounters” (Karlsson & Prieto, 2012, p. 144). Is it possible that the selection process is what made the stories of the participants meaningful? Selection of participants is a necessary step in all research. Here, we identified the participants, and they identified the interviewer as a certain type of person (Karlsson & Prieto, 2012). This brings expectations into the interview setting. As the research project was presented to the interviewees as focusing on user involvement among mental health service users the global interview context can be said to open up for certain kinds of stories. The fact that the participants brought up an impending closure of the CMHC came through as closely related to the global interview context as shaping the interview setting (the local interview context) and thus the content and form of the stories being told within it.

Focusing on the local interview context, i.e., the co-constructionist actions between the interviewer and the interviewee in situ (Helsig, 2010), makes possible an analysis of how the interview setting and present and ghostly audiences can be seen as co-authoring the stories being told. This second level of contextualization analysis opens up for an understanding of stories as performances as it matters that the interviewee talks as a representative of the category ‘mental health users’ to an interviewer representing the category ‘researchers’ and that the focus of the interview has been presented (in the global interview context) as user involvement. In other words, the second level of contextualization analysis aims at understanding stories as shaped by the setting and unfolding interaction during the interview conversation. The narrative environment in the setting was influenced by challenges to existing narratives (Gubrium, 2005) about the new health reform and the participants’ performance of user involvement towards a researcher.

Taken together, the analysis of how the global and local interview contexts form and thus co-author the stories of user involvement can help us see them as contextualized performances within a narrative environment in mental health care.

**Narrative performances as user involvement in context**

Stein, Ellinor, Tom and Inger were all at the time of the interviews voluntarily committed at the same CMHC. They were prepared to talk with a researcher about their user involvement experiences: how did they participate in their own treatment? The researcher met the participants in a complex and difficult situation;
why and how should they talk about user involvement when they were convinced that the center was going to close down? Our interpretations of the stories might be different from our participants’ interpretations and their experiences from the interview situation. The impending closure became a back-cloth for how we as researchers interpreted how the four participants enacted user involvement in their stories. At the CMHC there were several narrative environments and interpersonal relationships, the interview context being one of them. The treatment processes is a context-specific construct and in this article our study participants’ storytelling is understood as a performance made in relation to the new health reform and an impending closure of the CMHC. The excerpts analyzed here refer to larger sections of talk and interview exchanges where the interviewee’s stories are framed in- and through-interaction (Marais, 2015). The excerpts include the interviewer’s questions and comments to emphasize the importance of the local interview context, and the interpersonal relationship between interviewer and interviewee. We present detailed transcripts of interview extracts related to the narrative of the new reform. The excerpts are presented under headings and focus on what we interpret as the participants’ contextualized performance of user involvement.

Stein: There are stupid things being done here

Stein was the first interviewee on the third day of the one week visit at the CMHC. He told he had a bureaucratic position when he first came into contact with mental health care, and that he was used to public speaking. He then burned out and lost control of his life. He was placed in the mental hospital for 3 months, unable to make decisions about his treatment. Now, however, he expressed a clear interest in his everyday life and treatment. The interviewer (i.e. Rita) and Stein had talked for a long time, and Rita asked him whether he had something more to add before they ended.

Transcript 1

Rita: At the same time I must say that I am staying until Friday, so if you suddenly remember something, it is just to…often when you talk to people, and there’s been a lot going on, you are not able to remember everything [ you want to say]…

Stein: No, it won’t help anything at the moment, but there are stupid things being done here, it is… but I do not know, they [the professionals at the center] may not have allowed it either, it was that we [the users] did not … they [the politicians] should have contacted us as users before the decision was made that five beds would be removed from here-

Rita: Yes, because you are talking about the cutbacks now?
Stein: YES, now it’s already done, but it was a pity they never made contact with us so that we could also have been involved in the process and try to prevent it, and argued for the experience we have as [users]…

Rita: Yes.

Stein: So it was a little bit silly. But it is done now. However, I am considering whether I should send in an article to the newspaper…, well, I talked a little with Peder [a therapist] about it. He said it certainly could do no harm and it could even be positive if there was input from the users.

Rita: Yes, because you are the most important group in…

Stein: Yeah, like that’s it, so … now there’s like, how to say it, more responsibility and work going over to the municipality, and …They call it The Coordination Reform or whatever they call it, that thing …

Rita: Yes.

Stein: I do not know anything about that; I heard it the last time I was here -… When you are out in the community you might not get as good treatment as you get here [at the CMHC], then it may be that you go so far that you might end up at the mental hospital. Something that could have been avoided with the fact that you came here. Within the competent community who knows you. So I think it is very important … I do not know if it is called …what’s the name again; I mean an environment where there are more professionals?

Rita: Expertise?

Stein: Yes, that’s it, in a way that’s it, AND at the same time, when there are more users coming here [to the CMHC] we can exchange experiences, but when you are sitting, especially in a small municipality where you might only have a psychiatric nurse to relate to…you…yes, I don’t know.

There is a distinct line being drawn between ‘us’ and ‘them’ that permeates the storytelling. When Stein talks about the injustice being done to the service users as a group he presents himself as part of a mistreated passive patient collective (we, us), but when he talks about protesting he starts talking in first person tense presenting himself as more active and involved. Stein also acts submissive in relation to the interviewer through the way in which he describes himself as uninformed about the reform behind the upcoming events. Stein seems to relate to the interviewer as the expert and himself as an amateur when it comes to details concerning the reform. However, he continues to act as a spokesman for his fellow service users through the way in which he talks about users in general terms using words such as “we” and “you”. “Them” and “they” are either the professionals at the CMHC or the politicians making the decisions. He also recognizes the competence of the staff at the center in the little community.

When Stein talks about what he should have done or could do as an active politician he talks in a first person tense. Stein wants to participate in the debate around
the reform. He wants to fight for his fellow service users, and he is passing on the values from the CMHC concerning an impending closure. He is performing user involvement as resistance to the changes brought on by the new health reform.

In the local interview context, Stein is relating his storytelling to what he knows about user involvement. He is defining himself as an active user who participates, not only in his own treatment but also in resisting against the reform on behalf of both the users and the staff at the CMHC. At the same time, we could ask whether he could tell another story. The community commits him to be against the reform, supporting the employees and the users at the center. Stein's story is directed towards both the present and the ghostly audience of decision makers and politicians. By using a formal language, Stein seems to focus on being the users' spokesperson against an impending closure. In the local context, he clearly expresses his resistance several times as well as his desire for action; he plans to write something in the local paper. He also believes that the changes will result in people getting less treatment; he considers that people will be in worse shape before they finally get the help they need. He wants to take responsibility for the group of people he socializes with at the center, both users and employees. His storytelling functions as windows onto political movements and times and the story derives meaning from being part of a bigger picture (Andrews, 2007). His political performance is interwoven with the particular community he is a member of. His performance of user involvement is clearly related to being active, and he directs an appeal to politicians and authorities in the interview contexts.

Ellinor: I am in a safe environment

Ellinor came to the interview with Anita, who was an occupational therapist she had known for years. The two women sat close together on the sofa, and it seemed that it was important for Ellinor to have a person from the CMHC with her. When Rita asked Ellinor whether she could participate in decisions around her treatment, she said ‘INDEED’, at the same time as she turned to Anita. Rita then asked Ellinor how she felt about the CMHC.

Transcript 2

Ellinor: They listen to you.
Rita: Yes. So you don't feel any pressure here?
Ellinor: No pressure, and no coercion. I have to say that. That's why it feels good coming here.
Rita: Yes.
Narrative performances of user involvement

Ellinor: You know you have your nurses, you get the same one every time, you do not have to start again and again and again to tell your story. Eh, I will... many times, you know, right now, I thought I would manage without hospitalization, but then Anita says “a couple of days, time out, get away”. From everything. Yes, sort of – and that’s all right… I think my people at home also are very pleased that we have this place [the CMHC].

Ellinor: They know that I am in a safe environment
Rita: Yes.

Ellinor: And that I feel safe and … not least because I have been a couple of times in the mental hospital, or immediately after the electroconvulsive therapy … and it seemed I was … I was in the emergency department for 9 days before I came here.

Rita: Yes.

Ellinor: And it was seriously tiring. Of course, it was very hectic [at the mental hospital], and we were all different people, and different diseases, so when I put the bag outside the door, inside the door here [at the CMHC], I said, “Listen. Listen to the silence.”

Rita: Yes.

Ellinor: There … no, I must say that I (takes a deep breath) … I was in a conversation … yesterday. No, the other day and started to sort my problems, you know, and when I said, simply, “I cannot talk about it today”.

Rita: Yes.

Ellinor: For I’m so keyed up by the situation in which, somehow, with the threatening closure, and everything like this. It’s like that to me. Going really into me.

Rita: Hm.

Ellinor: I am terrified of losing the offer. I am.

Rita: Hm.

Ellinor: It is so important and we are many. They do a great job here. (Whisper :) They do.

For Ellinor, participating in her own treatment means allowing the clinicians to take responsibility for her treatment. Similar to Stein, Ellinor expresses loyalty towards the CMHC through the way in which she talks about her experiences from being admitted at the mental hospital. She performs as an apparently passive care receiver and being active in her own treatment means expressing a need of care. User involvement for her can be to let others make the decisions. While serving as the audience, Anita also served as a co-author for Ellinor by nodding and confirming her story during the interview. Ellinor’s story indicates that she understands user involvement as connected to being in need of care and help. Although some would define this as a typical user role and connect it to learned helplessness (Miller & Seligman, 1975), it could be her performance of user involvement as resistance
against the narrative of the reform. She could also have brought Anita with her for a number of reasons connected to different narrative environments that are hidden for the interviewer. Relational dynamics are central to an understanding of user involvement as a multilevel construct, and the interview context is bringing up involvement as a theme. In practice among the mental health professionals it could be an important task giving Ellinor necessary support during the interview. Ellinor seems to be using the interpersonal relationship with Anita to perform user involvement as being in need of support and care.

In the moment during the interview when Ellinor turns her storytelling to Anita, she emphasizes her support to the CMHC by reaffirming her resistance to an impending closure.

Anita plays an active role in the storytelling as listeners also play in story performances (Bauman & Briggs, 1990). The interview is always dialogical in its form; narrator and researcher establish an interpersonal relationship made up of institutional, imaginative, socio-categorical and other communicative frames which are enacted by both listener and storyteller during the interview (Lucius-Horne & Deppermann, 2000). Anita is thus also an important part of the storytelling as she acts as a co-author. Ellinor's story can be seen as a performance of user involvement through the ways in which she enacts her need of care. In both the global and local context user involvement can be a right to be in need of care and support from familiar people. In the local interview context, she performs user involvement as being able to choose not enter into conversations about difficult things.

Tom: It is money we are talking about

Tom was a man in his middle 40-ies, and he had struggled with alcohol abuse and violent behavior, depression and anxiety for years. He had tried to commit suicide several times, and told about using a lot of time being afraid. He was afraid of being kept in chains at the mental hospital. Rita asked him what his everyday life at the CMHC was like.

Transcript 3

Rita: Um … if you were to say something about life you have here.
Tom: No, everyday it … it is certainly better than life in the city, anyhow. I have the forest right outside the door here. I am happy to go in nature and stuff. But now it is so slushy, that one must almost wear waders. Just walk around in the morning, before breakfast, I use to go around the village, and stuff …And other times one may ride on a horse.
Rita: Hm
Tom: It is very important with activity, and to be outside. So …
Rita: But is it like that when you're here, that if you have some ideas or you feel like doing something, you ask the people working here
Tom: Oh yes
Rita: you do?
Tom: Yes. It may take some time here. But it comes. Is it possible, but it is difficult now with ..with all the cutbacks, and you know it here, it’s a HORRIBLE pressure on staff as well,
Rita: Really?
Tom: Yes, they want to help
Rita: Yes?
Tom: but there are cutbacks
Rita: When you say cutbacks, it means that there are fewer people here at work?
Tom: There are fewer people on the job, they have no opportunities, simply, to … to different desires that are … it..it always costs money, it is money we are talking about.
Rita: Hm
Tom: So that's a desperate situation for both patients and the … the professionals here. That's the story. And I do see it on them, too.
Rita: Yes.
Tom: For whatever they say, they put on masks and stuff, but you never have such a thick mask that you can cover the eyes, and I see it…

Tom underlines the importance of being in nature, having the possibility to recreation just outside his window while he is admitted. These activities are however, in danger of being lost because of cutbacks. “It is all about money”, Tom says. The new health reform brings cutbacks in the mental health care services. For Tom this is related to the outdoor activities. In Tom’s story, the authorities do not see the individual service user and her or his needs. In the local interview context, he clearly expresses loyalty towards the professionals at the CMHC; “they want to help” and “they have no opportunities”. He further describes the situation as horrible for both service users and employees. The employees are trying to protect the service users’ from their worries, but he can see their concerns in their eyes. In the local interview context Tom performs user involvement as related to him being able to engage in different activities and to the relations between the users and the professionals at the CMHC. In a study by Solbjør et al. (2013) service users describe high quality mental health service as the need for safe, stable and predictable care and support on one hand, and on the other encouraging and facilitating increased responsibility and influence. This describes a balance between care and responsibility. In the activities described by Tom, he has the opportunity to participate in his own treatment while doing things he likes. These activities represent another life than Tom’s life in the
city. But the cutbacks are not only taking the activities away; they are also making the professionals unable to act. Through his narrative performance of user involvement, Tom resists the changes brought on by the reform. His performance of user involvement in the storytelling context is transformed into a story of resistance.

In the global interview context Tom’s storytelling can be understood as a resistance story. He does not want the treatment to change; he wants to be able to go outside and ride horses for recreation, he needs these activities. Tom wants continuity in care. According to Nolan et al. (2011) a lack of continuity of care leads to feelings of loneliness, isolation and less opportunities for service users to contribute to their care plan. In line with Newman et al. (2015) we agree that continuity of care covers both health and social issues for many people with mental distress. Tom’s performance of user involvement is underlining the dynamical balance between care and responsibility. He see recreation as care, but he also has the responsibility to tell that he know what difficulties the professionals are handling with.

Inger: We are a little worried about these cutbacks

Inger came alone to the interview. She said she had been unsure whether she would participate in the study or not. She was eating a pear when she came in. Rita asked her, when she was finished, whether she wanted to throw it away, but she said no. She held on to the pear carcass in her hand during the whole interview. This defensive non-cooperative attitude made Inger seem very angry and uncomfortable in the interview situation. The interviewer and Inger talked about this for a while. Rita told her that she could withdraw from the study but she decided that she wanted to participate. Rita asked Inger whether she had felt some progress after she came to the CMHC.

Transcript 4

Inger: During these years?
Rita: Hm.
Inger: No, it's hard to say for sure eh…
Rita: I can try to say it in another way; if you should think about what has helped you the MOST during these years?
Inger: It’s hard to say, like that here, in the disease I have, so there is a risk that one gets worse and worse every time you get sick, so right now I’m in a very bad period where I don’t quite see how I … how to get out of the situation here [at the CMHC].
Rita: Yes.
Inger: So … so … so I – before it has sort of been more like manic period, and then I got medication for it, and so I might have been a little edgy, but I’ve gotten a job and stuff. But this time I have – I have been manic, and so I was a little better, and then I’ve got like a relapse, so right now I see dark on the situation, and it somehow … this is the worst – the worst period I had ever. I have been able to decide that I should cut down on drugs and stuff. But it has made … ehm..The way it looks now as it might have done that I have become in worse shape. So it’s not always that this user involvement is THAT good.

Rita: hm. (…)

Rita asks her, at the end of the interview, whether she has something she wants to add.

Inger: No, not really. (Pause)

Rita: Well, if you suddenly remember something, you know where to get in touch with me you’ll find me both at the University on the phone and on mail…

Inger: Hm. Yes.

Rita: …if something should come to your mind?

Inger: Hm. No, that is…but of course, we are a little worried for these cutbacks and all this, but – that is so.

She should have been at home already, but a while ago she decided that she wanted to cut down on her medication. Her situation worsened further, and she threatened suicide. Inger’s story of user involvement is characterized by an explicit criticism towards the mental health system as a whole, including healthcare professionals at a public nursing home that she has been to, the employees at the mental hospital, and towards the people working at the CMHC where the interview were conducted. She expresses doubts about the good of user involvement in situations like hers. Inger is blaming the system for letting her decide too much about her own treatment. If they hadn’t listened to her, she would have been home by now. In her story user involvement is just another idea from a system she doesn’t believe in. Her worry about an impending closure of the center is not as clear as in the other stories, but it is there. Her affiliation is not strongly linked to the CMHC; she is more intent on expressing an opposition to a health care system that fails to heal her. The impending closure might mean that she will be forced to receive treatment from the public nursing home again. Inger’s story pictures a chain of violations and improper treatment through years, and she gives the impression that nothing will surprise her anymore. Narrative interviews confront the interviewee with the task of giving a representative presentation of his narrative identity (Lucius-Hoene & Deppermann, 2000). When Inger’s story of user involvement is seen in the light of the global and local interview contexts it can be understood as a performance of resistance against having to talk about user involvement at all. Inger is critical
of the research project and the mental health system presented in and represented by the global interview context and of a researcher asking questions in the local interview context. She is also critical of herself; she should not have decreased her medication and blames the professionals for listening to her. The interview is a complex social situation with real and imagined participants (Lucius-Hoene & Deppermann, 2000), and by telling her story, Inger can be said to address the wider audience of health professionals who she feels have failed her.

Discussion

This study aims to contribute to the understanding of user involvement in mental health care through a narrative study of service users’ performances of user involvement in the interview context. The interview context is transferable to narrative environments occupied with user involvement, not only in mental health care. Narrative environments have particular ways of framing and doing matters of relevance to participants (Gubrium, 2005, p. 526). Narratives construct, reproduce and privilege certain kinds of accounts for institutional purposes (ibid.), while others stories challenge and resist ongoing accounts within the community. Institutions have their own practices. At the CMHC there was a narrative environment that connected user involvement and the new health reform together. In our study, the narrative of the reform presented a backcloth for the participants’ narrative performance of user involvement as resistance to the changes that a closure of the CMHC would bring for them. User involvement represents different things for different people. For Stein it was related to activism, for Ellinor it was related to care. User involvement for Tom meant to take part in activities, and the relationship between professionals and service users was important. For Inger it was related to making decisions. These different perspectives describe some of the complex challenges facing both users and professionals while trying to exercise user involvement in the everyday life of mental health services.

A narrative oriented approach to mental health implies the recognition that user involvement is a relational phenomenon, developed between the individual and his/her narrative environment. Each environment includes the actions, attitudes and stories of those to whom the individual relates (McDaid & Delaney, 2011). By thinking about user involvement as a relational and narrative phenomenon, the enactment of user involvement is radically contextualized. This leads us to implications for practice within mental health treatment and care.
Closing remarks

A narrative approach within mental health care should be concerned with environments that reflexively shape the realization of user involvement in practice to the everyday life in the CMHC. The tensions related to the impending closure promoted by the new health reform, as expressed by our participants through their different performances of user involvement, is of a kind that is not always obvious in society (Gubrium, 2005). They must be identified, and the narrative environment must affirm or challenge both old and new stories about social conditions. Only then can user involvement be an ongoing process for service users and professionals. By analyzing the global and the local interview contexts, we hope to emphasize the performative possibilities of conversation contexts, like the interview, as transferable not only to mental health practice, but also to other disciplines where user involvement is in focus. The service users were actively taking part in the debating the changes brought on by the new health reform, and performed user involvement when narrating experiences of related to worries due to the impending closure of the CMHC during the interviews. This indicates that narrative environments in mental health care demands our attention to turn to storytelling in practice. Stories are played out in the here and now of everyday life within mental health services. At the same time the creation and maintenance of narrative environments may facilitate contexts for continuity that has been promoted as important in mental health care (Nolan et al., 2011; Newman et al., 2015). Overall, professional care providers need to be aware of how storytelling and narrative environments can be used to develop different forms of user involvement.

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References


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