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Relational insight and user involvement in the context of Norwegian community mental health care:
A narrative analysis of service users' stories.

Rita Kristin Klausen
A dissertation for the degree of Philosophiae Doctor – August 2016

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The world is made of stories, not atoms.

- **Muriel Rukeyser[1]**

For my birds –

Illustration front page: colurbox

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[1]Rukeyser, M. (2015). Brainyquote.com. *http://www.brainyquote.com/quotes/quotes/m/murielruke131826.html*. Retrieved April 23, 2015

I thank my parents, Rigmor and Jan Klausen. You believe in me; that is the most wonderful gift a child can receive. My warmest thanks to my beautiful and wise birds: Frid Kjellsdatter Klausen and Ørn Severin Klausen. I am so glad the two of you landed on this planet. Finally, a very special thank you, Svein Henriksen, for meeting me on a dark December night and changing my life. Thank you for giving me a new and extended family, with extraordinary children and lots of love.

Rita K. Klausen
Tromsø, August 2016

Table of Contents

English abstract

At the time of this study, Norwegian community mental health services had experienced numerous changes within a deinstitutionalization framework, with more changes planned for the future. The need to emphasize service users' fundamental change from playing the role of a passive, patient to the role of an actively contributing individual with clearly defined rights and claims became more important.

The aim of the study *Relational insight and user involvement in the context of Norwegian community mental health care: A narrative analysis of service users' stories* was conducted both to investigate service users' insight into their mental illness and treatment and to support approaches that might be helpful in recognizing and utilizing service users' perspectives within mental health practice.

The research adopted a social constructionist approach with a narrative design. The focus was participants' narratives concerning both insight and user involvement. The study's relevance concerned not only how insights can be applied in mental health treatment through dialogue in a narrative environment but also whether this knowledge could facilitate the activation of user involvement.

Interviews were conducted with 30 service users from three community mental health centers in Troms and Finnmark. The service users shared stories about their experiences with mental health care. As researchers working on this project, we have gained deeper insights into the service users' knowledge that both interact and conflict with the changing social context of mental health practice. The three articles in the thesis relate to different dominant narratives within a compound field that moves in numerous directions. The articles 'attack' insight and user involvement from various perspectives, and we develop a new understanding of insight as a concept through our analysis of the service users' narratives as co-constructed stories in context. The narrative approach enables us to explain insight as a relational and dynamic process, not a trait exclusively inherent to the patient. Insight is necessary to implement user involvement in practice.

The study suggests that user involvement begins at the admission point, where the professional and the service user are placed in a situation in which the professional is expected to measure the service user's insight/ lack of insight. If the professional and the service user can participate in co-constructing storytelling practice in an everyday, experience-based language in this situation and throughout treatment, the likelihood of promoting insight will improve. Our findings are not only relevant to mental health services but also transferable to other disciplines in which user involvement is a central topic.

Norsk sammendrag

I tiden denne studien ble initiert hadde norsk distriktspsykiatri allerede gjennomgått mange endringer innenfor rammene av de- institusjonalisering. Flere endringer var også planlagt for framtiden. Det var et behov for å understreke denne grunnleggende endringen som viktig, også for brukerne. Fra å bli oppfattet som passive pasienter skulle de nå være aktivt, medvirkende individer med klart definerte rettigheter og krav.

Målet med studien *Relational insight and user involvement in the context of Norwegian community mental health care. A narrative analysis of service users' stories*[2] var å undersøke brukernes innsikt i egen helse og behandling, og legge frem mulige tilnærminger som kan være til hjelp for å anerkjenne og nyttiggjøre seg av brukernes perspektiver i praksishverdagen i distriktspsykiatrien. Studien hadde en sosialkonstruksjonistisk tilnærming med et narrativt design. Deltakernes fortellinger om innsikt og brukermedvirkning var i fokus. Studiens relevans var knyttet til hvordan innsikt kan anvendes i behandling, gjennom dialog i et narrativt orientert miljø, og på hvilken måte denne kunnskapen kan legge til rette for en aktivisering av brukermedvirkning.

Studien inneholder intervju med 30 brukere fra tre distriktspsykiatriske senter i Troms og Finnmark.

Deltakerne delte sine fortellinger om erfaringer fra distriktspsykiatrien, og som forskere i prosjektet, har vi fått en dypere innsikt i brukernes kunnskap, som både samhandler og er i konflikt med de endrende sosiale kontekstene innenfor distriktspsykiatrisk praksis. De tre artiklene i studien omhandler alle dominerende fortellinger innenfor et sammensatt fagfelt som beveger seg i mange retninger. Artiklene 'angriper' innsikt og brukermedvirkning fra ulike perspektiver, og vi utvikler en ny forståelse av innsikt som begrep gjennom en analyse av brukernes fortellinger som samkonstruerte fortellinger i kontekst. Gjennom den narrative tilnærmingen får vi tilgang til å forklare innsikt som en relasjonell og dynamisk prosess, og ikke en egenskap som utelukkende bor inne i pasienten. Innsikt er en forutsetning for å kunne implementere brukermedvirkning.

Denne studien hevder at brukermedvirkning starter ved første innleggelse. Ved det første møte plasseres behandleren og brukeren i en situasjon hvor behandleren er forventet å måle hvorvidt brukeren har innsikt eller mangler innsikt. Hvis behandleren og brukeren kan delta i en felles narrativ praksis på et hverdagsspråk, i denne situasjonen og gjennom behandlingsforløpet,

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[2] Relasjonell innsikt og brukermedvirkning i norsk distriktspsykiatri. En narrativ analyse av brukeres fortellinger.

hevder vi at sjansene for å fremme innsikt vil forbedre seg. Våre funn er ikke bare relevante for de psykiatriske helsetjenestene, men er også overførbare til andre disipliner hvor brukermedvirkning er et sentralt tema.

List of articles / liste over artikler:

This thesis is based on the following articles:

- 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*(6), 431-440.
- Klausen, R. K., Karlsson, M., Haugsgjerd, S., & Lorem, G. F. (2015). Motherhood and mental distress: Personal stories of mothers who have been admitted for mental health treatment. *Qualitative Social Work*, 1473325015584981.
- Klausen, R.K., Blix, B.H., Karlsson, M., Haugsgjerd, S., & Lorem, G. F. (2016). Shared decision making from the service users' perspective. A narrative study from community mental health centers in northern Norway. *Social Work in Mental Health*

1. Introduction

This thesis is one of two studies included in the research project *Insight and user involvement: A study of users' and health professionals' experiences of treatment and care of severe mental illness*[3]. This study has the title *Relational insight and user involvement in the context of Norwegian community mental health care: A narrative analysis of service users' stories.*

1.1 The context of the thesis

Our study[4] has a narrative frame and contains narratives of individuals who either have been admitted or receive assistance from northern Norwegian community mental health centers for their mental distress. The narratives are specific to the mental health culture that they construct and are constructed by 'the stories which our participants tell, and stories which we as researchers hear, are heavily influenced by the norms of the community' (Andrews, 2007). This study adopts a social perspective on mental health services.

The overall aim of this study was to explore not only service users' insight into mental illness and mental health treatment but also their experiences of the effect of insight on users' involvement, their relationships with others and their general life situations.

At the time of this study, Norwegian community mental health services had undergone numerous changes within a deinstitutionalization framework, with more changes planned for the future. The need to emphasize the fundamental change in the service user's relationship with the therapist from the role of a passive, patient characterized by obedience to authority to the role of an actively contributing individual with clearly defined rights and claims has become important (Ulvestad & Henriksen, 2007) in mental health services. According to Tritter and McCallum (2006, p. 166), '[p]rocesses of user involvement seek to transform the culture of healthcare'.

In this thesis, the concepts of user involvement and insight constitute the framework and the participants' narratives are the images within these frames. Both insight and user involvement are seen as crucial elements for discussing a new approach to service users' active treatment.

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[3] The other study is titled '*Research-based and user-based knowledge*', and is an ethnographic study by Vår Mathisen at the Arctic University of Norway UiT. Professor Aud Obstfelder at The Arctic University of Norway UiT is the principal supervisor of this project.
[4] In this thesis, I use 'our' study and 'we' when discussing the collaborative research project and analysis. I use 'I' when discussing the interviews and the thesis (representing the interviewer and the author of this text).

The representation of insight as a relational concept with shared decision-making (Storm & Davidson, 2010) can lead to an understanding of insight as a cornerstone in mental health practice. Insight is 'a multidimensional construct' (Cavelti, Kvrgic, Beck, Rüsch, & Vauth, 2012, p. 468) and closely associated with user involvement within mental health services (Roe, 2001). Insight 'turns out to be a major challenge especially in every day clinical practice' (Schennach et al., 2012, p. 626), and there has been a proliferation of research concerning insight (Arango & Amador, 2011). Individuals in need of mental health treatment state a desire for an increased influence in and responsibility for their life situation (Hem, 2008). Insight in an individual's own treatment and health is necessary to implement user involvement in practice (Quee et al., 2010). Thus, insight can affect the core clinical and value-related issues related to user-oriented treatment, autonomy, adherence and consultation. According to Ampalam, Deepthi and Vadaparty (2012, p. 46), insight represents an individual response to diagnosis; thus, insight depends on the meanings that individuals attach to their illnesses.

The new and active user role, as defined in the new policy guidelines (Ministry of Health and Care Services, 2009) concerning user involvement, requires new definitions of insight. User involvement and insight are core concepts of mental health treatment and occur together because if one falls away, the justification for the other follows. The concepts are woven together as in a Möbius strip[5]. Evidence indicates that the intention to implement user involvement in Norwegian mental health services is based on rhetoric rather than reality (Gudde et al., 2013).

Service users' narratives make important contributions that offer a broader picture of the compound that underlies both insight and user involvement within mental health services. Using narratives as points of departure, we investigate how the multiple storied experiences connected to service users' insight and treatment can contribute to the experience-oriented knowledge necessary to develop user involvement.

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[5] A Möbius strip is a continuous surface with only one side and is typically constructed by connecting the two ends of a rectangular strip of paper after making a half-twist (180 degrees relative to the opposite side) in the strip (http://www.physlink.com/Education/AskExperts/ae401.cfm).

1.2 Changes and continuity in the project

Both the conceptual framework of our project (insight and user involvement) and the participants' narratives are characterized by the surrounding changes and continuity within mental health services. The project transformed over the course of the study; the data's meaning changed over time as we became aware of new and changing aspects of the empirical field of mental health services. Naturally, this transformation affected the research process. In other words, preparing this thesis has involved a journey of change and continuity.

This study employed a narrative approach from the beginning. After closely studying the method, we decided to focus on narratives as co-constructions in context (Peterson & Langellier, 2006; Zilber, Tuval-Mashiach, & Lieblich, 2008). This methodological approach allows the researcher to explore a changing and multifarious social process as represented by our empirical field. The service user's narratives can be described as 'embedded' in the surrounding discourses (Ochs & Capps, 2001, p. 37).

The project's inherently dynamic nature is fundamental to understanding the study in its entirety. Denzin and Lincoln (2013) use the metaphor of bricolage (quilt making or montage) to describe the dynamic nature of a qualitative study; it can highlight interpretive, narrative and theoretical bricoleurs. These representations are fitted into a diversified context in which 'different tools, methods, and techniques of representation and interpretation are added to the puzzle' (Denzin & Lincoln, 2013, pp. 7-8). In this study, the process has been guided by our narrative approach.

This study views the concepts of insight and user involvement as fluid and requiring detailed review. This requirement applies particularly to the concept of insight. By thoroughly examining insight, we want to show that the practical consequences of a new development of this term will have consequences for how user involvement is exercised in mental health services.

1.3 My role as a researcher in the field and the project

The roots of my thesis can be traced to experiences in both my personal and professional life. Consistent with Richardson (1997), I am present in the text. My oldest brother died under dramatic circumstances in January 2006. He had been in occasional contact with mental health services throughout his life; those meetings were never easy for any of us, his family

members. I believe that the idea of being a 'mental health patient' scared him away from life. This event planted within me both a fervent commitment to and a deep interest in the multifaceted and extensive field of mental health services. I had worked as a family and network therapist at child welfare institutions for years prior to his death and had been concerned with child and adolescent mental health from a network perspective. It became clear to me that I wished to focus on user involvement in mental health services in my work. In the years following his death, I worked in service user-driven rehabilitation. In 2009, I completed my master's degree at the University of Nordland and focused on siblings as next of kin within mental health treatment. I employed autobiography and memory work as a theoretical approach[6]. I became involved in volunteer work related to substance abuse and mental health in my hometown and became increasingly concerned about the implications for an individual (and her/his family) upon being defined as mentally ill or in need of mental health services. How can these stories be told and heard?

According to Ochs and Capps (2001, p. 4-5), coherent linear narratives typically have the following characteristics:

'…a *plot structure that depicts a sequence of temporally and causally ordered events organized around a point, with a beginning that situates a significant, i.e., unexpected and hence tellable, incident and moves logically towards an ending that provides a sense of psychological closure'*.

These types of narratives employ various techniques such as foreshadowing and backshadowing, and life is therefore 'treated like [it is] structured, ordered and goal-directed' (Ochs & Capps, 2001, p. 5). However, life and life events are seldom simple and structured. They can be ambiguous, conflictual, unstable and subject to constant revision (ibid.). In a dynamic story, the technique of *sideshadowing* can be used to express the ever-changing nature of human life and events. Sideshadowing is defined as a technique in which the past is transformed into the present and captures 'the polyphonic and indeterminate quality of human events and non-events' (Ochs & Capps, 2001, p. 6). My belief is that our lives and life events are polyphonic in nature; in this context, I believe that my approach to this thesis can be defined as a *sideshadowed* path. Many narratives have led me to where I am today. These

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[6] I employed the theory advanced by Widerberg in her book *Kunnskapens kjønn. Minner, refleksjoner og teori [The gender of knowledge. Memories, reflections and theory],* Pax Forlag 1995.

narratives include not only my own personal and professional lives but also, and most importantly, the narratives of the study participants who needed help from mental health services. These individuals experience a daily struggle with their complicated and unpredictable lives. We interacted over the course of this project, and narratives were created. These co-constructed narratives constitute the foundation of this work. Moreover, I must emphasize that in line with Stenhouse (2009, p. 2), this thesis 'is my narrative of the research'.

1.4 Developing an approach and design

The study is a qualitative study with a narrative approach utilizing a co-constructive design. This design allows the researcher to develop stories in cooperation with the participants that focus 'not just on how stories are structured and the ways in which they work but also on who produces them and by what means; the mechanisms by which they are consumed; and how narratives are silenced, contested or accepted'(Andrews, Squire, & Tamboukou, 2008). In line with Riessman (1993, p. 1), we have focused on narrative analysis that 'takes as its object of investigation the story itself'. The purpose is also to see how the interviewees describe their experiences, not simply the content of their stories. Like many narrative researchers, we understand stories as 'interactions between storyteller and listener(s), researcher and research participant' (Squire, 2008).

Although the initial purposes of qualitative research can be explicitly stated, the outcomes cannot be specified in advance (Josselson, 2007). We adopted a social constructionist perspective, focusing on the participants' stories as co-constructions in context. Frank stresses that narrative research 'requires hearing participants' stories not as surrogate observations of their lives outside the interview but as acts of engagements with researchers' (Frank, 2005, p. 968).

We explore questions concerning insight and user involvement among service users in community mental health centers in Northern Norway. A narrative context-oriented approach allows us to investigate the service users' understanding of their own mental illness and treatment. By departing from co-constructed narratives, we emphasize insight as a relational and dynamic process and the service users' experience-oriented knowledge as vital for further developing user involvement in practice.

When considering insight from within a social constructionist perspective, it is important to acknowledge that insight is created out of the relations and contexts of everybody involved. Insight is not exclusively inherent to the service user. This acknowledgement closely ties insight as a process to user involvement. In this thesis, the perspective of insight has been adjusted to address the practical challenges linked to everyday mental health treatment instead of clinical assessments made by professionals. We see insight as characteristic of a relational and dynamic process; it is not limited to decision-making competence. What are the consequences of emphasizing that insight is a relational concept for how user involvement can be practiced in mental health services?

Almost all the study's participants were admitted or receiving outpatient care organized by their local community mental health centers. One participant claimed that she was healthy and no longer suffering from mental illness[7]. Except for that woman, all the participants were dependent on the mental health services and treatment provided by their community mental health centers. In relation to treatment and experiences of treatment, insight and user involvement are crucial concepts. Insight is *necessary* to implement user involvement in practice (Quee et al., 2010). When admitted to mental health treatment, the professionals consider whether the service user has insight, a decision that has major consequences for service users' ability to be involved in their treatment. If a person lacks insight, it will be difficult for him or her to make adequate decisions about health and treatment.

This thesis contributes to the field of mental health services by investigating the concept of insight and user involvement, with a particular focus on insight and its practical consequences for the individual service users and her/his possibilities for being involved in treatment. We develop a new understanding of insight as a concept by analyzing the service users' narratives as co-constructed stories in context. The narrative approach allows us to understand insight as a relational, dynamic process.

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[7] Before beginning to gather the empirical data, I thought that most of the service users would have insight and would be very interested in discussing user involvement. I will address this initial understanding in the discussion chapter.

1.5 A note on language

Mental health services represent a diverse research area with numerous different disciplines and directions therein. One of the many controversial topics in the field has been the issue of which terminology to employ when referring to the recipients of mental health services. Definitions of the recipients may be important with respect to how the individuals understand themselves in interactions with the support system; new concepts can help them think across inherited traditions, cultures and practices (Ulvestad & Henriksen, 2007). The terms used to describe service users can be either stigmatizing or empowering (Dickens & Picchioni, 2012). Research concerning this topic has concluded that a diversity of terms is used and that there is a need to respect individual preferences (Dickens & Picchioni, 2012; Simmons, Hawley, Gale, & Sivakumaran, 2010). Both while conducting interviews and while working with the data, this study has focused on using an experience-oriented language that does not always involve medical terminology. This approach is reflected in the articles. Below, I present four primary types of terminology that this thesis uses in various ways.

Mental illness and diagnoses are not simple topics and as concepts, they primarily refer to the 10th revision of the International Classification of Diseases by the World Health Organization (ICD-10)[8]. The ICD-10 contains a detailed classification of more than 300 mental and behavioral disorders (chapter V:ICD-10).The aim of psychiatric classification is to create order amid the diversity of psychiatric symptoms, syndromes and behavioral problems encountered in clinical practice (Malt, Retterstøl, & Dahl, 2003). The Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association, 1994) is the official set of diagnostic criteria for mental disorders in the United States; in Norway, the DSM is used as a supplement to the ICD (Dahl & Aarre, 2012a). According to Dahl and Aarre (ibid.), the purposes of the classification system in the clinical context are communication, control and understanding. Classification can be considered a necessity in cases of communication within health care, research and the community (especially concerning social security services). Classifications and diagnoses are important aspects of the context of community mental health centers, and service users relate to their diagnoses in various ways. All study participants indicated that the disease had made serious changes in their lives. However, the focus of this thesis is the service users' stories and how they experience mental health services. Although the ICD-10 is part of the terminology of mental health services, this

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[8] http://www.kith.no/upload/1816/Komplettt-Bl%C3%A5-bok_230905.pdf. Online edition of the ICD-10 in Norwegian.

study employs the terms used or referred to by the study's participants. Thus, the terms mental illness and diagnoses vary throughout the thesis. I prefer to use the term 'mental illness', which I consider to have a broader definition than, for instance, 'severe mental illness'. From a service user's perspective (not from a medical perspective), I think that everybody experiences his or her mental illness as either more or less severe. Although some might find the term 'mental illness' to be stigmatizing, I have chosen to use it[9].

Definitions of the participants may be a topic for discussion. The specific terms preferred by recipients of mental health services are unpredictable (Simmons et al., 2010). In this thesis, several terms are used: patients, service users, participants and interviewees. According to Dickens and Picchioni (2012, p. 116), the discourse surrounding the various terms is not settled; a diversity of strong opinions is expressed about the terms that are employed. When writing the thesis, I used the term 'service user' because I find that this term reflects not only the context in which these individuals are placed but also the fact that these individuals are *users* of mental health services. Although service user organizations in Norway generally use the term 'user' (cf www.erfaringskompetanse.no), I find the term 'service user' to be more informative and clear in relation to the mental health community context in which we are moving.

The terms 'community mental health center' and 'district psychiatric center' describe the same services, at least in Norway. However, the Norwegian mental health service employs a different terminology than its English and American counterparts to describe public services within mental health. District psychiatric centers are decentralized, specialized services that are termed community psychiatry in the international literature. Norway's district psychiatric centers are community mental health centers adapted to Norwegian conditions (Ministry of Health and Care Services, 2006). The term 'community mental health centers' is used throughout this thesis.

User participation and involvement are used interchangeably in this thesis. Although these concepts have become common in the vocabulary of mental health, they cover a wide range of activities (Peck, Gulliver, & Towel, 2002). These concepts can describe everything from a

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[9] Aneshensel et al. provide a broad definition of mental illness that is related to thoughts, emotions and actions that are experienced 'across diverse cultures, social structures, physical environments, and historical epochs' (2013, p.4) and is related to an objective reality.

situation of no involvement by the service users to a situation of full partnership in which service users and professionals collaborate regarding decisions about individual treatment (Towle et al., 2010). Consistent with Tritter and McCallum (2006), we understand these concepts as multifaceted and communicating meanings and actions in individual and societal decision-making processes. User involvement requires dynamic structures and processes that are recognized by both participants and non-participants (ibid.).

1.6 What is not included?

The interviews in the thesis capture many themes. I briefly mention four themes that could have been of particular interest to investigate, but for which there is no room. The first theme is that of the *cultural perspective*. Three refugees among the study participants had their asylum applications rejected. At the time of the interviews, they had been admitted to a community mental health center in an unfamiliar treatment context in the face of an uncertain future. However, I have chosen not to use the material from these interviews because of the study's limitations. The participants also included one Russian woman who had lived in Norway for many years, along with Sami participants. These participants were better acquainted with the Norwegian treatment culture than the refugees were, but it could still be interesting, in another context, to look at the wider cultural perspective[10]. This task could be accomplished in a follow-up study.

The second theme is *the new health reform*: the coordination reform and service users' understanding of the processes to which the reform might lead. It could have been particularly interesting to look at reform in connection with the treatment received by the service users in the community mental health centers[11]. At the time of the interviews, there were many political protests in communities in Northern Norway linked to cutbacks in the community mental health centers and a greater focus at the central level on municipal mental health services. All study participants lived in Northern Norwegian districts. Accordingly, their stories about the new reform provide perspectives from relatively rural areas. Because of this study's limitations, it has not been possible to treat this topic.

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[10] I also understand ethnicity /ethnic identity as a part of a cultural perspective.
[11] The reform represents a backdrop for another article by Klausen, Karlsson, Haugsgjerd and Lorem (forthcoming) but is not included in this thesis.

The third omitted theme embraces a more methodical perspective and relates to the possibility of choosing *a narrative content analysis* for all the conducted interviews. Choosing stories for focused attention is a crucial task within narrative research (Blix, 2013). By choosing 20 stories[12] for analysis, I based my attention on a 'practical wisdom gained through analytical experience' (Frank, 2012). The 20 stories were chosen because they give an impression of how insight is articulated through storytelling, which can have implications for mental health practice that considers user involvement. They also represent diversity with respect to how dominant narratives are understood, continued or discontinued by service users in community mental health centers at a given time in a given context (Blix, 2013). It is a privilege to have access to the comprehensive and exciting material included in these interviews. Nevertheless, it is important to note that five of the 30 interviews (two interviews that I chose to end, along with the interviews of three refugees) were neither transcribed nor included in the analysis[13].

The fourth and last theme that is *not* included in the thesis is the different treatment contexts in the three community mental health centers. It would have been interesting to investigate any similarities and differences among the various service users' diverse experiences at the three centers. Unfortunately, this topic did not fall within the frames of the investigation connected to insight and user involvement during this round.

There are many possibilities and choices within the stories. Thus, the challenge is to adhere to the study objectives and research issues. In this instance, insight and user involvement is the focus. My argument is obviously influenced by my understanding of the concepts, which are located in a social constructionist perspective that emphasizes interaction with the participants in the study.

1.7 Outline of the thesis
This thesis is organized into 10 chapters:
- Chapter 2 provides the background of the project. I describe contemporary Northern Norwegian mental health services. Transitional mental health service is discussed. I give some thoughts about the practical aspects of an individual service user's admission to a community mental health center to provide an understanding of what meets the individual service user when she/he is admitted.

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[12] These 20 stories are excerpted from 16 interviews.
[13] This will be further explained in chapter 6.

- Chapter 3 outlines the theoretical framework of the social constructionist approach selected, including the relationship between social constructionism and the narrative approach. Relevant narrative theory is presented. An important focus of the narrative approach in this thesis is that of narratives as co-constructions. I discuss dominant narratives as co-constructions. The researcher's role is presented and the interview is defined as a relational context. Finally, in this chapter I discuss narrative validity and reflexivity.

- Chapter 4 presents the literature review regarding insight and user involvement. I focus on a service user-oriented literature review and describe Norwegian clinical practice. I discuss the problem of insight and patient rights before investigating the clinical intention of discussing insight. I describe some theoretical positions from which to consider insight before underlining some relevant concepts central to the performance of insight. I look at narratives and insight before giving some thoughts connected to a conceptualization of insight in a social constructionist approach. The relationship between insight and user involvement is presented. In section 4.7, I briefly introduce user involvement in mental health care, followed by an exploration of the concept. I also present some user involvement models. Finally, I reflect on user involvement models.

- Chapter 5 presents the aims of the study. I also present the aims within each of the three articles upon which this thesis is based.

- Chapter 6 focuses on the project's methods and presents the three community mental health centers, the recruitment and the participants. The interview process is described. I present the analysis and give an impression of the co-constructed stories. I describe the selection of stories. Narrative context analysis is presented, followed by thematic analysis. I present the attention devoted to ethical mindfulness and narrative as ethics. Further, I focus on methodological and ethical reflections through the research process. I discuss the constructing of the service users and the researcher, before I ask why we should consider stories in context.

- Chapter 7 presents the findings of the study.

- Chapter 8 contains a discussion of methods and findings. First, I present my pre-understanding of the study. I examine user involvement in the research design. I present some thoughts on who own the stories in the study before reflecting on whether I am giving vulnerable service users a voice. I raise the question whether we

can trust the findings in the study. I discuss the study's findings. I reflect on the
potential theoretical consequences of relational insight for the practice field. I focus on
decision-making processes, patient rights and shared decision making. I look at mental
health services as in need of a more holistic perspective, with support systems that
focuses on the service users' personal and social capacities. I reflect on the dominant
narratives within our study and how they were challenged.

- Chapter 9 presents implications for practice and further research, with a focus on
  narrative care.
- Chapter 10 provides closing remarks.

2. Background: the changing social context of mental health care

The study background includes an introduction to the field of mental health services in the
local treatment context and what service users encounter when they are admitted to
community mental health centers in Northern Norway. The interviews in the study were
performed within this contextual frame. When the service users in our study told their stories,
the meaning-making process was related to a series of social interactions with other
individuals (Langellier, 2001) and their surrounding contexts. The mental health services and
the community mental health centers were central backdrops for storytelling by individual
service users. By introducing mental health services in Northern Norway and its
transformations and changes, we provide insight into what meets the individual service user
when she/he is admitted. I also present some considerations concerning transitional mental
health services. Finally, I give some thoughts about the practicalities of admission to
community mental health centers for individual service users.

2.1 Northern Norwegian mental health services

*Psychiatric treatment cannot be isolated from the context in which it occurs in, i.e. the social
reality we live in with the factors that affect mental health or mental illness* (Haugsgjerd,
1990a, p. 399).

Mental health services in Norway have transitioned away from institutions and toward the
community (Larsen, 2009). The country's mental health services have experienced numerous
reform processes that have been implemented in various stages (transforming from large
psychiatric institutions toward more individually adapted services). Health reforms were
implemented during the 1970s and several service users received treatment in community

mental health centers located closer to their homes. During the past 10 to 15 years, there has been a significant restructuring, moving toward more decentralized mental health services throughout the country (Pedersen, Sitter, Lilleeng, & Gravbrøt, 2013). Major changes involving new therapies, care settings, renewed legal frames, internal and institutional organization and the development of new research areas have become a reality (ibid.). We encounter diverse mental health services that reflect both the new demands of modern societies and how such societies address mental illness (Novella, 2008).

The term 'deinstitutionalization' refers to 'a complex and comprehensive transformation of mental health care service in a range of national contexts' (Joseph & Kearns, 1996, p. 179). The aim of deinstitutionalization is to achieve an ideal of freedom (away from the old, large institutions) and more active, social participation by service users (Lorem, 2006). The purpose is to ensure that a service user is as independent and self-reliant as possible (ibid.). Treatment is regarded as an *ongoing social process* with the goal of an improved quality of life for service users in their communities. Deinstitutionalization is understood as more than changing the locus of care (Lamb & Bachrach, 2001). According to Lamb and Bachrach (2001), service planning must be tailored to the needs of individual service users. Hospital care must be available for individuals who require it. Mental health services must be culturally relevant and service users must be involved in their service plans. Service systems must not be delimited by a predetermined ideology, and there must be continuity of care (ibid.). Mental health care is a diverse field that encompasses numerous areas of knowledge and practice (Haugsgjerd, Jensen, Karlsson, & Løkke, 2009). It is also a dynamic field, and the evolution of user involvement as a dynamic and process-oriented concept requires a new understanding of the concept of insight[14].

Specialized mental health services are now delivered closer to where recipients live (Bruun & Svendsen, 2011). According to the Region of Health North (Helse Nord 2005),[15] greater proximity and increased capacity and availability have offered more individuals the opportunity to receive treatment in their region. The Escalation Plan for Mental Health stimulated an increase in local treatment and the decentralization of specialist treatment (Ministry of Health and Care Services, 1997-98). Mental health services for adults in Norway consist of community mental health centers, specialized hospital departments and private

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[14] The concept of insight will be further and carefully discussed in chapter 4.
[15] Norway is divided into five health regions.

practice psychologists and psychiatrists operating upon agreement (Dahl & Aarre, 2012b). In addition, mental health services are managed at the municipal level. The most important components of mental health care should be delivered at a community level, and the provision of hospital care should be limited. A modern mental health service balances community- and hospital-based care (Thornicroft & Tansella, 2009). Community-based mental health services are designed to provide specialized, easily accessible, and coordinated inpatient and outpatient mental health services (Ministry of Health and Care Services, 1997). Community mental health centers are responsible for coordinating the majority of public services for adult mental health and possess the skills to assess and treat individuals who have the most common mental illness (Helse Nord, 2005). The centers are part of the specialized services in mental health care for adults outside the central psychiatric hospitals; however, both professionally and organizationally, they belong to the same regional health authorities (Haugsgjerd et al., 2009). Norway's community mental health centers are specialized and independent units that are 'responsible for general mental health services to the population within a specific geographic area' (Storm, Hausken, & Knudsen, 2011, p. 2). Ideally, each community mental health center should have an outpatient clinic, a mobile team, and one or more inpatient departments[16]. Community mental health centers are also responsible for assisting community health services by providing advice and guidance and ensuring the continuity of specialized mental health services (Pedersen et al., 2013). The centers should also be low-threshold services that provide emergency care intended to prevent hospital admissions. The national health plans emphasize that specialist health and community health services have a shared responsibility. Through new knowledge regarding prevention and health promotion measures, specialized health services will be transformed from passively accepting service users for treatment to actively preventing illness (Helse Nord, 2005, p. 8).

Report No. 25 to the Storting "Transparency and comprehensiveness. About Mental Illness and Mental Health Services" (Ministry of Health and Care Services, 1997) concludes that service users did not receive the help they required, staff felt that they had not performed their duties satisfactorily, and the government failed to provide the population with adequate treatment options. The Escalation Plan for Mental Health (Ministry of Health and Care Services, 1997-98) emphasizes the need to strengthen each link in the chain to develop a comprehensive and coherent treatment network. In Health Region North, this approach

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[16] Ministry of Health and Care Services, 1997.

involved increasing adult psychiatry within both outpatient and inpatient services and expanding the number of beds at psychiatric hospitals. According to the action plan for mental health (Helse Nord, 2005), at the time that report was written there remained a lack of capacity, quality, organization, participation, interaction and accessibility of mental health services in Northern Norway.

Community mental health centers in Northern Norway cover large areas of the region. Currently, there are 14 community mental health centers in Northern Norway covering 87 municipalities (Gammersvik, 2009). However, Northern Norway's community mental health centers vary substantially with respect to their organization, professional services, specialist coverage, professionalism and quality, use of resources, cooperation with local authorities and design (Sletnes, Hansen, Winther, & Magnussen, 2008; Vorland, 2009). There are variations among the centers regarding 'the service content to be provided, available resources and provider's competence' (Storm et al., 2011, p. 2). In 2005, Health Region North reported not only that the two largest towns in Northern Norway, Bodø and Tromsø, have insufficient acute psychiatric capacity at their psychiatric hospitals but also that the community mental health centers lack sufficient specialized expertise to provide instant assistance at all hours. In psychiatric hospitals, these deficits cause overcrowding in acute wards and increased pressure on general wards (Helse Nord, 2005, p. 16). According to Gammersvik, (2009), Northern Norway experiences challenges concerning service user involvement and policies /procedures in psychiatric hospitals regarding service user flow; furthermore, many community mental health centers do not sufficiently cooperate with the relevant municipalities.

2.2 Transitional mental health services

'The treatment context is central, and the human experience of the treatment context is important' (Haugsgjerd, 1990b, p. 387).

Norway's mental health services are changing. Consistent with Joseph and Kearns, we agree that 'both deinstitutionalization and restructuring are complex processes with distinct attributes that manifest themselves at the national, regional and local scales' (1996, p. 182). A community-based mental health care system can be understood as more multifaceted than its psychiatric hospital predecessors and generates uncertainty regarding future services and treatment (Thornicraft & Tansella, 2009). Norway's Coordination Reform is a step towards

greater autonomy for the individual service user. Moreover, there is also a clear goal of reducing the costs of Norway's health-care system[17].

Instead of a linear process, the changes in mental health services and the restructuring of the care system can be described as cycles of care that often pass through four stages: optimism (the community mental health approach), building (decentralized community mental health centers and smaller residential and day-care facilities), disillusionment (scandals, inquires and public reaction) and control (the attempt to differentiate between 'safe' and 'risky' patients) (Thornicraft & Tansella, 2009, pp. 26-28). These cycles of care present different approaches to mental health care services from the service users' perspective. Mental health services are experiencing an ongoing, dynamic process that is subject to substantial guidance from central authorities but is implemented through local expressions within the individual community mental health centers and municipalities. Community mental health care should prioritize 'accessibility, comprehensiveness, continuity and co-ordination' (Thornicraft & Tansella, 2009, p. 33), and the level of user involvement should increase at all levels of mental health services.

Despite Norway's focus since the 1980s on user involvement in mental health, little is known regarding the degree to which user-oriented mental health services have been established (Storm et al., 2011). Instead, we have knowledge related to the lack of user involvement (Lorem, Hem, & Molewijk, 2014; Lorem, Steffensen, Frafjord, & Wang, 2014). The changes within mental health services have effected changes in the role of the service user (Lammers & Happell, 2003). When transitioning mental health services toward more community-based services, service users' power is more embedded in day-to-day care delivery, in contrast to the situation in psychiatric hospitals. One important characteristic of user-oriented services is that service users are encouraged to actively participate in decisions about their treatment. The right to participate is anchored in legislation and service users and professionals should engage in greater cooperation to clarify choices so the best option for the individual can be chosen (Ministry of Health and Care Services, 2009). This factor does not always indicate that opportunities for user involvement are improved.

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[17] http://www.regjeringen.no/nb/dep/hod/tema/samhandlingsreformen/om-samhandlingsreformen/samhandlingsreformen-i-kortversjon.html?id=650137.

According to Saraceno (2009), service users should be partners in care. Moreover, their family members should be involved. Thus, the community service will become a more dynamic, interactive setting in which ethics, experience and science are mutually reinforcing. Deinstitutionalization is an ongoing process of social change and represents an overarching trend in mental health services. These changes substantially influence the lives of the service users, 'who constitute a diverse and heterogeneous group' (Lamb & Bachrach, 2001, p. 1043) in need of individualized care.

2.3 Admission to a community mental health center

Service users have different needs and pathways (Ministry of Health and Care Services, 2006). For some service users the need for assistance emerges from a crisis, whereas for others, long-term thinking and planning over time has a greater influence. Many individuals who require mental health services need assistance from several levels of the mental health system. For many service users, the primary approach is to contact their general practitioner (GP), who will consider whether municipal mental health services /outpatient services could be useful. If not, the GP will refer the individual to either an acute psychiatric ward at the hospital (depending on the severity of the situation) or to various programs within community mental health centers.

Upon admission to specialist care, the service user will be re-examined by a specialist who makes decisions about the measures to be implemented. In an unclear situation or when the professionals are unsure of the diagnosis, the service user is often admitted to the psychiatric hospital for observation. Examples of admission criteria for inpatient care at community mental health centers include early intervention /preventing psychosis, preventing suicide, preventing acute crises from developing into long-term problems, and treating extensive deficits in everyday functioning (Ministry of Health and Care Services, 2006). The goal is to collaborate with the service user on admission to ensure that the intervention can be initiated at the lowest possible level of mental health services (ibid.). If the service user is admitted to a community mental health center, it is also important for the community mental health center to establish collaboration with the service user's home municipality.

Service users are diagnosed in accordance with the guidelines in the diagnostic system ICD-10 (ICD-10). The ICD-10 is based on three professional purposes: *communication,* which indicates the need for appropriate professional communication; *control*, which indicates

identifying preventive measures, providing effective treatment and limiting complications; and finally, *understanding* with respect to research and clinical work (Dahl & Aarre, 2012b, pp. 25-26). In Norway, the Statistical Manual of Mental Disorders (DSM) is used as a supplement to the international classification system ICD-10[18]. These diagnostic manuals are usually perceived as guidelines to help the professionals assess and classify a service user's mental illness. Diagnosis is not always easy to determine; it can be a process to arrive at a category that is consistent with the individual's mental distress.

Treatment can begin when the service user is admitted to a community mental health center. The field of mental health care features various treatment cultures. Service users experience different treatment cultures within the system. These cultures exist in 'a continuum where monologue and dialogic cultures represent endpoints' (Kogstad, Hummelvoll, & Eriksson, 2009). It is central to acknowledge the contrasting service that users receive in different treatment cultures (ibid.) and give individual users a choice that enables the receipt of their preferred treatment.

Upon admission, the clinician must assess whether the individual has insight into her/his own health and treatment. From a medical perspective, insight is predominantly understood as exclusively inherent in the service user. Although the concepts of insight and user involvement are further discussed in chapter 4, it is important to mention here that insight is understood as a core concept within mental health treatment that determines whether a service user is capable of participating in and making decisions about her/his treatment.

3. Theoretical framework

In the next chapter, I provide an account of the theoretical framework of this thesis. This framework constitutes the basis for studying the diverse and ever-changing social processes of mental health care. I first present the social constructionist approach. I examine the relationship between social constructionism and the narrative approach. I present relevant narrative theory. The chosen narrative perspective is that of narratives as co-constructions in context. I discuss dominant narratives as co-constructions. Furthermore, I provide a brief overview of the researcher's role. I also present the interview context as a relational context. Finally, I offer some considerations about narrative validity and reflexivity.

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[18] In section 3.2, I examine how the DSM can be understood as a narrative source.

3.1 The social constructionist approach

The social constructionist approach is an interdisciplinary research position adopted by many historians, anthropologists and sociologists (Khalifa, 2010), along with psychologists (Burr, 2003)[19]. This approach is primarily concerned with the processes 'by which people come to describe, explain, or otherwise account for the world (including themselves) in which they live' (Gergen, 1985, p. 266). According to Burr (2003), although this approach contains an array of features, one common key assumption is the adoption of a critical stance towards a taken-for-granted understanding of the world. Social constructionists do not deny the existence of an objective reality—instead, they maintain that the meaning of reality is socially constructed (Andrews, 2012). Concepts are constructed instead of discovered; moreover, they correspond to something real in the world (ibid.). Society is both a subjective and an objective reality in the world; 'the former is brought about through the interaction of people with the social world, with this social world in turn influencing people resulting in routinization and habitualization' (Andrews, 2012, p. 40). Habitualization gradually becomes a general store of knowledge (dominant narratives), and this knowledge is 'institutionalized by society to the extent that future generations experience this type of knowledge as objective' (ibid.).

What principally constitutes both our relationships and ourselves is the social reproduction and transformation of structures of meaning, conventions, morals and discursive practices (Cromby & Nightingale, 1999). Reality is constructed 'in language systems in which we exist' (Whiting, 2007, p. 141), and several social constructionists are concerned with the performative role of language (Burr, 2003). Social constructionists understand language as having practical consequences for people (ibid.). If, for instance, we understand *insight* as a constructed concept belonging to a particular culture and time, we can understand some of the consequences of insight /lack of insight. Social practices and interactions are especially interesting within social constructionism. Instead of pathologizing the service user's lack of insight as an inner defect, the social constructionist approach focuses on how insight as a construction emerges through the interactions between the service users and all the people involved in the process (Burr, 2003). Accordingly, there is a focus on processes above

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[19] Young and Colin (2004) distinguish between constructivism as a more individually oriented approach (which is occupied with meaning-making and construction of the world through individual processes) and constructionism, which has a focus on the construction of social and psychological worlds through social processes and interaction.

structures that naturally considers knowledge as something that people create together. How we understand the world is both historically and culturally specific. The social practices in which individuals are engaged and the interactions in which they participate are of great interest. When considering insight and user involvement, this leads us to a focus on the interaction in which these concepts are being discussed or told. Within our study frame, this interaction occurs within the interview context, the research interview, which is considered a transferable image to the therapeutic setting between the service user and the clinician in mental health treatment.

Are the interviews in the study transferable as constructions of knowledge when we discuss insight and user involvement? Can they tell us something about what a good clinical practice within mental health services can be? Both insight and user involvement are founded within communities of meaning-making, and I find it important to question the taken-for-granted medical knowledge concerning insight. Is insight exclusively inherent in the service user? Is insight measurable? Are there gold standards for measurements? From a social constructionist approach, it is important to ask new questions, 'often evaluative, political and pragmatic' (Young & Collin, 2004, p. 377) questions, about the choices being made. 'Meaning is constructed in a social, historical and cultural context, through action and discourse in which we form relationships and community' (Young & Collin, 2004, p. 378). We can see insight as a constructed concept, within historical and cultural contexts, that needs to be challenged as a discourse or 'a way of thinking'. Scientific knowledge is generated through relationships and reflective inquiry (Blustein, Schultheiss, & Flum, 2004) within the social constructionist approach. The researcher is seen as being 'closer' to the participants and the knowledge created is a product of the social interaction between the researcher and the participants (Blustein et al., 2004; Burr, 2003). Relational processes and language are important features of social construction (Blustein et al., 2004). From a Bakhtinian perspective on social constructionism, knowledge emerges from the interaction of voices in dialogism (Yüksel, 2009). Bakhtin understood language as 'a living, socio-ideological thing' (Bakhtin, Wright, & Holquist, 1981, p. 293); for the individual, conscious language 'lies on the borderline between oneself and the other' (ibid.). In my view, the relational approach that lies within the social constructionist approach can form the basis for a richer contextualized view of insight and user involvement that can lead to a mental health practice in which new questions can be asked. Insight as a concept is constructed both in constructions of 'insight' that are attributed to professionals and in terms of service users' self-constructions (Malson, Finn, Treasure,

Clarke, & Anderson, 2004). This thesis seeks to adopt a new, social constructionist perspective on insight as a co-constructed, dynamic process.

3.2 The relationship between social constructionism and the narrative approach

I present the relationship between social constructionism and the narrative approach by taking a closer look at Tekin's 'Self concept through the diagnostic looking glass: Narratives and mental disorder' (2011). The paper is highlighted in this context to give the reader an example of how social constructionism can affect narratives and how narratives can affect social constructionism. In that paper, Tekin discusses the Diagnostic Statistical Manual of Mental Disorders (DSM) as a source of narrative 'affecting the diagnosed subjects' self-conceptions and possibilities for self-development' (2011, p. 358). Tekin defines narratives as playing 'a crucial role in understanding ourselves and others, as well as establishing a self-concept' (2011, p. 360). Narratives are sense-making tools (ibid.) and organize our lives, put experiences into context, and enable us to make sense of the events in our lives. The DSM functions not only as a tool for clinicians to determine and communicate diagnosis and develop methods for treatment but also as a guide for service users to make sense of their mental illness. Obtaining a DSM diagnosis can systematize a service users' experience with mental illness, explaining difficult feelings and thoughts. Simultaneously, it can affect a service user's autobiographical and social narrative (Tekin, 2011). Tekin further uses the concept of 'looping effects' (2011, p. 367) to explain the many social interactions that take place in relation to the DSM as a source of narrative:

The parameters in the "looping effects" schema include the following:

'.... (1) institutions,(2) knowledge, (3) experts, (4) classification, and (5) classified people. The interaction between these elements leads to looping: the experts in human sciences, who work within certain institutions that guarantee their legitimacy, authenticity, and status as experts, become interested in studying the kinds of people under a given classification; possibly to help them or advise them on how to control their behavior. These experts generate knowledge about the kinds of people they study, judge the validity of this knowledge and use it in their practice, and create certain classifications or refine the existing ones. Such knowledge includes presumptions about the people studied, which are taught, disseminated, refined, and applied within the context of the institutions. For instance, it may entail de facto assumptions,

e.g., multiple personality patients were subjected to sexual abuse as children' (Tekin, 2011, p. 367).

Tekin sees these 'looping effects' as starting points to explore how diagnosis functions as a narrative source that affects the service user's autobiographical and social narratives. We can also understand the two main topics in this thesis—insight and user involvement—as narrative sources constructed by certain 'parameters'. If we use insight as an example, we have service users who are seeking help as subjected to *classifications*. The *experts*, including researchers, create these *classifications* to define insight/lack of insight (the clinicians who diagnose and make treatment plans, the researchers who conduct research to provide explanations for mental illness, and mental health professionals who are in the practice field). The *experts* work in *institutions* and generate *knowledge* about insight/lack of insight, which contributes to the creation process of the concept (classifications, treatment methods, clinical research experiments and different approaches). The *classified people* who are defined as having insight or lacking awareness acquire knowledge about their condition from the experts, and this knowledge changes their self-perception or understanding, which in turn changes their autobiographical and social narratives (Tekin, 2011). As Tekin underlines, the DSM as a narrative (or insight as a narrative source) is a double-edged sword for the service user. Although it might be a positive process for recovery, it might also, as a symptom-based approach and biomedical disease model, remove the service user from other elements in life that are central. More seriously, it might reduce the service user's experiences to 'a neurobiological imbalance that is unchangeable' (Tekin, 2011, p. 377).

Later in this chapter, we take a closer look at dominant narratives. These is a close alliance between what Tekin (2011) defines as 'parameters' in the 'looping effect' and the co-constructions of dominant narratives. The narratives in our study are seen not simply as reflections of internal or external 'realities' 'but as instances of social practice in which the nature of "reality" (of themselves and of their treatment experiences) were actively constituted and negotiated in the context of the wider discursive field' (Malson et al., 2004, p. 484).

3.3 Relevant narrative theory

When adopting a narrative approach, one of the first questions to consider is how we define a narrative. I follow Denzin's (1989, p. 37) 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. A narrative relates events in a temporal, causal sequence'. Let us look at one of many narratives in the study and use it as an example[20].

Marianne, a mother of three, was diagnosed as bipolar some years ago. Her story addressed how her children were affected by her mental illness. She wanted the mental health professionals to talk with her children about what was going on. I asked her whether she had missed her children while she was admitted:

Yes, of course I did, but I just thought that they needed to speak. As much as I have to go to a psychiatrist or a psychologist and chat, the kids have to be allowed to go…they've got so many thoughts in their heads, and I was not able to talk like that with them. I had enough with myself. So Elise, the public health nurse here at our home - she has been fantastic for them. She had them in conversation until she somehow thought that (pause) that things looked all right (Klausen, 2015).

We can see from the excerpt that this narrative has a beginning, a middle and an end. It has a plot: it describes how worried Marianne was for her children while she was admitted. It has an internal logic and relates the events in a temporal, causal sequence: Marianne wanted professionals to talk with her children about what was going on. The community clinic nurse did just that and could reassure Marianne that things were fine. Stories are produced, distributed and circulated in society (Gubrium, 2005). How stories relate to particular social contexts requires an understanding of how these contexts affect words. A story can have different meanings in different settings. The social consequences of narratives must be understood in relation to what is at stake in the storytelling context (Gubrium, 2005).

There are a variety of schools in the field of narrative research, and there is 'a tremendous cross-disciplinary interest in the narrative concept' (Schiff, 2012, p. 33). Narrative studies are conducted in several scientific fields, including history, anthropology, ethnography, psychology, socio-linguistics, sociology and health science (Spector-Mersel, 2010). Moving

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[20] This narrative is taken from the second article in the thesis: 'Motherhood and mental distress: Personal stories of mothers who have been admitted for mental health treatment.'

from a marginal early status, the field now includes 'a rich, interdisciplinary, still-expanding corpus of theoretical and research studies' (Mishler, 2006, p. xi).

According to De Fina and Georgakopoulou (2012), narrative is epistemological in its aims; thus, narrative offers an antidote to rationality and the quantitative measures that characterized social science four decades ago. Furthermore, it is a political tool for the expression of lay experiences and voices. It represents an alternative to the modernist reality and was regarded as 'a postmodern reaction to a modernist bias' (De Fina & Georgakopolou, 2012, p. 20). Moreover, the narrative paradigm overlaps with social constructionism, which regards social reality as 'constructed, fluid and multifaceted' (Spector-Mersel, 2010, p. 211). The narrative paradigm contends that social reality is a primarily narrative reality (ibid.). According to Smith and Sparkes (2008), our lives are storied and therefore, identity is narratively constructed. Narratives are rooted in the 'here and now' of the narrator; stories that are told are always related to the past and the future from the perspective of the 'here and now'. Moreover, stories can never tell the whole story; they cannot contain everything.

My point of departure is a perspective of narratives as co-constructions in socially situated actions and performances of identity (Karlsson, Löfdahl, & Pérez Prieto, 2013; Mishler, 1999). This perspective focuses on the making of the stories and the researcher as a co-constructor of the stories performed. We define the narratives in our research as topical life stories (Betraux, 1981; Pérez Prieto, 2006) because they focus on a limited period in the participants' lives, namely, their stories related to receiving mental health treatment as a service user. Numerous approaches can be taken in narrative research. Topics such as identity (Blix, 2013), large or small stories (Georgakopoulou, 2006), counter narratives (Andrews, 2004; Bamberg, 2004), illness narratives (Hyden, 1997; Langellier, 2001; Stephens, 2011), political narratives (Andrews, 2007; Whooley, 2006) and institutional stories (Linde, 2009) are some of the considerations that have occupied narrative scholars. The narrative researcher pays attention to both content ('the told') and the structure of narration ('the telling') (Josselson, 2011b). I do the same by focusing on narratives as co-constructions in context.

This approach implies a desire to remain close to what I experienced as co-constructions in dialogues with the study participants; the interviews focused on the individual experience of participating in mental health treatment. For example, if the topic of power and oppression had been a prominent theme in the dialogues, a more 'Foucaultian' approach could have been

appropriate[21]. The choice to rely on Bakthin for guidance through the scientific jungle is explained by his approach to the dialogical nature of utterances and being in the world. The self is always constructed in relation to other individuals (Josselson, 2011b), and the adoption of this approach in narrative research indicates that no individual or story is considered final or fixed: all stories are open ended and offer possibilities for new revisions to the future contained in them. Consistent with Josselson (2011b, p. 227), I understand narrative analysis as a focus on 'patterned relationships in the flow of events and experience within a multi-voiced self that is mutually constitutive interaction with its social world'. Things exist only in relation to others and we are always in dialogue with other individuals and the world (Robinson, 2011, p. 4). This coincides with both a social constructionist perspective and a focus on the telling as co-construction.

3.3.1 Narratives as co-constructions

Mishler (1995) divides narrative inquiry as applied to studies of narratives into 3 models. The first model concerns causal explanations between the telling and the told and regards narratives as giving access to experiences. In 1967, the well-known sociolinguists Labov and Waletzky offered their pioneering work on personal narrative; from a performance perspective, they textualized experiences in a manner that presumes a real event prior to the storytelling (Labov & Waletzky, 1967). The second model focused to a greater extent on the telling and textualization; how text attains coherence and structure in a meaning-making event. The third model focused on the function of personal narratives and the breakthrough to storytelling as performances become reality (Langellier & Peterson, 2006). Consistent with Langellier and Peterson (2006, p. 152), I understand narratives as follows:

'...embodied in participants who tell personal stories of experience, situated in the interactional and material constraints of the performance event, and embedded within discursive forces that shape experience, narrative, and selves.'

Narratives vary in their degree of embeddedness in surrounding discourses and social activity (Ochs & Capps, 2001), and there is clear interest among narrative social constructionist

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[21] Foucault describes power as a panoptic gaze, the aim of which is to control the masses by monitoring the individual. This is also true in mental health services, in which Foucault argues that doctors owned the power of knowledge and that science was based on observations, classifications and the examining eye (Terkelsen 2010, Foucault 1976).

researchers regarding the situational context (De Fina & Georgakopolou, 2012). Working with narrative as co-constructions 'requires theory which take context as serious as it does text' (Langellier, 1999, p. 128). A focus on the cultural production and reproduction of identities and experience is also central (ibid.). Langellier and Peterson (2006) emphasize that being framed, reflexive and emergent specifies the text-context relations in narratives. Both the performer and the audience define the narrative as a storytelling event and the storytelling is reflexive in the sense that it is both a doing and a re-doing. In our study, the participants' experiences are seen as important to investigate. These experiences were constructed during the interview talks between them and me as an interviewer; *a while-doing and re-doing* of the experiences that co-constructed the narratives.

Narratives are also emergent in a manner that permits change: '[e]mergence may refer to new text structures, event structures, and social structures, that is, to new stories, new storytelling events, and new identities' (Langellier & Peterson, 2006, p. 155). Co-constructed narratives are always situated and thus, told within the frames of external and internal rules for certain narratives; the approach naturally shapes the telling. Co-constructed narratives can also both legitimize and critique power, and the telling is understood to be political (Langellier & Peterson, 2006). Following Andrews (2007), I agree that when we relate our stories to our lives, we say something to other individuals regarding our political worldviews. The shifting contexts of bodies, situations and dominant narratives imply that a co-constructed narrative cannot be removed from its context if we wish to obtain a deeper understanding of 'what it is, how it works, and what it does in the world' (Langellier & Peterson, 2006, p. 166).

3.3.2 Dominant narratives as co-constructions

The three articles in this thesis describe frameworks of meaning presented by the participants in which they both mirror and challenge various dominant narratives (Andrews, 2004). Dominant narratives explain, according to modernist theory, 'the deeper reality underlying the surface of the world' (Burr, 2003, p. 11). In modernism, the common feature of theories concerning rules and structure in social phenomena was often called 'metanarratives' or grand theories (ibid.). Conversely, postmodern theory rejected both the idea of an ultimate truth and the idea that the world is a result of hidden structures. Social change is not understood as 'a matter of discovering and changing the underlying structures… through the application of a

grand theory or metanarrative' (Burr, 2003, p. 12). Instead, we co-construct and reconstruct narratives through social interaction[22].

In this thesis, we regard dominant narratives not as 'ultimate truths'; instead, in line with Hänninen (2004) we understand that the cultural stock of stories represents the entirety of narrative representations that an individual hears or reads throughout life, and in every culture, some stories are more dominant or powerful than other stories. These dominant narratives are collective stories that shape personal identities and narratives (Esteban-Guitart, 2012). One dominant story about (for instance) insight is that lack of insight is a core concept of schizophrenia (Ampalam et al., 2012). Another dominant story within mental health research is that mentally ill women are inherently bad parents (Diaz-Caneja & Johnson, 2004).

Dominant narratives can be traditional narratives, and they relate a personal story to given cultural standards (Talbot, Bibace, Bokhour, & Bamberg, 1996). By personalizing the dominant narrative, interviewees can construct themselves as protagonists who resist antagonistic forces (ibid.). Bamberg (2004) describes two interpretations of dominant narratives. The first interpretation relates to how narrators position themselves in relation to their stories, whereas the second interpretation describes how narrators are subjected to dominant narratives from which they cannot escape. We are surrounded by pre-existing sociocultural forms of interpretation (Bamberg, 2004). Although we are dependent on these dominant narratives (which provide us with guidance and direction in everyday life), they simultaneously render us blind to our actions. Bamberg emphasizes the complicated relationship of this double-binding; our smaller, daily employed dominant narratives are also components of a larger dominant narrative; these narratives are 'thoroughly interwoven with each other' (Bamberg, 2004, p. 361).

Andrews (2007) underlines this binding, contending that stories provide us with only partial insight into the narrators' lives. Moreover, she argues that stories can be understood as windows into political periods that are not reducible to individual human beings (Andrews, 2007). Stanley (2007) also emphasizes that dominant narratives specify and control how social processes are performed, arguing that counter-narratives challenge dominant narratives and offer alternatives to dominant discourses. Andrews (2004) emphasizes that there are often

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[22] See section 3.1 on the social constructionist approach regarding habitualization (Andrews, 2012) and dominant narratives.

complicated relationships between personal narratives and dominant narratives, and it is interesting to investigate how these dominant stories are used to tell new stories.

Following a social constructionist approach, I emphasize that what are regarded as dominant narratives are capable of change (Blix, 2013). Individuals expand the boundaries of and challenge dominant narratives in different ways (Andrews, 2004), and holding a perspective on narratives as socially situated actions (Karlsson, 2006) entails an approach in which an individual is never regarded as 'fixed in any representation of his or her words and cannot claim any finality to what a story means because any story has potential for revision in future stories' (Josselson, 2011b, p. 227). Narratives are woven into contextual conditions, implying both that interaction is the prerequisite for the construction of narrative and that narrative is a specific type of interaction (Becker & Quasthoff, 2005).

3.3.3 The role of the researcher

The researcher may be understood as 'a bricoleur, as a maker of quilts' (Denzin & Lincoln, 2013, p. 7), who assembles representations that fit within a specific thesis. Research is an interactive process shaped both by numerous factors (including my personal history, biography, gender, and social class) and by the individuals who participate in the study (Denzin & Lincoln, 2013). As an investigator of narratives, I am not neutral about politics and the social contexts of which this thesis is a part; these issues are one reason for examining the questions that I do (Andrews, 2007). M. Andrews discusses the tell-ability of stories as related to the level of intimacy between narrator and interviewer but emphasizes the importance of context (ibid.). Researchers often make the mistake of assuming they are 'giving a voice' to marginalized individuals. These empowerment narratives might mask inequalities instead of redressing them, giving the impression that the research participants are 'speaking for themselves' instead of what they are really doing: answering specific questions, with little input into how their stories are represented in the final text (Andrews, 2007). It is problematic to view our task as researchers to assist others in articulating their narratives without asking the essential question: 'From whose point of view is someone, or a community, voiceless?' (Andrews, 2007, p. 41). We agree with M. Andrews (ibid.) that this point of view is likely that of a group or position that distinguishes itself from the group that it seeks to empower. The paradox of the approach of 'giving a voice to' is that it creates distance. Following Andrews (2007), we must place ourselves at risk while conducting research; it is a journey to enter someone else's life experience and participate in the storytelling process. The narrative

researcher works on multiple tasks: 'performing the story as a narrator and reflecting on the story told as a researcher, continually moving between these and other subjectivities as the conversation unfolds' (Arvay, 2003, p. 166).

3.3.4 The interview as a relational context

The Russian philosopher and literary theorist Bakhtin researched the modern novel (Bakhtin et al., 1981; Bakhtin, Holquist, & Emerson, 1986), but has become well known for his theories connected to language and communication. His contribution to the field concerning polyphonic dialogues is easily transferable to the research interview context. The research interview is polyphonic in nature; it is a context 'in which there are many voices and discourses that cross each other simultaneously to produce knowledge about personal narratives and social life' (Tanggaard, 2009, p. 1500). No utterances can be regarded as independent units; they exist in the world within a contextual meaning, and the understanding of a speech whole is always dialogic (Bakhtin et al., 1986). Language is social, and the living language consists of combinations of different social languages (Tanggaard, 2009) in which certain languages (narratives) are more dominant or authoritarian than other languages. Bakhtin defines language as heteroglossic, complex and a combination of different social languages (Bakhtin et al., 1981). In the research interview context, this heterogeneity may appear in the form of the interviewee or the interviewer belonging to different communities or groups or being in opposition to various dominant narratives (Tanggaard, 2009). As a researcher, I belonged to a certain community and social language. The participants in the study belonged to some of the same communities as me, whereas others in our communities and speaking our social languages were different. Following these considerations of heteroglossia, there is no general language, but instead, transmissions of past and present discourses that surface during an interview. In a social constructionist approach, narratives are regarded as emergent and defined as 'a joint venture and the outcome of negotiation by interlocutors' (De Fina & Georgakopoulou, 2008, p. 381). Tanggard (2009) emphasizes that there is no inherent dichotomy between subjective meanings and objective reality; the interview is a shared dialogue in which socially embedded discourses intersect and may produce new meanings or stories. Hydén, who has many years of experience with qualitative studies of men's violence towards women in intimate relationships, discusses interviews in which sensitive topics might be a part of the dialogue between the interviewee and interviewer and emphasizes that any topic may be sensitive to the other (Hydén, 2008). Hydén's work actualizes the tension between being a researcher and a therapist and discusses

the risk of being overly focused in the interview on the darker aspects of the narrator's story, which may both 'cause suffering and seriously limit your research' (Hydén, 2008, p. 225). In her later work, Hyden (2014) presents the teller-focused interview, which is grounded in a dialectic manner of thinking about the narrator and the interviewer. These individuals are defined as partners who have different tasks and responsibilities in the research process (ibid.), and Hydén emphasizes both the differences and similarities between being a researcher and a psychotherapist. The two roles belong to different settings and communities, but the commonality involves offering a third ear (or voice); in this way, the world can change and become plural instead of binary, and a more complex dynamic can emerge (Hydén, 2014). Hydén also relates her discussion to Bakhtin and stresses that 'one of the most important issues for the teller-focused interview to handle is the multi-voice character of the accounts' (Hyden, 2014). Hydén's work is concerned with what might appear to be sensitive topics, and she relates those topics to relational circumstances. In the relationship between the narrator and the teller and the surrounding contexts that characterize this relationship, both similarities and differences may be stressed. Hydén defines this process as 'a dance of balancing involvement' (Hyden, 2014). The researcher must balance her involvement with the narrator's storytelling to ensure that the power relations are as balanced as possible (with the knowledge of the interview as an ongoing co-construction).

3.3.5 Narrative validity and reflexivity

Altheide and Johnson define validity as reflexive accounting, 'which places the researcher, the topic, and the sense-making process in interaction' (2013, p. 390). Polkinghorne (2007) contends that there are degrees of validity that rely on a consensus within a community of speakers. Validating knowledge is an 'argumentative practice' (Polkinghorne, 2007, p. 476), and readers should be able to follow the research process to make their own judgment about validity. Heikkinen, Huttunen, Syrjälä and Pesonen (2012) present five validation principles for action research and narrative inquiry that I find relevant for this thesis. The first principle is what the authors term historical continuity. In narrative research, historical continuity relates to how logical and coherently the narrative proceeds. The second principle involves reflexivity, which is related to subjective adequacy. In this study, I must make the nature of my relationship with my research object transparent. The third principle concerns the ontological and epistemological presumptions to be addressed; what are my presumptions concerning knowledge and reality? How do I define narratives and their relation to the world? Have I made my research transparent: are the research methods and materials presented such

that my readers can follow the process? The principle of dialectics is also central: how have my insights developed in dialogue with others? The fourth principle relates to ethics: how are ethical problems addressed? Does the research provoke discussion in the field of mental health services treatment? Does the research cause service users to believe in their own capabilities and possibilities to act and therefore encourage new practices and actions? While conducting the interviews, several participants emphasized the importance of participating in research concerning user involvement. I had the sense that they believed that this research would 'do' something. I find this especially challenging, indicating that the ethics of the study are constantly at stake. The final principle concerns evocativeness: how well does this research evoke memories, mental images or emotions related to the theme? (Heikkinen et al., 2012, p. 8). These principles can be regarded as a guide for the entire research process, and Heikkinen et al. (2012) define research as practice to include physical (time and space), semantic (language) and social (relational) dimensions. These principles are not established as a list of criteria. Instead, they are both tentative and in flux (ibid.).

Having situated the study in a theoretical framework that involves the social constructionist and narrative approaches inspired by Bakhtin's relational dialogism, I turn to the literature review concerning insight and user involvement.

4. Literature review—insight and user involvement

Why focus on insight in relation to user involvement? Insight has developed as an important clinical phenomenon (Shad et al., 2015). It is considered a core concept within mental health services that has serious consequences for the individual service user's admissions and treatment. Assessment of insight is complicated, and there is often a question of whether the service user's explanation corresponds with professional opinion. However, it is important to realize that insight is a dynamic concept among professionals in mental health services; different professions and people will have different understandings of insight. In line with Hamilton and Roper (2006), we argue that a professional's opinion about a service user's insight will shift. In the same way, a service user's opinion of insight will vary.

There has been a transformation from a passive *recipient* of treatment and care to an active participant and user of services that has occurred both within policy documents and in practice in light of Norway's deinstitutionalization process. This transformation presupposes a service user who is not only involved in treatment but also an active part of the decision-

making process. How can we promote insight and user involvement in a way that can inspire better clinical practice? There has been little qualitative research, and even less narrative research, concerning insight among service users (Korsbek, 2013). According to Bracken et al. (2012), there has been a technological paradigm within mental health services in which mental health problems can be mapped and categorized with the same logic used in the rest of medicine. Most research on insight stresses biomedical interventions as important for successful treatment (Macnaughton, 2008). Our study strives to contribute to changing this view; we look at insight as a dynamic concept, not a static and measurable term. Accordingly, there is a need for empirical studies of insight and user involvement that focus on the importance of insight in relation to treatment. In light of this need, our study fills a gap with its focus on service users' narratives that can provide a richer understanding of experiences related to insight and user involvement. The clinical perspective is challenged by service user experiences that focus on first-person perspective, underlining insight as a social co-construction that includes all involved people. It is our intention that the study's orientation toward insight as a relational and dynamic process with significant consequences for user involvement will provide mental health practice with new perspectives.

4.1 A service user-oriented literature review

There is substantial disagreement within various research fields concerning insight and user involvement. These discussions concern the decisions made in the everyday lives of service users. In everyday practice, insight is challenging for both clinicians and service users. It is important to emphasize the connection between the challenges linked to insight *in practice* and research that focuses on *these challenges.* This highlights insight as an extensive and compound issue in clinical practice and research closely linked to user involvement in mental healthcare. Academic and practical developments in mental health have emphasized service users' perspectives. This is particularly true with respect to user involvement (Nolan, Hanson, & Magnusson, 2011), whereas issues related to insight have not kept pace. If research and practice concerning insight develops in the same direction as user involvement, it will have consequences for questions related to treatment and compliance. Within this study, service users' perspectives are linked to listening to what service users say and experience. Furthermore, this study promotes service users' best interests through joint storytelling to develop *real* user involvement.

I argue that a presentation of insight and user involvement in mental health services should specify a relational approach based on a dialogical practice in which service users' experience-based language can form the foundation for shared decision making.

The literature review constitutes the entrance to the concepts of insight and user involvement and is intended to form the basis of an understanding of the study's aims. I have focused on studies that do not always provide a comprehensive or complete picture of the ongoing academic debates surrounding insight and user involvement. Instead, the literature review adopts a *service user-oriented perspective* that concentrates on discussions linked to insight in clinical everyday life. I start this section by painting a picture of Norwegian clinical practice, focusing on insight into patients' rights. I introduce the clinical intention of discussing insight. I present the development of decision-making models that are closely related to insight. I also discuss autonomy and coercion. I give some thoughts on narratives and insight. I place our research within the frames of a social constructionist perspective and look at the consequences of this frame has for the concepts of insight and therefore, user involvement. The relationship between insight and decision-making processes is highlighted.

User involvement is the topic of the second part of the literature review. The ideal of user involvement is described in the Escalation Plan for Mental Health (Ministry of Health and Care Services, 1997-98). The Plan's requirements include service that is both comprehensive and coordinated. A good professional environment is important. Furthermore, it is important to ensure that users are treated with respect, that mental health services are provided on the basis of shared values, and that the user experiences the continuity of stable relationships. People who need help should get help, and people with mental illness should receive adequate services in line with the legislation (Granerud, 2011). These requirements must be considered goals in mental health service work. Thus, user involvement is both a legal right and a means to ensure the protection of user needs in care and treatment. A central goal of improvement is to build users' rights to participate in the formulation and execution of services. In this section, I examine user involvement in mental health care. Next, I present various degrees and models of user involvement as central in relation to insight. I offer an exploration of user involvement before reflecting on that concept.

4.2 Norwegian clinical practice: The problem of insight and patients' rights

Norwegian health legislation is associated with a general rule of consent. Man is autonomous and has a full right to determination with regard to his own freedom, health and life. This principle is affirmed both in international human rights instruments and in the Norwegian Patient Rights Act. Decision-making competence can be remitted only when the patient is obviously unable to understand what consent entails (Ministry of Health and Care Services, 2011)—in other words, when he or she lacks insight. Within this understanding, this concept is linked to physical or mental disorders, senile dementia or mental retardation patients. An assessment of decision-making competence is linked to an assessment of the person's ability to understand. Furthermore, it must be obvious that the person is unable to understand the rationale for health care and what consent entails. The patient should also have received enough information about her/his health condition, possible causes and prognosis, along with the possible risks and side effects of health treatment (ibid.). The information given must establish a basis for discussion, and the patient's degree of understanding is also related to the dissemination of information. This information should be adapted to the individual patient's circumstances and needs. In practice, this means taking into account the background and circumstances connected to the patient and her/his illness, age, mental state, language, culture and experience. Furthermore, the patient's consent, shall not lapse for more than the extent necessary. Not having consent in one area does not mean you do not have consent in other areas. In Norway, it is the professional who decides whether the service user is competent to consent (Ministry of Health and Care Services, 2011).

4.2.1 The clinical intention of discussing insight

The purpose of discussing insight in mental health-care practice, from the professional's point of view, is clinical and involves an attempt to identify the problem with regard to enhancing service users' insight level or awareness of illness. A procedure developed by Amador et al. called the 'Scale to Assess Unawareness of Mental Disorder' (1993), emphasizes not only general awareness of the disorder but also the specific symptoms of

'*hallucinations, delusions, thought disorder, inappropriate affect, unusual appearance, stereotypic or ritualistic behavior, poor social judgment, poor control of aggressive and sexual impulses, slow or impoverished speech, flat or blunt affect, avolition-apathy, anhedonia or asociality, poor attention, confusion-disorientation, unusual eye contact, and poor social relationships*' (Shad et al., 2015, p. 113).

For each of these topics, the service user is asked about his/her awareness in both the present and the past. According to Amador et al. the scale is a 'standardized scale on which ratings are made on the basis of patient interviews' (1993, p. 874). This scale gives an idea of how complicated and extensive it is to conduct an interview related to measuring insight from a clinical perspective. A great deal is based on the professional's discretion. Although measuring insight in praxis can be understood as part of the need to prepare a diagnosis, it becomes difficult when insight is related to static and essentialist characteristics[23] of the individual service user. According to Hamilton and Roper (2006, p. 417), 'no assessment of insight is simply made or sustained in a clinical setting'. When talking with service users about their mental illness or treatment, clinicians and family members alike are often frustrated by the service user's lack of insight (Amador & Kronengold, 2004). This is an area of potential conflicts. Service users who feel coerced into accepting medication and services for a condition that they do not believe they have often refuse help and are exposed to more coercive treatment because they are unaware of their mental illness in a medical/clinical sense. A relational concept of insight creates the dynamics that seek to convey the different perspectives so the people involved can share treatment decisions. A differentiated understanding of insight can form the basis for better and more sensitive communication about insight among everybody involved. A more respectful dialogue about insight might also raise awareness during both the decision-making process and the actual practicing of user involvement (Lorem, 2014).

Insight into illness involves the service user's awareness of her/his illness (Engh, 2010). Grisso and Appelbaum (1995; Grisso, Appelbaum, Mulvey, & Fletcher, 1995) define four standards in the MacArthur Treatment Competence Study for determining whether a service user has insight: the ability to communicate a choice, understand relevant information, appreciate the nature of the situation and its likely consequences, and rationally manipulate information. The MacArthur study is, however, considered inadequate from a relational-oriented perspective because of its oversized focus on trait descriptions and cognitive properties. In contrast to Grisso and Appelbaum (Grisso & Appelbaum, 1995; Grisso et al., 1995), Wang et al. (2011) define insight as a patient's recognition of having a mental illness,

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[23]In mental health practice, an essentialist perspective would be that either you have insight or you lack insight.

the social consequences of the diagnosis and the need for treatment. Insight has been more broadly defined as connected to five dimensions: (1) the patient's awareness of having a mental illness, (2) awareness of the social consequences of the illness, (3) awareness of the need for treatment, (4) awareness of the symptoms and (5) attribution of symptoms to the illness (Mintz, Dobson, & Romney, 2003, p. 75). Amador and David (2004) report that as a multidimensional concept, insight is not only shaped by individual psychology and the limitations of biology (as in cognitive limitations and anosognosia[24]) but also affected by social constructions of the illness.

A different approach to this definition is presented by Kravetz, Faust and David (2000) and, Alreja, Sengar, Singh and Mishra (2009), who describe the field as 'a mélange of ideas about awareness of illness, acceptance of illness, willingness to take medication or other treatment, and endorsement of other expectations that are applied to people with mental disorders' (Alreja et al., 2009, p. 39). In their view, the one constant in the literature is that insight is based on the extent to which the patient acknowledges a biomedical explanation for the illness (ibid.). Insight can be studied as a set of descriptive beliefs and a personal narrative (Roe & Kravetz, 2003). Insight can be understood as dynamic and provisional, 'not only within the context of the particular communicative event but also, potentially, within a particular story line, and it is the discursive form of what is being said that is crucial in understanding and exploring insight' (Galasiński, 2010, p. 66).

To make a preliminary summary of the definition of insight, there is disagreement within the literature regarding not only what insight is but also its etiology (Galasiński, 2010; Galasiński & Opaliński, 2012; Kinderman, Setzu, Lobban, & Salmon, 2006; Osatuke, Ciesla, Kasckow, Zisook, & Mohamed, 2008; Saravanan, Jacob, Prince, Bhugra, & David, 2004). The definition of insight has changed over time, and in line with other literature reviewers (Mintz et al., 2003), I agree that 'it might be difficult to make meaningful comparisons across studies' (Schwartz, 1998).

If we attempt to look at the concepts of insight and lack of insight from a practical standpoint, we can say that the concept of insight is, on a medical and clinical horizon, related to whether

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[24]Anosognosia, which is the lack of an awareness of an illness, is a common symptom of schizophrenia and bipolar disorder with psychotic features (The Anatomical Basis of Anosognosia – Backgrounder: http://www.treatmentadvocacycenter.org/about-us/our-reports-and-studies/2143.)

the service user has an understanding of being mentally ill (Skårderud, Stänicke, Haugsgjerd, Maizels, & Engell, 2010). Insight is related to illness and understood as the opposite of 'lack of insight'. Lack of insight means that one does not think one is ill, or at least not in the sense presented by mental health professionals (often in the form of a diagnosis and the need for medication). Conversely, insight means that you understand that you are experiencing a condition that falls under the diagnostic term of mental disorder and therefore that you need mental health treatment.

Lack of insight has primarily been connected to severe mental illness and psychotic disorders. Nevertheless, lack of insight is not exclusively to psychotic conditions. People with severe obsessive-compulsive disorder, eating disorders, dementia, some serious anxiety disorders, hypochondriasis or even deep depression can express a lack of insight (Skårderud et al., 2010).The same is true of certain rare neurological disorders caused by various brain injuries. According to Dam (2006, p. 114), 'insight is used as a means to describe the patient's understanding of his or her disorder and to assess the necessity of treatment, compliance, suicide risk and prognosis'. In line with this notion, the concept of insight 'can be used in connection with all illnesses, psychiatric as well as somatic' (ibid.).

In connection with less serious mental disorders, the term insight is used, for example, in the context of psychodynamic psychotherapy (Messer & McWilliams, 2007). Insight therapy is a term for psychotherapies with a sufficient intensity and duration that aims the service user to gain insight into the emotional and relational factors, past and present, that have given rise to complaints /symptoms and /or maintain them. The aim is that the service user obtains an understanding of his or her own contribution to the state for which assistance is sought. Service users should achieve an experience of ownership of their own feelings, motives and choices, and a strengthened agency, perception of own possibilities of action and responsibility for their actions. Increased ability ownership and agency thus occur with increased ability to accountability, accountability for self-care and responsibility for relations with other people. From this point of view, insight can be defined as 'gaining a new perspective or a new understanding' (Bohart, 2007, p. 258).

Psychoeducation as a method has come into the mental health field in recent years (with courses in stress coping, anxiety coping, depression mastering, etc.). It might add an element to the more traditional concept of insight, namely, the ability to understand which conditions

in situation and lifestyle that can protect against the risk of exacerbation /relapse and which precautions should be taken to avoid this risk (Teichert, 2009).

The introduction of mentalizing-based treatment is attributable to the concept 'mentalizing ability', which is widely known in academic circles. 'Mentalizing' refers to general human phenomena and is a collective term for implicitly and explicitly interpreting one's own and others' attitudes as meaningful utterances of inner life, whether we are discussing needs, desire, emotions or common sense (Skårderud & Sommerfeldt, 2008). Mentalizing means the ability to understand how oneself and one's behavior are perceived by other people and how to act upon on them. It also means the ability to 'read' other people's state of mind and intentions somewhat correctly, thus regulating one's emotions in line with a realistic view when encountering others.

From a mental health treatment standpoint, the difference concerning insight is related to the degree of insight. The objective of treatment is to increase the service user's ability to realistically interpret the world around her/him and the feelings and thoughts in her/his own mind, thus giving her/him the ability to act in the world for the benefit of both themselves and their surroundings.

A study by Lorem (2005) that investigates how insight was evaluated by mental health professionals and used in treatment reveals that therapists essentially define insight in line with the scientific literature; it involves knowing that one has an illness, what that illness is and how to relate to it. However, when therapists described how insight was performed in practice, the term seemed to include several dimensions. It appears that various aspects of insight were assumed in various types of situations. Insight was understood as an awareness of suffering (you know you are sick) and recognition of the need for help. Furthermore, it was related to behavior (to behave in a manner that avoids creating negative repercussions), as rational learning (one can learn from one's experiences and explain one's own situation), as an understanding of causes (in agreement with the clinician's assessment) and as compliance with treatment (consent to treatment and if necessary, medication). Based on these dimensions, it may appear that professionals have focused on service users' lack of insight instead of on having insight. This may indicate a problem-oriented focus concerning insight.

The two concepts—illness insight and lack of insight—thus show that the phenomena is both multifaceted and changing. Within the picture as presented above, these are also concepts that belong to the expert's language. In the Norwegian context, it is the doctor, psychologist, clinician or professional who assesses whether insight is present in the meeting with the service user. Insight is primarily seen as exclusively inherent to the service user. This results in the highest degree of actualization of the challenge of how insight can be performed in dialogues between service users and professionals in everyday life during mental health treatment.

4.3 Theoretical positions from which to consider insight

As an introduction to this section, I first underline insight and lack of insight as related to many topics in clinical practice. One topic that treats this issue is neuropsychological impairment (Karow et al., 2008), a second is phase of illness (Quee et al., 2010; Wang et al., 2011), a third is psychopathology (Mingrone et al., 2013), further self-stigma and recovery orientation (Kvrgic, Cavelti, Beck, Rüsch, & Vauth, 2013), and depression and suicide risk (Ampalam et al., 2012). According to Macnaughton (2008), the dominant view in insight research is that biomedical interventions are important for producing insight, which in turn promotes compliance. Treatment adherence will enable the individual to achieve control over symptoms and obtain a better quality of life.

Lysaker, Roe and Yanos (2007) illustrate how research has paradoxically linked insight to both improved functional outcomes and reduced hope and self-esteem. The insight paradox is well known in this field and affects numerous aspects of illness and care. Poor insight has been synonymous with poorer compliance (Grisso, Appelbaum, & Hill-Fotouhi, 1997), clinical results (Quee et al., 2010), social function and relationships with mental health professionals (Kvrgic et al., 2013). Poor insight has been understood as a deficit within the individual, without reference to the service users' surrounding contexts (Dolson, 2005). Greater insight has been related to depression, and Ampalam et al. (2012, p. 45) insist that 'most clinicians believe that poor insight… though problematic for treatment adherence, may be protective with respect to suicide'. Within the clinical approach, greater insight is related to adherence and satisfaction with antipsychotic treatment, and improving insight has been a primary focus of treatment (Schennach et al., 2012).

Decision-making competence, compliance, adherence and concordance are topics that are seen as critical to service users' abilities to participate in their own treatment and are treated as decision-making models that are closely related to insight. Autonomy and coercion are also important perspectives in relation to decision making. Because of the limited scope of this thesis, the presentation of these perspectives will not be extensive. The literature review is intended to give the reader an insight into the field.

4.3.1 Development of decision-making models

Insight has been considered important for the 'engagement in treatment, the psycho-therapeutic progress and a good prognosis' (Karow et al., 2008). Various schools of thought have presented a diverse spectrum of research connected to insight in mental health treatment with emphasis on different aspects of practical challenges.

Decision-making competence is related to the service user's right to refuse or accept recommended treatment (Appelbaum & Grisso, 1988). When a service user is considered incompetent to make a treatment decision, he or she is denied this right and others make the decision. In clinical practice, the professional often presumes competence on the part of the service user. Often the professional will use subjective judgment and clinical experience when deciding whether the service user has competence to make decisions concerning treatment and will not apply the standards suggested in the literature (Vollmann, Bauer, Danker-Hopfe, & Helmchen, 2003). Decision-making competence is understood as a person's ability to 1) understand relevant information, 2) retain that information, 3) use that information as part of the decision-making process, and 4) communicate his/her decision (Appelbaum & Grisso, 1988; Grisso & Appelbaum, 1995; Grisso et al., 1995; Richardson, 2010). The MacArthur Treatment Competence Study by Grisso and Appelbaum underlines the definition of decision-making competence with a clinical intention; they seek to identify where a lack of competence resides according to the definition of competence so that professionals can work with the service user to improve insight. They also underline insight as a nuanced concept that cannot be circumvented in practice and is too multifaceted to be reduced to a matter of agreement with the clinician (Grisso & Appelbaum, 1995). Appelbaum et al. (1998) have developed a new instrument to operationalize a patient's ability to make competent treatment decisions (Owen et al., 2013). The MacArthur Competence Assessment Tool is a semi-structured interview that focuses on understanding, appreciation, reasoning and expressing a choice (ibid.). This approach focuses on what professionals require to enable the service user

to obtain better insight. According to Vollmann et al. (2003, p. 1470), '[C]ontroversy surrounds the question of whether objective testing methods can replace clinical assessment of competence'. The MacArthur Competence Assessment Tool has been criticized for its focus on exclusively cognitive biases and its lack of more empirical, methodological and ethical perspectives (Breden & Vollmann, 2004).

Compliance has been defined as whether a person's behavior corresponds with medical or health advice (Morris & Schulz, 1992). Essentially, it is related to taking medications, following diets and more practical issues. Compliance is a descriptive term that describes the extent to which the service user follows the doctor's advice. Thus, it says something about how the service user acts, but nothing about intentionality (Lorem & Bakken, 2007). Compliance is measured both directly (considering, for instance, medication) and indirectly (for instance, therapeutic or preventive outcome) (Morris & Schulz, 1992). Compliance with treatment is seen as 'the key link between process and outcome in medical care' (Vermeire, Hearnshaw, Van Royen, & Denekens, 2001, p. 339). Medical non-compliance has been a central focus in research (Gray, Wykes, & Gournay, 2002; Vermeire et al., 2001), and compliance research has generally focused both on non-compliance and on strategies to improve compliance (Morris & Schulz, 1992). According to Lorem and Bakken (2007) the concept of compliance has been criticized for 'medicalizing' the problem; in addition, it is the clinician who has the power to define compliance. Vermeire et al. (2001) see compliance as a word with negative connotations and understand the definition as suitable only for medical interventions. Vuckovich find the term compliance to be politically incorrect, primarily because of its 'implications of coercion' (2010, p. 77). Vuckovich writes in the context of involuntary psychiatric treatment and discusses the term compliance with respect to the concept of adherence. According to Vuckovich, medication adherence is the goal in this context. However, coercion is necessary to achieve the remission of psychosis. In this way, Vuckovich distinguishes between the terms compliance and adherence: '[F]or patients' long-term benefit, the ultimate goal is adherence, but when involuntary patients are psychotic and very disabled by illness, the immediate objective is compliance' (2010, p. 78). This gives the discussion of *which concepts to use and when* a new perspective.

Adherence in relation to mental health treatment is challenging for clinical practice (Thompson & McCabe, 2012) and likely to be influenced by a 'complex interaction of treatment, patient and clinician factors' (Byrne & Deane, 2011, p. 284). It has been argued

that the term adherence focuses more closely on a collaborative clinician-service user relationship than does the term compliance (DiMatteo, Haskard-Zolnierek, & Martin, 2012; Martin, Haskard-Zolnierek, & DiMatteo, 2010). In other words, adherence is understood as an alternative to compliance (Vermeire et al., 2001). According to this perspective, service users' adherence is linked to communication, and collaborative communication and inclusion of the service users' perspective in relation to treatment decisions is underlined (Thompson & McCabe, 2012). DiMatteo et al. (2012) present a clinically useful model for improving adherence among service users. The model consists of three important clinical actions. The first action involves giving the service user the right information. This includes encouraging the service user's participation in treatment and treatment decisions, listening to the service user's concerns, and building trust and empathy. The second action involves helping service users believe in and commit to treatment. This action addresses the service user's beliefs, attitudes and motivation, as expressed in cognitive, social, cultural normative and contextual factors. The third action involves helping service users overcome practical barriers to treatment adherence (DiMatteo et al., 2012, p. 74). This model addresses non-adherence as a compound problem that can be overcome only through the participation of both the clinician and the service user. The model also includes all the members of the service user's healthcare team and the service user's significant others (ibid.).

Concordance is a newer, alternative model that emphasizes consensus and compliance (Lorem & Bakken, 2007). This model was introduced by a report by the Pharmaceutical Society of Great Britain in 1997[25], which introduced the concordance model as a shared decision agreement. The report underlined the model as a 'paradigm shift' from more compliance-oriented practice to a change in culture (Segal, 2007). The concepts of compliance and adherence have been exposed to sustained criticism alleging that both concepts have limitations in the context of health-care treatment (Bissell, May, & Noyce, 2004). Critics have claimed these perspectives to focus on whether service users are following their doctors' orders (Segal, 2007). Concordance, however, is based on service users' increased involvement in treatment processes. The term has been mostly linked to the domain of prescription of medication; however, it is also related to the concept of shared decision making (De las Cuevas et al., 2011). Concordance is known as a more patient-centered approach and like shared decision making, there are four central elements: partnership, communication,

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[25] Marinker (1997) *From compliance to concordance: achieving shared goals in medicine taking.* London: Royal Pharmaceutical Society; Merck, Sharp and Dohme.

information giving and agreement (Jordan, Ellis, & Chambers, 2002). According to Jordan et al. (2002), the main difference between shared decision making and concordance is that whereas shared decision making is about the whole process, concordance is about the outcome of the process[26]. Segal (2007, p. 92) criticizes concordance as a concept not in turmoil with paternalistic medicine, 'but rather an instrument of a more cagey paternalism'. It focuses on illness description and diagnosis to establish the basis for potential solutions (Lorem & Bakken, 2007).

The transition between the models presented in this section is fluid and overlapping. It can be difficult to distinguish one model from another, thus underlining some of the challenges experienced by professionals in deciding whether a service user has insight. The change from compliance to concordance also says something about the transition from a passive service user role to a service user who is expected both to take part in decision making and to contribute to his or her recovery. The changing definition of the service user is enshrined in § 3.1 of the Patients' Rights Act: 'Patient and users have the right to participate in the implementation of health services. This includes the patient's right to participate in choosing between available and justifiable examination and treatment. The form should be adapted to the individual's ability to give and receive information.' (https://lovdata.no/dokument/NL/lov/1999-07-02-63#KAPITTEL_3). The Patients' Rights Act further emphasizes that services shall be designed (to the extent possible) in collaboration with service users. The question of insight actually becomes more important with this development within user involvement in mental health policies and guidelines. The crucial question is whether we have the type of clinical practice demanded by the new role of the service user. In addition, how can professionals and service users work together to promote insight? This issue will be further examined in the discussion chapter.

4.3.2. Autonomy and coercion

Autonomy is a central concept in relation to insight. Beauchamp and Childress (2001) present a perspective on personal autonomy that emphasizes an individualistic and rationalistic understanding of the concept. Autonomy has been considered a key concern in biomedical ethics (Entwistle, Carter, Cribb, & McCaffery, 2010). It is a central concept in modern health ethics; traditionally, control over one's actions and the capacity for rational deliberation have

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[26] Shared decision making will be further discussed in section 3.3.2, which concerns various models of user involvement.

been central elements in discussions of the concept (MacDonald, 2002). In general, personal autonomy is associated with service users' ability to make decisions about which health care interventions he or she will receive (Entwistle et al., 2010). Walter and Ross (2013, p. 172) assert that autonomy is 'best understood relationally' because individuals are socially embedded in and formed by the context of the social relationships to which they belong. A relational understanding of autonomy can offer valuable additional insights for clinical contexts (Entwistle et al., 2010). The participants in our study are always located within interpersonal relationships and broader social contexts while admitted. Critics of the more traditional perspective on autonomy understand individual autonomy as 'socially constructed'; 'the capacity and opportunity for autonomous action is dependent upon our particular social relationships and the power structures in which we are embedded' (MacDonald, 2002, p. 197). For the participants in our study, their relationships with certain persons and the community mental health center or mental hospital must be constituted such that the participants can be afforded genuine opportunities to make choices that affect their treatment (MacDonald, 2002). Relational autonomy highlights the social and situation-specific nature of the concept; therefore, it can facilitate more nuanced assessments of the forms of support that mental health professionals can offer service users (Entwistle et al., 2010). Health interactions can exacerbate or alleviate service users' potential for autonomy, and the concept of insight can be understood as a core concept for developing the basis for relational autonomy.

Coercion is another central topic. The concept of insight has implications for compulsory treatment, but the use of coercion falls outside of the purposes and limitations of this thesis. Accordingly, I give a brief overview of coercion in relation to insight. Coercion is a compound notion that combines 'persuasion' with compulsory treatment order' (Szmukler, 1999). Coercive treatment is relatively common in mental health care (O'Brien & Golding, 2003) and often arises out of complex situations (Lorem et al., 2014). Coercion involves restraints of service users' actions and decisions and is often understood by professionals to be for the service users' own good (O'Brien & Golding, 2003). A mutual understanding of coercion is difficult to achieve because service users and professionals often evaluate coercion differently (Lorem et al., 2014). Coercion is directly related to the notion that service users are 'incompetent to make decisions for themselves or to lack autonomy' (O'Brien & Golding, 2003, p. 170). The traditional justification for coercion has been that service users lack competence (insight) and professionals are free to coerce them for their own good (ibid.).

Coercion is also related to the paradox of insight[27] as a concept: service users are 'doomed to' confirm their diagnosis regardless of how they react to the information that they receive. If they accept a diagnosis, for example, they agree to terms, despite the fact that if they really have the disease, they are not supposed to be able to have such insight and ability to consent. To agree with a diagnosis mean that all your beliefs, ideas and decisions as a service user become attached to a diagnosis that coincides with a lack of insight. If the service user, however, either denies the diagnosis or refuses to accept it, this action can be used as evidence that the person lacks insight and therefore must have a mental disorder (Roe & Davidson, 2005; Roe & Kravetz, 2003). The paradox of insight can be seen as a 'Gordian knot'[28] that leads to more compulsory care, which complicates both alliances and service users' experience of care (Lorem et al., 2014). Coercion is controversial and the dilemmas of clinical assessments have become as diverse as the principal discussions related to the concept (ibid.).

4.4 Narratives and insight

Insight is a controversial concept in a field that is no less complicated or controversial. Critiques of current research are made from both within and outside a quantitative paradigm (Galasiński, 2010). Contradictory findings and the lack of a gold standard measuring renders insight controversial in the research (Schennach et al., 2012).

Qualitative research concerning insight (Galasiński, 2010; Galasiński & Opaliński, 2012; Korsbek, 2013; Roe & Kravetz, 2003; Williams, 2008) has offered further perspectives on the topic. However, there are few qualitative studies, and both Williams (2008) and Korsbek (2013) primarily attempt to revise the concept of insight into new theoretical recovery approaches. Williams (2008) emphasizes the need for an approach that includes the post-diagnosis recovery phase in which the roles of socialization, identity and stigma are underlined. Consistent with Roe (2001), Korsbek (2013) considers the most important question for the recovery process to be the transformation of one's identity as a patient into one's identity as an individual. There is, according to Korsbek (2013), a lack of empirical studies on personal recovery stories connected to insight and the importance of insight in

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[27] The paradox of insight is particularly linked to schizophrenia.
[28] An intricate knot tied by King Gordius of Phrygia and cut by Alexander the Great with his sword after hearing an oracle promise that whoever could undo it would be the next ruler of Asia. This concept illustrates an exceedingly complicated problem (http://www.thefreedictionary.com/Gordian+knot).

relation to treatment. In a qualitative, constructionist discourse study by Galasinski and Opalinski (2012), nine specialist psychiatrists were interviewed. The study focused on insight in practice, and Galasinski and Opalinski found the specialists to be embodiments of the dominant medical perspective. The service users were expected to 'adopt and accept the psychiatric view and understanding of their experiences' (2012, p. 1465).

Roe and Kravetz (2003, p. 423) consider narratives useful in examining a lack of awareness as an alternative to the biomedical approach. They describe a narrative approach as 'relatively open-ended and free from a priori assumptions' (ibid.). Galasinski develops the narrative approach within a discursive framework and defends it as being outside the 'the rigid medical frame' (2010, p. 80). He holds that the clinical model of insight is problematic and concludes that narrative data offer an alternative perspective. Insight must be defined as dynamic and context-dependent and is a discursive, performative and constructed concept. Galasinski indicates a different approach to insight in psychiatric practice (ibid.). Consistent with Gilleen, Greenwood and David (2011, p. 61), who understand insight to be 'multiply fractionated and multiply determined' and note that therapeutic interventions might be beneficial for treating individuals who lack awareness of their illness, we recognize the need for a different and more dialogue-oriented approach to insight.

Narratives can illustrate the variations of insight. Galasinski is the only qualitative researcher of whom we are aware who, consistent with our study, insists that insight is a verb; it is something being performed, something that an individual does (Galasiński, 2010, p. 74). However, Galasinski appears to devote little attention to the social experiences associated with receiving and approving a diagnosis of mental illness. Engaging in insight involves the adoption of a new identity that changes both how individuals perceive themselves and how they are perceived by other individuals (Alreja et al., 2009).

4.5 A conceptualization of insight from a social constructionist perspective
Chapter 3 of the thesis outlined the social constructionist perspective and narrative approaches chosen as epistemological and ontological background for our research. In this section, I focus on the conceptualization of insight in a social constructionist perspective. As we have seen, there are many practical approaches to insight and decision making concerning whether a service user can be defined as either having or lacking insight. Social constructionism focuses on how knowledge is constructed in daily interactions between people (Burr, 2003).

Knowledge is 'historically situated and embedded in cultural values and practices' (Iversen, Gergen, & Fairbanks, 2005, p. 694). Meaning-making is a social, fluid and discursive process, and therapeutic relationships are dependent on the therapist and service users' actions in therapy (Sutherland, 2005). In the context of therapy or admission to mental health care, the relationship between the professional and the service user can emerge and evolve in the interactions that are occurring (ibid.). Decisions concerning insight can be understood as reducing a challenging process into a narrow and simplified structure based on the expert's view, which is not in contact with the service users' understanding.

The social constructionist approach sees the world as a product of social processes, and therefore there 'cannot be any given determined nature to the world or people' (Burr, 2003, p. 5). Burr claims that no inner essence makes people what they are. Essentialism is considered to trap people in limited personalities and identities that can lead to pathology within traditional psychology, which leads to an even more oppressive practice (ibid.). Reality (and henceforth concepts such as insight and user involvement) is something we construct between us, making our own versions. Insight is always derived from looking upon the concept from one perspective or another. All knowledge is time and culture-bound and from this perspective, insight is something co-constructed between the service user and all the people involved at a certain moment. This approach adds a dynamic and relational character to the concept of insight. Dolson (2005, p. 75) defines insight as a product of the clinical interview, 'namely, the dialogic relation between the patient and the clinical interviewer'. Dolson further claims that the production of insight is 'ultimately a processual and transactional phenomenon which arises out of the narrative construction of experience and the dialogic negotiation of the individual's "authored" experience' (2005, p. 75). I find Dolson's point of view to be interesting, but it emphasizes co-construction to a lesser extent.

Based on a social constructionist approach, the DSM is problem-centered and tends to favor the expert's view as more important than the experience-oriented knowledge of the service user. Critics may define the DSM as a social construction 'that privileges the professional and disempowers the client' (Iversen et al., 2005, p. 695). The professional's process of deciding whether the service user has insight is related to a tradition within a particular culture that fundamentally opposes the social constructionist approach. When discussing the relation between social constructionism and the narrative approach in section 3.2, we saw that the

DSM could be understood as a source of narrative, which in turn makes it a more process-oriented construction than a static manual.

In line with Iversen et al. (2005) I think it is essential to *not* look at social constructionism as *definitive*, but instead to view the theoretical position as a contribution to a constructive and reflexive dialogue concerning practical challenges. I understand insight as a relational process. Within the constructionist perspective, we can define insight as an ongoing process; '[c]onstructionist theory invites the practitioner to question, displace, and/or eschew the traditional position of authoritative voice in favor of a dialogic and collaborative orientation' (Iversen et al., 2005, p. 699). By investigating the concept of insight in collaborative inquiry with the service users and making room for experience-based language in the dialogue, we are approaching insight from a social constructionist understanding. We can challenge existing realities, realize new and other realities and engage in collaboration while continuing the dialogue concerning insight (Iversen et al., 2005). Relational insight is further discussed in the last section of this chapter.

4.6 The relationship between insight and user involvement

User involvement strengthens the quality of treatment services that are tailored to the service users' needs and opportunities. User involvement at the individual level involves meeting service users with respect and sensitivity, along with increasing their opportunities to influence their treatment. Service users are entitled to access information about rights, illness and opportunities[29]. User involvement also includes an overarching perspective that treatment not only represents society's desire to persuade service users to engage in specific types of behavior (e.g., preventive medicine) but also seeks to strengthen service users' potential to recover. User involvement is intended not only to counter stigma and prejudices but also to empower the individual service user. To implement this in practice, certain conditions must be present:

-Service users must be competent to make decisions concerning treatment.
-Professionals must provide service users with the necessary information about treatment methods and measure the likely benefit and purpose of treatment along with the risks and

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[29] See The Patient Rights Act: http://lovdata.no/dokument/NL/lov/1999-07-02-63.

alternative treatments.

-Service users must have the opportunity to make decisions free of coercion.

The problem is that the ability to express consent in an appropriate manner can be impaired in certain stages of life and illness. This means that some service users may have a limited ability or be unable to give informed consent to treatment. The consequences of limited/lack of insight have many challenges in practice, especially user involvement. Professionals might have different views of insight depending on whether they emphasize decision competence, compliance, adherence, being aware of symptoms (Beck-Sander, 1998) or implications for user involvement.

That said, what happens when professionals encounter service users who appear to lack insight? How should we strive for a form of insight into dialogue with such service users? Insight is related to increased user involvement and thus is a goal for all mental health treatment in Norway.

If professionals inform a service user that her/his understanding of herself/himself and her/his position in relation to the world is distorted (i.e., not in conformity with the common human reality), we challenge the person's concrete delusional performances. If we say, 'this is a delusion' or 'you're psychotic', service users might get the impression that it is easy for the clinician to label her/him and her/his experience, with the potential result of a struggle between two irreconcilable positions (Bentall & Swarbrick, 2003).

It is important to listen to service users' own perception of reality, especially during their first contact with admission or treatment. It is common to think that the service user is experiencing a conflict between two competing tendencies: the tendency of a closed, self-centered, solipsist "omniscience" (giving rise to delusions) on the one hand, and the tendency to continuously take into other people's influence as a corrective or supplement to one's own understanding (learning from experience) on the other hand (Bion, 1984). In psychiatric practice, we meet individuals, each with a unique life history and unique biological and experience-based assumptions. We must draw attention to the service users' beliefs about themselves and their own value both in relation to other people and with regard to their place in the world (Haugsgjerd, 1983).

A receptive and reflective dialogue in which service users' understanding of themselves, their position and any task in the world, their relationship to people (living and dead), bodies (real and imaginary) and the world are being listened to in a sensitive manner can be stimulating to insight. Language is a bridge between subjective perceptions of reality (Haugsgjerd, 2013).

Such insight is not limited to only the first encounter with mental health services. People suffer from prolonged mental illness and sometimes situations will emerge in which there is a possibility of a renewed interest in the real world outside one's own thoughts. These situations may be associated either with new people entering treatment relationships or with a change in the person's life situation, such as moving from one care or treatment device to another. I think this also might occur in a dialogue in which the relational, dynamic understanding of insight is underlined.

4.7 User involvement in mental health care

To date, there is consensus on user-oriented practice in mental health services (Storm, Rennesund, Jensen, & Mikkelsen, 2009). Norwegian legislation provides clear guidelines for improving services to individuals with mental illness through the Escalation Plan for Mental Health 1999-2008[30]. User involvement is both a legal right and a means to ensure the protection of user needs in care and treatment. The Patient Rights Act further emphasizes a patient's right to participate in treatment and the right to information (Patient Rights Act, 1999, § 3-1[31]). User involvement raises numerous practical, ethical, moral, methodological and philosophical questions (Nolan, 2007). The concept is multifaceted, diverse and presents numerous challenges.

4.7.1 An exploration of the concept of user involvement

The transition from hospitals to community-based treatment in which service users' power is embedded in day-to-day care delivery requires service users to be partners in their own care (Saraceno, 2009). User involvement has been regarded as a measure to ensure more focused, efficient, client-oriented and service-minded health services (Andreassen, 2007). It can be argued that service users' involvement calls into question the basis of treatment philosophies, norms, rules and service provision (Storm & Davidson, 2010). Participation is regarded as a

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[30] http://www.regjeringen.no/nb/dep/hod/tema/psykisk_helse/opptrappingsplanen-for-psykisk-helse-199.html?id=274864 (Ministry of Health and Care Services 1997-98).
[31] http://lovdata.no/dokument/NL/lov/1999-07-02-63

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). 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).

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). The classical ladder of citizen participation proposed by Arnstein (1969) describes eight steps of involvement. The two first steps, manipulation and therapy, describe participation without delegating power. The next levels on the ladder are related to symbolic involvement: informing, consultation and placation. The next three steps describe genuine forms of participation: partnership, delegated power and citizen control (Haukelien, Møller, & Vike, 2011). Participation can occur in numerous forms and according to Arnstein (1969), genuine participation implies a redistribution of power (Rise, 2012). Hickey and Kipping (1998) define user involvement as service users who participate in decision-making processes, building on Arnstein's ladder when they describe participation as a horizontal continuum from a consumerist approach to a democratization approach. The positions along the continuum are as follows: 1) information/explanation (service providers provide users with information and explanations, but the latter are not included in decision-making); 2) consultation (service providers seek advice from users but do not always use this advice in the decision-making process); 3) partnership (decisions are made in cooperation); and 4) user control (users make decisions) (Hickey & Kipping, 1998). The two latter positions belong to a democratization approach and 'refer to involvement in decision-making at a community level' (Hickey & Kipping, 1998, p. 84). The consumerist approach 'is concerned mainly with increasing the amount of services users have in deciding upon a particular service' (ibid.). The democratic approach is traced to civil rights and service user movements (Beresford, 2002). According to Beresford (2002), this is an explicitly political approach that prioritizes inclusion, autonomy, independence and self-advocacy (Brosnan, 2012). Tritter and McCallum (2006) suggest that Arnstein's ladder does not capture the intricate nature of user involvement and argue that user involvement requires dynamic structures and processes legitimized by both participants and non-participants (Tritter & McCallum, 2006, p. 157). These processes must be operated on the health care system, organization, community and individual levels (ibid.).

According to Storm et al. (2011), Norwegian law has secured participation rights for service users in decisions relating to the design and implementation of health services. User involvement has become a fundamental right in Norway's mental health service and is typically divided into the individual, healthcare system and political levels. At the individual level, user involvement is defined as participation in the selection, design and use of available mental health services. At the healthcare system level, the concept implies that service users enter into an equal partnership with mental health services and are active in planning and decision making related to treatment throughout the process. User involvement at a political level is defined by an active role in various user groups and organizations related to political processes (Haukelien et al., 2011). The most common type of service user involvement in Norway has been the use of advisory boards with representatives from various user organizations that provide feedback on service delivery, offer recommendations for service development and collect treatment feedback from patients (Andreassen, 2007).

Aspects and definitions of user involvement are occasionally similar and overlapping; however, they also differ (Rise, 2012). Participation is defined differently; as previously discussed, some scholars divide the concepts into degrees of participation (Arnstein, 1969), whereas other scholars regard participation as a continuum that is influenced by service users' mental state at various points in time (Hickey & Kipping, 1998). In a qualitative study, Lammers and Happell (2003) demonstrate that service users consider participation at any level within the system to be a choice made by the individual based on ability. Thompson (2007, p. 1297) defines participation as 'co-determined by patients and professionals, and occurring only through the reciprocal relationships of dialogue and shared decision-making'. According to Rise (2012, p. 27), these different definitions offer the impression of a 'broad, many-sided, complex, and rather blurred area'. In a study by Mathisen, Obstfelder, Lorem and Måseide (2015) that focuses on how user involvement is enabled in practice, user involvement is defined as 'situational events characterized by relational work, interaction and cooperation as precondition and result'[32]. In this study, we agree with Rise (2012), who notes that the aim of user involvement is to achieve shared decision making between the users and providers of mental health care.

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[32] Own translation.

4.7.2 User involvement models

Service user involvement is represented in many forms (Basset, Newton, Beales, Collins, & Basset, 2013). There are several approaches to user involvement: the concept is rooted in various theoretical traditions and has various methodological perspectives. Therefore, it can be difficult to provide concrete content for user involvement to service users and healthcare professionals with respect to day-to-day care in psychiatric wards and community mental health centers (Storm et al., 2009). This difficulty has resulted in different models of user-involvement, including the following: patient participation (Hickey & Kipping, 1998; Thompson, 2007; Tritter & McCallum, 2006), patient-centered care (Montgomery, 2013), shared decision making (Charles, Gafni, & Whelan, 1997; Koerner, Steger, Ehrhardt, & Bengel, 2013), the recovery model (Borg, Karlsson, & Kim, 2009a) and service user leadership (Basset et al., 2013).

Patient participation can be defined as a process in an inpatient mental health context in which patients can be either passive participants or active participants, depending on their mental health symptoms, motivation for user involvement and interest in user involvement (Storm & Edwards, 2013). Patient-centered care includes several dimensions: respect for patients' values, preferences and expressed needs; coordination and integration of care; information; communication and education; physical comfort; emotional support; involvement of family and friends; and continuity of care (Edgman-Levitan, Daley, & Delbanco, 1993; Montgomery, 2013). Health care should be safe, effective, timely, equitable and patient-centered. It is important both to understand the service user's experience of illness and to address the service user's needs within an increasingly complex and fragmented health care delivery system (Barry & Edgman-Levitan, 2012).

Shared decision-making is concerned with ensuring that medical decisions are made in collaboration between service users and health professionals (Clayman, Makoul, Harper, Koby, & Williams, 2012). In a qualitative study that involved both health professionals and service users in the context of shared decision making, Koerner et al. (2013) find that shared decision making is 'a vital success for internal and external participation' (Koerner et al., 2013, p. 165). External participation is defined in terms of time, respect, shared decision making, individuality and trust. Internal participation is defined in terms of communication and cooperation, leadership, shared decision making and conflict management. Koerner et al.'s (2013) study primarily focuses on the micro-level (individual service user) and the meso-

level (the individual team members); it does not consider the macro-level (the system level) in detail (Koerner et al., 2013). According to Fukui, Salyers and Matthias (2014), shared decision making is the basis on which service users and health professionals meet. They emphasize the importance of support from significant others (e.g., social workers, peers, and case managers) both before and after mental health treatment. Shared decision making in relation to insight and user involvement will be further investigated in the discussion chapter.

The recovery model extends beyond the aforementioned user involvement models (Storm & Edwards, 2013). Service user involvement is regarded as fundamental to recovery, and mental health services are to be person centered and attentive to the individual's goals, strengths, hopes and needs. The use of everyday language is central to the development of personal relationships and the promotion of community integration (Borg, Karlsson, & Kim, 2009b; Storm & Davidson, 2010; Storm & Edwards, 2013). Borg et al. (2009a) identify four practical challenges related to user involvement. First, there is a tendency toward collision between the service user's everyday life and the mental health professional's medical approach. Second, there is a connection between power and knowledge, and user-based or socially oriented knowledge is difficult for many practice cultures to implement because they 'are not on the gold-standard list of evidence-based practice' (Borg et al., 2009a, p. 288). Third, Borg et al. discuss the problems of mentalism and microaggressions (2009a, p. 290). Whereas mentalism is the oppression of individuals through mental health diagnosis, microaggressions are disrespectful and humiliating communications (for example, labeling individuals as treatment resistant and non-compliant). Finally, deinstitutionalization has led to various services and programs. These services may provoke strong associations with former institutions with respect to regulations and degrees of control. There is a need to seriously consider user involvement at all levels, including the micro, meso and macro levels (Storm & Edwards, 2013). Recovery, as a concept and area of knowledge, is understood differently in diverse environments (Borg & Karlsson, 2011). The same is true for the other user involvement models presented in the literature. Basset et al. (2013) find that service users can occupy a leadership role if they are given relevant training and development opportunities. Those authors describe a training program in the UK in which service users are trained for leadership. The service users define leadership as, inter alia, using their experiences to offer advice to other service users, being a proactive member of society, and accumulating knowledge about how leadership operates (Basset et al., 2013, p. 139). Service user leadership can take many forms, and Basset et al. underline that it can range from 'having more control

in your own personal care and day-to-day life to shaping the future of mental health services at a national level and everything that sits between' (2013, p. 135).

4.7.3 Reflections related to user involvement

User perspective and involvement do not represent an individual concept but instead encompass meanings at several levels (Borg et al., 2009a, p. 286). The challenges of user involvement in practice are well known and there remain concerns about the implementation of patient-oriented care (Storm & Edwards, 2013). There is little empirical knowledge concerning the role of user involvement in Norwegian community mental health centers (Storm et al., 2011). In her thesis, Rise (2012) concludes that although respect and decision-making are the core principles of user participation in the Norwegian context, there are clearly implementation problems at the system level and concerning outcome measures.

As previously noted, user involvement models have implications for the roles of service users (Storm & Edwards, 2013). According to Volden (2011), a new perspective on the service user is needed. The service user role does not overshadow an individual's other roles (as an employee, student, mother or daughter). Being a service user indicates only that an individual is currently a user of mental health services, and that role is relevant only while the services are being used. The role of a service user is time limited, and a mental illness no longer precludes participation in society (ibid). The literature has recognized the positive contribution that service users can make to social care planning and development (Carr, 2004). From this perspective, the policy of user involvement can be understood as a result of individuals with mental health problems having organized themselves because they believe that their knowledge is important and that they should be involved in formulating health and welfare services (Alm Andreassen, 2013). Service users have become political actors (ibid). In Norway, Professor Marit Borg et al. have laid a foundation to educate service users who wish to become associate researchers. In this research tradition, the scientist no longer has absolute control over the development of knowledge; instead, service user groups participate in research design and execution (Borg, 2009).

In this thesis, we see user involvement as dependent on the assessment of whether a service user has or lacks insight. This gives us a picture of the centrality and importance of the dialogues between clinicians/professionals and service users in treatment. Our goal is thus to investigate how insight can be performed in dialogue in everyday life to promote user

involvement during mental health treatment. Treatment cannot be regarded as existing in a vacuum (Saraceno, 2009), and the surrounding context of insight and user involvement is a vital aspect of the bricolage.

5. Aims

This study's overall aim was to explore service users' insight into mental illness and mental health treatment, along with their experiences of how insight affects user involvement, relationships with others and general life situation.

Insight is a precondition for valid consent and consequently, for user participation (Appelbaum, Appelbaum, & Grisso, 1998; Beauchamp, 2003; Lorem et al., 2014). If health professionals fail to recognize or understand the insights service users express about own suffering and life situation, it will influence the possibilities to activate the service users' perspective and involvement in treatment. We recognize the complicated and ever-changing social contexts within mental health services. This study focuses on how insight can affect individual treatment in everyday life during admission. Our intention is to provide knowledge to support approaches that help recognize and utilize the service user's perspective in mental health practice.

It is a core idea of this project to uphold and develop insight into a relational concept. By exploring service users' stories about experiences, evaluations, needs and self-identity, we wanted to analyze that which characterizes service users' insight and how dialogue as a source can recognize this insight. We hope that a new perspective on the concept of insight will guide us to new and varied methods of activating user involvement both in community mental health centers and in mental health in general.

The overall research questions for the study were as follows:

- What understanding do service users have of their mental illness and treatment? What aspects of service users' life situations are important for other individuals to understand?
- What experiences have service users had concerning interaction and involvement in treatment? How are these situations interpreted when the service user either is involved or chooses not to be involved?

- What does it mean for an individual service user to lack insight?

The study's articles highlight the research questions in different ways and underline not only the combination of insight and user involvement but also the changing social contexts within mental health services.

Article 1:

The study's primary goal was to explore the process of insight by analyzing service users' narratives. Through a case study, we intended to explore how stories are reflected and shaped by the relationship between the interlocutors. The main question is whether using a performative narrative perspective enables a relational concept of insight and thus is something that is developed in the dialogue instead of through the static characteristics of the patient.

Article 2:

This study's goal was to contribute to our knowledge of mothers diagnosed with a mental illness and their experiences of admission for mental health treatment. A central part of user involvement is connected to admissions and opportunities to express these users' treatment wants and needs. We discuss how mothering by women diagnosed with mental illnesses is created within the discourses of good motherhood and how clinical practice can be improved to activate these mothers' insights into their situation.

Article 3:

This study's goal was to contribute to the understanding of user involvement in mental health care. Both users and professionals must make many decisions about treatment and care either during admission or while in outpatient care. This article examines service users' experiences of being involved in shared decision making while admitted to a community mental health center or in outpatient care organized by the community mental health center.

6. Methods

The thesis is based on the narrative analyses of 25 interviews (and 1 pilot interview) with service users in three community mental health centers in Norway's two northernmost counties. The following chapter presents the three Northern Norwegian community mental health centers, the recruitment process, and the participants. I write about the interviews

before I offer an impression of the co-constructed stories. The narrative analyses conform to the theoretical framework used in the study and present the analysis used in the articles upon which this thesis is based. This includes narrative context analysis and thematic analysis. The selection of stories is described. The ethical approach of the project is described and I give some thoughts about narrative as ethics. Finally, I thoroughly present some of my methodological and ethical reflections during the research process.

6.1 The three Northern Norwegian community mental health centers

The 14 community mental health centers in Northern Norway cover 87 municipalities. Broad evidence reveals that community mental health centers in the north differ from the rest of the country with respect to their organization, professional services, specialist coverage, professionalism and quality, resource allocation, collaboration with local authorities and dimensions (Vorland, 2009). We chose to conduct our study in three community mental health centers in Northern Norway because little research in this area has asked service users to tell their stories of being admitted to community mental health centers in the region (Storm et al., 2011). The three centers cover 18 municipalities[33]. The three centers were inpatient wards with 15, 10 and 6 beds, respectively, at the time of the interviews. The centers also offered outpatient services and planned admissions. Although the units were approved for voluntary treatment under the Mental Health Act[34], two of the centers could also accommodate involuntary service users, i.e., they offered 'coerced psychiatric care without overnight'[35],to users for whom the psychiatric hospital in the region was the responsible decision maker. Coercive measures were not allowed in any of the centers. In addition, service users were offered crisis intervention, observation and assessment, treatment, milieu therapy, medication, and follow-up after an intox /suicidal act. Although there were differences in the centers' emphasized specialties, all three emphasized treatment-related clarification and stabilization in an unclear and difficult period, when monitoring and evaluation may be especially important for the future health care of the individual service user. All three community mental health centers are located in rural areas and the study participants all lived in smaller municipalities. If the participants were to be admitted to the region's psychiatric hospital, most of them would be far from home.

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[33] An area of the same size as the Republic of Serbia; approximately 77,000 sq km.
[34] Lov om Psykisk helsevern.
[35] Tvang Uten Døgn.

6.2 Recruitment

The study's focus on user involvement and insight were reflected in the inclusion criteria: the service users had experienced considerable changes during their lives because of a mental illness, they had been acutely admitted to a psychiatric hospital[36] and they were able to provide informed consent.

The recruitment of the study participants began after receiving formal approval from the Regional Committee for Medical and Health Research Ethics (Reference no.2011/775, Appendix 1 a-c). We contacted three community mental health centers and presented the project over the telephone. Their responses were all very positive and we had a dialogue meeting with each center. The professionals emphasized the importance of research that focused on the service users' stories and experiences and were deeply committed to promoting user involvement. They were also interested in practice-oriented research that could be valuable to their practice. All three centers decided to participate in the study and received information about the project (Appendix 2).

The participants were recruited through a local research assistant at each center. The local research assistant orally presented the study to potential participants at each community mental health center. The local research assistants were familiar with the inclusion criteria for the study and selected the participants who would be invited to participate. Information letters were distributed and interested individuals signed letters of consent (Appendix 3). These letters were retained at the centers until I arrived to conduct the interviews. Before this point, the participants had the option to withdraw from the study if they changed their minds[37]; in addition, they could ask questions about the project. Prior to conducting the interviews, I read the informed consent document with the participants and reconfirmed that each individual still wished to participate in the study. I also explained the research focus of the study again and asked whether the individuals had questions before we began the interviews. The individuals were aware that I was a researcher from the UiT/The Arctic University of Norway, and some participants asked whether I was a doctor. When I informed them of my background (as a family and network therapist), they had no reaction. Each service user was permitted to bring someone with them to the interview, including a professional from the community mental

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[36] One participant had never been admitted to a psychiatric hospital; however, she wished to participate in the study. Thus, we included her.

[37] The participants could also withdraw from the study after their interviews.

health center or someone with whom they felt safe (a friend or a family member). I conducted one interview with each service user.

6.3 The participants

Initially, 29 individuals agreed to participate in the study. At the first center, I conducted 12 interviews with 3 men and 9 women. At the second center, I conducted 10 interviews with 6 men and 4 women. At the third center, I conducted 7 interviews with 3 men and 4 women. One elderly woman who contacted me after I left the second center. She was an outpatient there, had heard about my project and wished to participate. I subsequently decided to interview her and we met at her sister's home several months later. Overall, I conducted 30 interviews[38]. The participants represented a heterogeneous group with various stories related to their experiences as service users. The participants' mental illnesses had manifested at different stages of life and they expressed diverse, individual needs for assistance related to their everyday lives. As noted above, I excluded five interviews from the transcription and analyzes. Table 1 includes only participants whose interviews have been transcribed and analyzed.

To attend to the individual participants' anonymity and act in accordance with necessary ethical considerations, the participants are not presented in further detail than that which is presented in Table 1. It is important to mention that the participants in the study are from small communities, and recognition would be possible if each participant's age, gender, sociocultural affinity, etc. were stated.

Table 1.

	Men	Women
Participants	9	16
Age	30-64	19-87
Troms county	3	8
Finnmark county	6	8

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[38] If the pilot interview is included, I conducted 31 interviews.

Marital Status and children	Married: 0 Married with children: 1 Partner: 0 Partner with children: 0 Single: 5 Single with children: 2 Uncertain relationship status: 1 Widower: 0	Married: 0 Married with children: 5 Partner: 3 Partner with children: 3 Single: 2 Single with children: 2 Uncertain relationship status: 0 Widow: 1
Language[39]	9 Norwegian	16 Norwegian
In work /or in various programs[40]	Working full time: 1 Working part-time: In programs from The Norwegian Labor and Welfare Organization[41]/or receiving disability benefits: 7 Student/interrupted studies: Retired: Does not say: 1	Working full time: 3 Working part-time: 2 In programs from The Norwegian Labor and Welfare Organization[42]/or receiving disability benefits: 6 Student/interrupted studies: 3 Retired: 2 Does not say: 2
Age when first time admitted	Age 20-25: Age 25-30: Age 30-35: 3 Age 35-40: 1	Age 15-20: 4 Age 20-25: 1 Age 25-30: 2 Age 30-35: 2

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[39] The participants were not asked about their nationality/origin. As researchers know, questions about ethnicity/identity can be sensitive topics; for instance, claiming a Sami identity can be complicated for some in Northern Norway (Blix, 2013). As seen from Table 1, all the participants spoke Norwegian during the interviews. Although the Russian woman and the Finnish-Sami woman were both offered interpreters, they wanted to speak Norwegian.

[40] Some of the participants both received disability benefits from The Norwegian Labor and Welfare Organization and were working part-time.

[41] NAV in Norwegian.

[42] NAV in Norwegian.

Appendix

Appendix 1

a) Information about the decision of Regional Committee for Medical and Health Research Ethics.

Region:	Saksbehandler:	Telefon:		Vår dato:	Vår referanse:
REK nord	Øyvind Strømseth	99299922		05.05.2011	2011/775/REK nord
				Deres dato:	**Deres referanse:**
				22.03.2011	

Vår referanse må oppgis ved alle henvendelser

Geir Fagerjord Lorem, Universitetet i Tromsø
Institutt for helse og omsorgsfag, Universitetet i Tromsø, Breivika

2011/775 Innsiktens skjulte natur? Forståelse av innsikt og brukermedvirkning sett fra brukerens ståsted. Et narrativt prosjekt.

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional forskningsetisk komité for medisinsk og helsefaglig forskningsetikk i møtet 14.04.2011.

Forskningsansvarlig: Lasse Lønnum
Prosjektleder: Geir Fagerjord Lorem

Prosjektomtale (original):
Bakgrunn:Studien ønsker å undersøke brukernes forståelse av egen helse og behandling. Vi ønsker økt kunnskap om brukermedvirkning med særlig vekt på innsikt og sykdomsforståelse. Metode: Studien vil intervjue inntil 30 brukere av distriktspsykiatriske sentre i Troms og Finnmark, i alderen 18-65 år. Dybdeintervju er nødvendig for å få tilgang til brukernes erfaringer fra behandling. Intervjuguiden vil bli behandla i en egen pilotundersøkelse, hvor en bruker som tilhører pasientgruppen vil kunne gi tilbakemelding på intervjuguiden. I intervjuene vil det åpnes opp for brukernes refleksjoner over erfaringen i sin helhet, med et ivaretakende perspektiv Tema for intervjuene: Tanker om egen livssituasjon, brukermedvirkning og kontekstens betydning (se intervjuguide). Relevans:å fokusere på hvordan innsikt kan fremmes for den enkelte bruker i hverdagen. Denne typen kunnskap vil kunne bidra til utvide synet på ulike måter å aktivisere brukerkompetanse på.

Forskningsetisk vurdering

De prosjektene som skal fremlegges for REK er prosjekt som dreier seg om "medisinsk og helsefaglig forskning på mennesker, humant biologisk materiale eller helseopplysninger", jf. helseforskningsloven (h) § 2. "Medisinsk og helsefaglig forskning" er i h § 4 a) definert som "virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom". Det er altså formålet med studien som avgjør om et prosjekt skal anses som fremleggelsespliktig for REK eller ikke.

I dette prosjektet synes formålet å være å fokusere på økt kunnskap om brukermedvirkning med særlig vekt på innsikt og sykdomsforståelse.

Komiteen er usikker på om prosjektet er fremleggingspliktig og ber om at prosjektleder utdyper hva man forstår med økt kunnskap om brukermedvirkning med særlig vekt på innsikt og sykdomsforståelse, sett hen til det som er nevnt over om hvilke prosjekt som er fremleggingspliktige. Herunder om søker på brukernivå ønsker å se på individnivå eller systemnivå.

Komiteen har følgende merknader som ønskes besvart før komiteen kan ta endelig stilling til søknaden:

Besøksadresse:
TANN-bygget Universitetet i Tromsø
9037 Tromsø

Telefon: 77644000
E-post: rek-nord@fagmed.uit.no
Web: http://helseforskning.etikkom.no/

All post og e-post som inngår i saksbehandlingen, bes adressert til REK nord og ikke til enkelte personer

Kindly address all mail and e-mails to the Regional Ethics Committee, REK nord, not to individual staff

1. Søknad/protokoll
2. Informasjonsskriv/samtykkeskjema
3. Dispensasjon
4. Forskningsbiobank
5. Koblinger av helseopplysninger

Vedtak

Prosjektleders tilbakemelding imøteses. Den videre behandling av prosjektsøknaden vil bli foretatt av full komité

 Med hjemmel i helseforskningsloven § 10, jfr. forskingsetikkloven § 4, utsettes endelig vedtak i saken. Det bes om tilbakemelding om de merknader som er anført før endelig vedtak fattes. Komiteens leder tar stilling til godkjenning av prosjektet etter mottatt svar.

Vi ber om at alle henvendelser sendes inn via vår saksportal: http://helseforskning.etikkom.no eller på e-post til: post@helseforskning.etikkom.no.

Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen,

Øyvind Strømseth
Senorrådgiver

Veronica Sørensen
førstekonsulent

Kopi til: lasse.lonnum@uit.no

Appendix 1

b) Reply to the decision of Regional Committee for Medical and Health Research Ethics.

Tilbakemelding Skjema for tilbakemelding på vedtak i de regionale komiteer for medisinsk og helsefaglig forskningsetikk (REK)

Dokument-id: 185477 Dokument mottatt 10.05.2011

Innsiktens skjulte natur? Forståelse av innsikt og brukermedvirkning sett fra brukerens ståsted. Et narrativt prosjekt.

1. Generelle opplysninger

a. Prosjekt

Innsiktens skjulte natur? Forståelse av innsikt og brukermedvirkning sett fra brukerens ståsted. Et narrativt prosjekt.

Opprinnelig søknad ble behandlet av REK nord

Saksnummer 2011/775

Prosjektbeskrivelse

Formålet med vår studie er å beskrive og analysere brukernes innsikt i egen lidelse og behandling. Studien søker å få frem brukernes/pasientenes opplevelse, vurderinger, behov og kompetanse i den hensikt å øke kunnskapen om rammebetingelsene for brukermedvirkning. Hensikten er å bidra til å beskrive hva innsikt kan være, og hvordan det kan henge sammen med måten brukeren beskriver seg selv på i sammenheng med behandlingsapparatet.

1. Nåværende forskningsansvarlig

Institusjon:	Universitetet i Tromsø
Kontaktperson:	Lasse Lønnum
Stilling:	Universitetsdirektør
Telefon:	77644990
Mobiltelefon:	77644990
E-post adresse:	lasse.lonnum@uit.no

Initiativtaker er Prosjektleder eller forskningsansvarlig (Bidragsforskning)

Prosjektstart 01.08.2011

b. Prosjektleder:

Navn:	Geir Fagerjord Lorem
Akademisk grad:	Dr Art
Stilling:	Førsteamanuensis
Arbeidssted:	Universitetet i Tromsø
Arbeidsadresse:	Institutt for helse og omsorgsfag
	Universitetet i Tromsø
	Breivika
Postnummer:	9037
Sted:	Tromsø
Telefon:	77646533
Mobiltelefon:	97773453
E-post adresse:	geir.lorem@uit.no

2. Tilbakemelding

a. Komiteens vedtak

2011/775 Innsiktens skjulte natur? Forståelse av innsikt og brukermedvirkning sett fra brukerens ståsted. Et narrativt prosjekt.
Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional forskningsetisk komité for medisinsk og helsefaglig forskningsetikk i møtet 14.04.2011.
Forskningsansvarlig: Lasse Lønnum
Prosjektleder: Geir Fagerjord Lorem
Prosjektomtale (original): Bakgrunn:Studien ønsker å undersøke brukernes forståelse av egen helse og behandling. Vi ønsker økt kunnskap om brukermedvirkning med særlig vekt på innsikt og sykdomsforståelse. Metode: Studien vil intervjue inntil 30 brukere av distriktspsykiatriske sentre i Troms og Finnmark, i alderen 18-65 år. Dybdeintervju er nødvendig for å få tilgang til brukernes erfaringer fra behandling. Intervjuguiden vil bli behandla i en egen pilotundersøkelse, hvor en bruker som tilhører pasientgruppen vil kunne gi tilbakemelding på intervjuguiden. I intervjuene vil det åpnes opp for brukernes refleksjoner over erfaringen i sin helhet, med et ivaretakende perspektiv Tema for intervjuene: Tanker om egen livssituasjon, brukermedvirkning og kontekstens betydning (se intervjuguide). Relevans:å fokusere på hvordan innsikt kan fremmes for den enkelte bruker i hverdagen. Denne typen kunnskap vil kunne bidra til utvide synet på ulike måter å aktivisere brukerkompetanse på.
Forskningsetisk vurdering
De prosjektene som skal fremlegges for REK er prosjekt som dreier seg om "medisinsk og helsefaglig forskning på mennesker, humant biologisk materiale eller helseopplysninger", jf. helseforskningsloven (h) §2. "Medisinsk og helsefaglig forskning" er i h § 4 a) definert som "virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom". Det er altså formålet med studien som avgjør om et prosjekt skal anses som fremleggelsespliktig for REK eller ikke.
I dette prosjektet synes formålet å være å fokusere på økt kunnskap om brukermedvirkning med særlig vekt på innsikt og sykdomsforståelse. Komiteen er usikker på om prosjektet er fremleggingspliktig og ber om at prosjektleder utdyper hva man forstår med økt kunnskap om brukermedvirkning med særlig vekt på innsikt og sykdomsforståelse, sett hen til det som er nevnt over om hvilke prosjekt som er fremleggingspliktige. Herunder om søker på brukernivå ønsker å se på individnivå eller systemnivå.
Vedtak

Prosjektleders tilbakemelding imøteses. Den videre behandling av prosjektsøknaden vil bli foretatt av full komité

Med hjemmel i helseforskningsloven § 10, jfr. forskingsetikkloven § 4, utsettes endelig vedtak i saken. Det bes om tilbakemelding om de merknader som er anført før endelig vedtak fattes. Komiteens leder tar stilling til godkjenning av prosjektet etter mottatt svar.

Vi ber om at alle henvendelser sendes inn via vår saksportal: http://helseforskning.etikkom.no eller på e-post til: post@helseforskning.etikkom.no.

Vennligst oppgi vårt referansenummer i korrespondansen.

b. Komiteens spørsmål eller vurdering

I dette prosjektet synes formålet å være å fokusere på økt kunnskap om brukermedvirkning med særlig vekt på innsikt og sykdomsforståelse. Komiteen er usikker på om prosjektet er fremleggingspliktig og ber om at prosjektleder utdyper hva man forstår med økt kunnskap om brukermedvirkning med særlig vekt på innsikt og sykdomsforståelse, sett hen til det som er nevnt over om hvilke prosjekt som er fremleggingspliktige. Herunder om søker på brukernivå ønsker å se på individnivå eller systemnivå.

c. Tilbakemelding til komiteen

Avklaring av formål for forskningsprosjekt

Bakgrunn og kontekst

Vi ser dessverre at det er oppstått uklarhet omkring prosjektets formål og dermed REK søknaden. Spørsmålet REK reiser er om dette er et helsefaglig forskningsprosjekt som omfattes av helseforskningslovens virkeområde. Forskningsprosjektet involverer i alle fall både mennesker og opplysninger disse gir om egen helse og sykdom, spørsmålsstillingen er dermed om dette prosjektet søker ny kunnskap om helse- eller sykdom, og eventuelt på hvilken måte prosjektet kan være relevant for fagområdet.

Nettverk for tvangsforskning innen psykisk helsearbeid er etablert ved Universitetet i Tromsø, Institutt for samfunnsmedisin, og består av psykiatere og forskere fra ulike medisinske fakultet i Norge. Nettverket ønsker blant annet å fremme forskning på pasientenes sykdomsinnsikt, samtykkekompetanse, og selvbestemmelse som et av flere prioriterte områder. I strategiplanen sies det: "I tråd med en utvikling der pasienter har fått større innflytelse over egen behandling og hvor samtykke har fått stadig større betydning som grunnlag for medisinske inngrep, er pasientenes samtykkekompetanse grunnleggende. I psykiatrien blir spørsmålet særlig aktualisert ved at evnen til å forstå sin egen situasjon på en rasjonell måte kan bli påvirket av lidelsen" (www.tvangsforskning.no).

Formål med prosjektet

Formålet med vår studie er å beskrive og analysere brukernes innsikt i egen lidelse og behandling. Studien søker å få frem brukernes/pasientenes opplevelse, vurderinger, behov og kompetanse i den hensikt å øke kunnskapen om rammebetingelsene for brukermedvirkning. Hensikten er å bidra til å beskrive hva innsikt kan være, og hvordan det kan henge sammen med måten brukeren beskriver seg selv på i sammenheng med behandlingsapparatet.

Prosjektet tar altså sikte på å beskrive brukerens perspektiv på samspillet med helsepersonellet. Brukeren som individ må altså forstås i en sosial kontekst og i kontekst av institusjonene som yter helsetjenestene. Vi har et annet delprosjekt som fokuserer på fagutøverperspektivet. Individnivå og systemnivå bør nok dermed ansees som komplementære.

Valget av metode følger av formålet. "Dersom formålet med en studie er å finne ut noe om pasienters og helsepersonells opplevelser eller oppfatninger av sykdom og helsetjenester, og gjerne hvordan de kommuniserer om dem seg i mellom, er ulike kvalitative forskningsmetoder velegnet" (Veiledning for forskningsetisk og vitenskapelig vurdering av kvalitative Forskningsprosjekt innen medisin og helsefag, utgitt av NEM).

Videre står det: "Eksplorerende design er som regel aktuelt ved de fleste kvalitative forskningsprosjekter". Vi har valgt narrative metoder for intervju og analyse som er både åpne og utforskende i sitt design. Styrken i et slikt design er å åpne opp for rike beskrivelser. Fordelen er at man ikke binder materialet i forhold til teori eller spørsmålsstillinger, ulempen er at man ikke kan utsi noe om innsiktsnivå på individ eller gruppenivå. Prosjektet vil potensielt gi mulighet for å beskrive brukerens innsikt i egen situasjon ut fra deres beskrivelser og vi kan følgelig videreutvikle muligheten for å implementere brukermedvirkning og brukerens perspektiv i klinisk praksis.

Kunnskap om innsikt

Hvem kan ha nytte av en slik studie? Hva betyr dette i praksis? Vi oppfatter prosjektet som et viktig prosjekt

av flere grunner. Prosjektsbeskrivelsen forankrer prosjektet både i

- Samfunnsmessig relevans (gjennom politisk intensjon om å implementere brukermedvirkning)
- Klinisk relevans (gjennom intensjonen om å aktivere bruker/pasients perspektiv/ønske om å gjøre brukermedvirkning)
- Vitenskapelig relevans (gjennom potensiell utvidelse av innsiktsbegrepet og kunnskap om rammevilkår for brukermedvirkning innen psykisk helsevern).

En grunnantagelse vi jobber ut fra er at det å gjøre brukermedvirkning innen psykisk helsevern støter på helt andre utfordringer enn innen andre deler av helsevesenet pga av lidelsen/sykdommens natur (jfr. nettverk for tvangsforskning). Innsikt er derfor ikke tilfeldig valgt fordi det er nært knyttet til forståelsen av de alvorlige sinnslidelser.

Utgangspunktet for studien kan formuleres som et dilemma: På den ene siden uttrykker fagutøvere helt klart idealer om brukerorientert praksis, samtidig etterlyser brukere større grad av medvirkning og innflytelse. Her er det tydelig at det er skjer noe underveis i samspillet. Det er disse prosessene vi ønsker å få bedre kunnskap om.

Annen medisinsk forskning og litteratur om innsikt

I psykisk helsevern er begreper om innsikt brukt for å beskrive hvordan mennesker med psykiske lidelser forstår sin egen situasjon og lidelse, gjerne omtalt som sykdomsinnsikt. Temaet er imidlertid omdiskutert.

- Kringlens lærebok i psykiatri viderefører ideen om en tett sammenheng mellom psykoser og sykdomsinnsikt. Mens andre forskere (Grisso og Appelbaum) har forsøkt å frigjøre innsiktsbegrepet fra sykdomsbegrepet og mener at man kan empirisk tilbakevise påstanden om at psykotiske personer mangler innsikt som sådan.
- Sammenhengen mellom innsikt og psykoser begrunnes også noe ulikt i litteraturen. Noen beskriver manglende sykdomsinnsikt som et definerende trekk ved psykose, mens andre ser svekket eller manglende innsikt som et resultat av en underliggende psykisk forstyrrelse.

- Nyere medisinske forskningsprosjekt på sykdomsinnsikt kobler ofte innsikt direkte til samtykke- eller beslutningskompetanse. Kjernespørsmålene er da evnen til å forstå relevant informasjon, anerkjenne behov for hjelp, anvende informasjonen på egen situasjon og uttrykke et informert valg.
- Innsikt i betydningen samtykkekompetanse nevnes spesifikt i forbindelse med unntaket fra hovedregelen for samtykke for helsehjelp (pasientrettighetsloven § 4). Det er også relevant for berettigelsen av tvang innen psykisk helsevern.

Det tidligere forskningsprosjektet "Innsikt og samtykkekompetanse" hadde denne sammenkoblingen av innsikt og samtykkekompetanse som utgangspunkt. Det vi imidlertid fant ut var at situasjoner der innsikt hadde vært tematisert innebar langt flere aspekter enn det som dekkes av innsikt som beslutningskompetanse eller anerkjennelse av hjelpebehov. Det betyr i praksis at klinikerne i studien forholdt seg til problematikken på en langt mer fleksibel måte enn litteraturen skulle tilsi. Man kunne f eks anerkjenne en pasients strategier for å mestre symptomer eller livssituasjon som tegn på innsikt, selv om det ikke nødvendigvis var uttrykt gjennom et valg eller en beslutning.

Helt uproblematisk var det ikke. Behandlerne har gjennom dette begrepsapparatet stor definisjonsmakt hvis innsiktsbegrepet blir tøyelig. Det var særlig tydelig i konfliktfylte situasjonsbeskrivelser når for eksempel atferd og oppfatninger av egen situasjon gikk på tvers av behandlingssystemets vurderinger ble beskrevet som manglende sykdomsinnsikt. Studiens begrensning var også at den kun inkluderte helsepersonell. Vi mangler også observasjonsdata.

Studien vi nå ønsker å igangsette søker gjennom to delprosjekt å bidra med å gi utvidede beskrivelser av innsiktsbegrepet basert på data fra både pasient/brukere og fagutøvere. Prosjektet det her er spørsmål om inkluderer pasientperspektivet. Vi har valgt brukermedvirkning, og ikke tvang eller opplevelse av tvang, for også å inkludere eksempler der brukers innsikt i egen situasjon har fått gjennomslag og kanskje innebåret endringer i forhold til individuell plan, alternative tiltak eller praktiske tilpasninger.

Kunnskap om innsikt har også relevans i forhold til sentrale sykdomsbegrep, samt at det har implikasjoner for vurdering av pasienten særlig ved vegring/nekting av behandlingstiltak. Det å støtte brukermedvirkning vil bidra til en bedre kvalitet på omsorgen for brukere med alvorlige psykiske lidelser ved at de kan få en mer aktiv og deltagende rolle i forhold til avgjørelser som berører egen situasjon.

Vi har f eks planer om i etterkant av studien å etablere samarbeid med et eller to sykehus i landsdelen for implementering av resultatene fra studien i klinisk praksis. Dette kan bidra til å utvide kunnskap grunnlaget og kvalitetsutvikle det akuttpsykiatriske tilbudet i spesialisthelsetjenesten og kommunehelsetjenesten.

Framgangsmåten er basert på aksjonsforskning, utviklet av Jan Kåre Hummelvold, der det anvendes arbeidsgrupper sammensatt av helsepersonell, brukere og forskere. Intensjonen er teoretisk og praktisk

fagutvikling med tanke på å beskrive, analysere og forbedre rutiner, begrep og handlinger som stimulerer til økt bruk av brukermedvirkende arbeidsformer i praksis. Dette metodevalget støtter opp om brukermedvirkning ved at brukerne selv får en aktivt deltagende rolle i et prosjekt som direkte berører egen situasjon. På den måten bidrar brukeren selv til å utvikle en bedre kvalitet på forskningen, omsorgen og behandlingen til personer med alvorlige psykiatriske lidelser, sammen med helsepersonalet i psykisk helsevern. Vi ser dette som et mulig post.doc-prosjekt som en oppfølging til studien.

Avslutning

- Sykdomsinnsikt er sentralt i sykdomsbegrepene innen psykiatrien, særlig psykosebegrepet
- Innsikt er sentralt for vurderingen av pasientens forhold til egen situasjon, sykdom og behandlingstilbud, og da særlig med hensyn til mestring og etterlevelse.
- Innsikt, og da særlig i betydningen beslutningskompetanse, er sentralt i begrunnelsen for bruken av tvang og muligheten for brukermedvirkning

Hovedformålet er dermed knyttet til annen medisinsk og helsefaglig forskning som fokuserer på innsikt. Vi har en relasjon til nettverk for tvangsforskning innen psykisk helsevern. Vi mener også at prosjektets formål faller innenfor helseforskningsloven. Resultat fra tidligere studie gir også håp om å gi ny, supplerende kunnskap på dette området. Vi tror også at resultatene kan gi kunnskap som kan bedre dialogen mellom bruker og helsepersonell.

Argumenter for fremleggsplikt er derfor at

- Vi søker ny helserelatert kunnskap hvor bruk av intervjudata om deltagernes helse og sykdomserfaringer står sentralt i prosjektet.
- Prosjektet søker å frambringe ny kunnskap om helserelaterte og sykdomsrelaterte forklaringer som er relevante for brukermedvirkning.
- eventuelle tiltak og råd i forhold til brukermedvirkning innen psykisk helsevern som kan fremkomme av prosjektet, kan få klinisk betydning og forankring i helsevesenet.

Ut fra argumentasjonen ovenfor mener vi at prosjektet hører best hjemme innen helseforskningsloven, snarere enn f eks inn under NESH eller NSDs fagområder. HOD har gjentatt uttrykt at helseforskningslovens virkeområde skal forstås vidt. NEM oppfordrer derfor REK til en romslig tolkning av fremleggelsesplikten der man, som regel, i tvilstilfeller tar prosjekt-søknader til behandling (NEM BS 13 2010/137).

En viktig årsak til at vi håper at REK vil behandle saken er at forskningen skal foregå hos en sårbar pasientgruppe. REK har den beste kompetanse i forhold til å vurdere forsvarligheten av forskning innen dette empiriske feltet. Jeg vil følgelig, som prosjektsleder, føle meg tryggere på de godkjenninger og begrensinger REK ville pålegge oss som forskningsgruppe.

Jeg har etter beste evne forsøkt å besvare spørsmålsstillingen REK har reist gjennom å tydeliggjøre både problemstillinger og forskningsmiljøet knyttet til formålet. Hvis ønskelig, kan jeg gjerne møte for komiteen og besvare eventuelle spørsmål dere måtte ha for ytterligere utdypning.

Vennlig hilsen

Geir Lorem
 Førsteamanuensis
 Prosjektsleder

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d. Dokumentasjon

Annen dokumentasjon vedlegges

Svarbrev

---

3. Vedlegg

#	Type	Filnavn	Lagt inn dato
1.	Annen dokumentasjon	svar REK .doc	10.05.11

4. Ansvarserklæring

Jeg erklærer at prosjektet vil bli gjennomført i henhold til gjeldende lover, forskrifter og retningslinjer

Jeg erklærer at prosjektet vil bli gjennomført i samsvar med opplysninger gitt i opprinnelig søknad og tilbakemeldingen til komiteen

Jeg erklærer at prosjektet vil bli gjennomført i samsvar med eventuelle vilkår for godkjenning gitt av REK eller andre instanser

Appendix 1

c) Approval Regional Committee for Medical and Health Research Ethics.

Region:	Saksbehandler:	Telefon:		Vår dato:	Vår referanse:
REK nord	Veronica Sørensen	77620758		24.06.2011	2011/775/REK nord
				Deres dato:	**Deres referanse:**
				22.03.2011	

Vår referanse må oppgis ved alle henvendelser

Geir Fagerjord Lorem

Institutt for helse og omsorgsfag, Universitetet i Tromsø, Breivika

2011/775 Innsiktens skjulte natur? Forståelse av innsikt og brukermedvirkning sett fra brukerens ståsted. Et narrativt prosjekt.

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk i møtet 16.06.2011.

Forskningsansvarlig: Gyrd Thrane
Prosjektleder: Geir Fagerjord Lorem

Prosjektomtale

Bakgrunn:Studien ønsker å undersøke brukernes forståelse av egen helse og behandling. Vi ønsker økt kunnskap om brukermedvirkning med særlig vekt på innsikt og sykdomsforståelse. Metode: Studien vil intervjue inntil 30 brukere av distriktspsykiatriske sentre i Troms og Finnmark, i alderen 18-65 år. Dybdeintervju er nødvendig for å få tilgang til brukernes erfaringer fra behandling. Intervjuguiden vil bli behandla i en egen pilotundersøkelse, hvor en bruker som tilhører pasientgruppen vil kunne gi tilbakemelding på intervjuguiden. I intervjuene vil det åpnes opp for brukernes refleksjoner over erfaringen i sin helhet, med et ivaretakende perspektiv Tema for intervjuene: Tanker om egen livssituasjon, brukermedvirkning og kontekstens betydning (se intervjuguide). Relevans:å fokusere på hvordan innsikt kan fremmes for den enkelte bruker i hverdagen. Denne typen kunnskap vil kunne bidra til utvide synet på ulikemåter å aktivisere brukerkompetanse på.

Tilbakemelding

Prosjektleder har gitt en grundig tilbakemelding på komiteens anførsler. Sykdomsinnsikt er sentralt i sykdomsbegrepene innen psykiatrien, særlig psykosebegrepet, og er således sentralt i begrunnelsen for bruken av tvang og muligheten for brukermedvirkning. Komiteen finner at prosjektet faller innenfor helseforskningsloven.

Samtykkekompetanse

Forskning som inkluderer personer uten, eller med redusert samtykkekompetanse, kan bare finne sted dersom eventuell risiko eller ulempe for personen er ubetydelig, personen selv ikke motsetter seg det, og det er grunn til å anta at resultatene av forskningen kan være til nytte for den aktuelle personen eller for andre personer med samme aldersspesifikke lidelse, sykdom skade eller tilstand. Det må heller ikke være grunn til å tro at personen ville motsatt seg deltakelse i forskningsprosjektet hvis vedkommende hadde hatt samtykkekompetanse. Det er også et krav at tilsvarende forskning ikke kan gjennomføres på personer med

Besøksadresse:	**Telefon:** 77644000	All post og e-post som inngår i	Kindly address all mail and e-mails to
TANN-bygget Universitetet i Tromsø	**E-post:** rek-nord@fagmed.uit.no	saksbehandlingen, bes adressert til	the Regional Ethics Committee, REK
9037 Tromsø	**Web:** http://helseforskning.etikkom.no/	REK nord og ikke til enkelte personer	nord, not to individual staff

samtykkekompetanse. Søker har i hovedsøknaden redegjort godt for hvordan disse hensynene skal ivaretas i prosjektet. Den som skal være i kontakt med deltakerne har også bred klinisk erfaring for å kunne gjøre de nødvendige vurderinger underveis i studien.

Komiteen har ingen merknader til prosjektsøknaden.

Komiteen har ingen merknader til informasjonsskriv og samtykkeerklæring.

Vedtak

Med hjemmel i helseforskningsloven § 10, jfr. forskingsetikkloven § 4 godkjenner komiteen at prosjektet gjennomføres i samsvar med det som framgår av søknaden.

Godkjenningen av prosjektet gjelder til 31.12.2015. Av dokumentasjonshensyn skal opplysningene likevel bevares inntil 31.12.2020. Opplysningene skal deretter slettes eller anonymiseres, senest innen 30.06.2021.

Opplysningene skal lagres avidentifisert, det vil si adskilt i en nøkkel- og en opplysningsfil.

Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder for «Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren».

Prosjektet skal sende sluttmelding til REK nord på fastsatt skjema senest 30.06.2016.

Tillatelsen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden og protokollen, og de bestemmelser som følger av helseforskningsloven med forskrifter.

Dersom det skal gjøres endringer i prosjektet i forhold til de opplysninger som er gitt i søknaden, må prosjektleder sende endringsmelding til REK. Vi gjør oppmerksom på at hvis endringene er "vesentlige", må prosjektleder sende ny søknad, eller REK kan pålegge at det sendes ny søknad.

Vi ber om at tilbakemeldinger til komiteen og prosjektendringer sendes inn på skjema via vår saksportal: http://helseforskning.etikkom.no. Øvrige henvendelser sendes på e-post til post@helseforskning.etikkom.no.

 Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen,

May Britt Rossvoll
Kontorsjef

Veronica Sørensen
Førstekonsulent

Kopi til: gyrd.thrane@uit.no, post@legemiddelverket.no

Appendix 1

d) Application for extension Regional Committee for Medical and Health Research Ethics.

Prosjektendring Skjema for søknad om godkjenning av prosjektendringer i de regionale komiteer for medisinsk og helsefaglig forskningsetikk (REK)

2011/775-16
Dokument-id: 683044 Dokument mottatt 07.01.2016

Innsiktens skjulte natur? Forståelse av innsikt og brukermedvirkning sett fra brukerens ståsted. Et narrativt prosjekt. (2011/775)

1. Generelle opplysninger

a. Prosjektleder

Navn:	Geir Lorem
Akademisk grad:	Dr Art
Stilling:	Professor
Hovedarbeidsgiver	UiT The arctic university of Norway
Arbeidsadresse:	Institutt for helse og omsorgsfag
Postnummer	9037
Sted	Tromsø
Telefon	77646533
E-post adresse	geir.lorem@uit.no

b. Prosjekt

Hvilket prosjekt skal endres?	Innsiktens skjulte natur? Forståelse av innsikt og brukermedvirkning sett fra brukerens ståsted. Et narrativt prosjekt. (2011/775)

c. Ny Prosjektleder?

Skal prosjektet ha ny prosjektleder?	Nei

d. Forskningsansvarlig(e)

Forskningsansvarlig(e) som beholdes

Institusjon	Kontaktperson	Stilling	E-post adresse
Universitetet i Tromsø, Helse- og omsorgsfag	Gyrd Thrane	Instituttleder	gyrd.thrane@uit.no

e. Prosjektmedarbeider(e)

Ingen prosjektmedarbeidere

2. Endring(er)

a. Endringen(e) innebærer

Endring av prosjektstart og prosjektslutt

Prosjektstart	24.06.2011
Prosjektslutt	31.12.2016

b. Begrunnelse for endringen(e)

Praktisk, faglig og vitenskapelig begrunnelse for endringen(e)

Vi ønsker å oppbevare data tilhørende prosjektet til 31.12.2016. Dette på grunn av forsinkelser i prosjektet. 2 artikler basert på dette prosjektet er publisert i internasjonale tidsskrifter (nivå 2); Qualitative Inquiry og Qualitative Social Work. Arbeidet med sammenskrivingen av prosjektet er nesten ferdigstilt, og hovedbegrunnelsen for forsinkelsen er at den tredje artikkelen som skal inn i avhandlingen har tatt lengre tid å få publisert. Denne artikkelen var inne til review i et nordisk tidsskrift som brukte 13 måneder på å gi oss tilbakemelding. Dette forsinket oss kraftig. Etter vurderinger så vi oss nødt til å omarbeide teksten, og denne er nå sendt inn til et internasjonalt tidsskrift (Social Work in Mental Health) og vi venter på en ny vurdering. Arbeidet som gjenstår er altså publiseringen av denne teksten, og å avslutte sammenskrivingen.

3. Avveining av nytte og risiko ved prosjektendringene

Hvorfor er det forsvarlig å gjennomføre endringene? Gi en begrunnet avveining av fordelene og ulempene ved prosjektendringene.

Av hensyn til deltagerne ønsker vi å beholde koblingsnøkkel og samtykkeskjema til avhandlingen er levert. Ulempen ved dette er at vi beholder personidentifiserbare opplysninger lengre enn avtalt, men fordelen er at deltagerne har mulighet til å ta kontakt (og eksempelvis få slettet data dersom ønskelig) helt frem til den siste artikkelen er publisert.

4. Vedlegg

Ingen vedlegg

5. Ansvarserklæring

Jeg erklærer at prosjektet vil bli gjennomført

i henhold til gjeldende lover, forskrifter og retningslinjer

i samsvar med opplysninger gitt i denne søknaden

i samsvar med eventuelle vilkår for godkjenning gitt av REK

Appendix 1

e) Approval of extension Regional Committee for Medical and Health Research Ethics.

Geir Lorem
Institutt for helse og omsorgsfag

2011/775 Innsiktens skjulte natur? Forståelse av innsikt og brukermedvirkning sett fra brukerens ståsted. Et narrativt prosjekt.

Forskningsansvarlig: Universitetet i Tromsø
Prosjektleder: Geir Lorem

Vi viser til søknad om prosjektendring datert 07.01.2016 vedrørende forlengelse av prosjektperiode/oppbevaring av data for ovennevnte forskningsprosjekt frem til 31.12.2016.

Søknaden er behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) ved sekretariatsleder på fullmakt gitt av komiteen med hjemmel i forskningsetikkforskriften § 10 annet ledd.

Av informasjonsskrivet til deltakerne fremgår det at studien skulle avsluttes i 2015 og at navnelistene da ville bli slettet. Under forutsetning av at de inkluderte må informeres om forlenget oppbevaring av data er det fattet slik

vedtak
Med hjemmel i helseforskningsloven § 11 godkjennes prosjektendringen.

Endringen godkjennes under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden, endringssøknaden, oppdatert protokoll og de bestemmelser som følger av helseforskningsloven med forskrifter.

For øvrig gjelder de vilkår som er satt i forbindelse med tidligere godkjenning av prosjektet.

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding på eget skjema senest et halvt år etter prosjektslutt, jf. helseforskningslovens § 12. Dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden må prosjektleder sende søknad om prosjektendring til REK, jf. helseforskningslovens § 11.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningslovens § 28 flg. Klagen sendes til REK nord. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK nord, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

May Britt Rossvoll
sekretariatsleder

Besøksadresse:
MH-bygget UiT Norges arktiske universitet 9037 Tromsø

Telefon: 77646140
E-post: rek-nord@asp.uit.no
Web: http://helseforskning.etikkom.no/

All post og e-post som inngår i saksbehandlingen, bes adressert til REK nord og ikke til enkelte personer

Kindly address all mail and e-mails to the Regional Ethics Committee, REK nord, not to individual staff

Monika Rydland Gaare
rådgiver

Kopi til: *postmottak@iho.uit.no*

Appendix 1

f) Letters to the participants concerning extension of the study

UiT

**NORGES
ARKTISKE
UNIVERSITET**

Institutt for helse- og omsorgsfag

Deres ref.:

Vår ref.: 2011/775/REK

Dato: 14.01.2016

Unntatt offentlighet jf: offl. § 25,1

Til deltaker i forskningsprosjektet
«Innsiktens skjulte natur? Forståelse av innsikt
og brukermedvirkning sett fra brukerens ståsted.»

Intervju gjennomført i 2011

Informasjon i forbindelse med forskningsprosjektet «Innsiktens skjulte natur? Forståelse av innsikt og brukermedvirkning sett fra brukerens ståsted.»

Viser til din deltakelse i det overnevnte forskningsprosjektet i 2011. Takk for at du deltok på intervju. I forbindelse med forsinkelser i sluttføringen av prosjektet, ønsker undertegnede å informere deg om følgende endring:

- Oppbevart data i forbindelse med studien vil ikke slettes i 2015, men når studien er avsluttet, senest 31.12. 2016.

Alle opplysningene om deg er behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Når studien avsluttes, i 2016, vil navnelistene slettes. Informasjonen vil lagres i anonymisert form med tanke på eventuell oppfølgingsstudie.

Det vil ikke være mulig å identifisere deg i resultatene av studien.

Dersom du har spørsmål kan du kontakte Rita K. Klausen på telefon 776 60713 og e-post : rita.k.klausen@uit.no.

Vennlig hilsen

Rita K. Klausen
PhD- stipendiat/ forsker
Senter for omsorgsforskning
Nord

Appendix 2

Information letter to managers of community mental health centers

INFORMASJONSSKRIV TIL DISTRIKTSPSYKIATRISKE SENTER ……. AVDELING ….

Innsiktens skjulte natur? Forståelse av innsikt og brukermedvirkning sett fra brukerens ståsted.

Kriterier for deltakelse:

Studien søker inntil 30 deltakere fra pasientgruppen med psykiske lidelser fra 18 – 65 år, og begge kjønn ønskes representert. Det er en forutsetning at studiens deltakere har relevant erfaring i form av en eller flere sykehusinnleggelser. Brukerne er knytta til DPS, enten døgnenhet eller voksenpsykiatrisk poliklinikk.

Bakgrunnsinformasjon om studien:

Hensikten med denne studien er å undersøke brukernes innsikt i egen lidelse og behandling. Studien ønsker å bidra til å gi et språk som omhandler hva innsikt kan være, og hvordan det kan henge sammen med måten brukeren beskriver seg selv på i sammenheng med behandlingsapparatet. Prosjektet vil arbeide med å ved å vektlegge kommunikasjon som griper fatt i brukerens kompetanse på seg selv og sin helse. Studien ønsker å fokusere på hvordan innsikt kan fremmes for den enkelte bruker i hverdagen. Denne typen kunnskap vil kunne bidra til utvide synet på ulike måter å aktivisere brukerkompetanse på.

Hva skal studiedeltakeren være med på?

Studien søker deltakere som vil la seg intervjue med lydopptaker. Intervjuene er regna å ta mellom 1 til 1,5 timer. Det vil være en prosjektmedarbeider som gjennomfører intervjuene, og deltakerne kan, dersom ønskelig, ha med seg en støtteperson under selve intervjuet. Studiet vil bli gjennomført i tråd med forskningsetiske retningslinjer der taushetsplikten overholdes, opplysninger anonymiseres, deltagelse er frivillig og det innhentes informert samtykke fra brukeren. Dersom bruker har redusert samtykke, eller er umyndiggjort, tas dette hensyn til og aktuelt personale eller verge tas kontakt med dersom bruker har ønske om å delta i prosjektet.

Mulige fordeler ved deltakelse:

Informanten har ingen direkte fordeler ved å delta i studien. Det kan være motivert egeninteresse å formidle egne erfaringer med helsetilbudet i forhold til et forskningsprosjekt. Pasientene kan verdsette å få tematisert

forhold som ellers ikke snakkes om i en behandlingssammenheng. En samtale med en utenforstående (her forskeren)om situasjoner man har opplevd som vanskelige/ krenkende kan oppleves som både interessant og forløsende i forhold til refleksjoner rundt egen erfaring. Erfaringskunnskap kan vekke engasjement hos den enkelte pasient, og skape rom for samtaler med eksempelvis helsepersonell.

Mulige ulemper ved deltakelse:

Hva gjelder ulemper for den enkelte, vil informanten gjennom intervjuet blottstille noe av seg selv. Det kan i gitte tilfeller være belastende å snakke om forhold som berører egen sykdom og behandling, mulige vanskelige og/ eller krenkende erfaringer. Dette fordrer en særskilt etisk bevissthet hos intervjuer. Dersom det skulle oppstå behov, vil intervjuer kunne formidle hjelp, oppfølging eller andre tiltak som vil være nødvendig. Det er viktig at informanten er forstått med at dette som skjer er en del av forskning, og ikke behandling.

Forskningsetikk

Deltakerne vil bli bedt om å undertegne en samtykkeerklæring slik at samtykke til deltakelse er frivillig og informert. Det er sentralt at deltakerne er kjent med at intervjuet er en del av et forskningsprosjekt og ikke vil ha betydning for deres behandling på tidspunktet for intervjuet. Deltakerne kan når som helst avbryte intervjuet, og intervjuer vil kunne stoppe intervjuet, dersom deltakeren viser tegn til å ikke være komfortabel i situasjonen. Det vil påpekes til deltaker at intervjuet ikke vil få negativ innvirkning på deres behandling. Det samme gjelder dersom de ønsker å avbryte deltakelse i studien.

Prosjektet er godkjent av Regional komitè for medisinsk og helsefaglig forskningsetikk, Nord- Norge (REK Nord) 24.06.2011. For ordens skyld, er godkjenningen fra REK vedlagt.

Personvern

Alle opplysninger som samles inn vil avidentifiseres, og kun brukes slik som beskrevet i hensikten med studien. All informasjon vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. Det vil være en kode som knytter deltakeren til personlige opplysninger, og det er kun prosjektleder og intervjuer som vil kjenne til denne kodingsnøkkelen. Det vil ikke være mulig å identifisere deltakerne i resultatene av studien når disse publiseres.

Universitetet i Tromsø ved administrerende direktør er databehandlingsansvarlig.

Etter gjennomføring av intervjuene vil deltakerne, dersom de ønsker det, få tilsendt en kort oppsummering av funn og et antall eksemplarer av avhandlingen til det aktuelle distriktspsykiatriske senteret etter disputas.

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Dersom de trekker seg fra studien, kan de kreve å få slettet innsamlede data, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Studien er finansiert gjennom forskningsmidler fra Universitetet i Tromsø, Institutt for helse- og omsorgsfag.

Vennlig hilsen

Rita K. Klausen

Stipendiat

Humanistisk helseforskning

Appendix 3

Information letter and consent form

Forespørsel om deltakelse i forskningsprosjektet

"Innsiktens skjulte natur?

Forståelse av innsikt og brukermedvirkning sett fra brukerens ståsted."

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie for å undersøke brukernes forståelse av egen helse og behandling. Vi ønsker kunnskap om brukermedvirkning med særlig vekt på innsikt og sykdomsforståelse.

Vi har tatt kontakt med deg fordi du har erfaring fra å være en bruker av distriktspsykiatriske tjenester. Vi ønsker å spørre deg om dine erfaringer i forhold til din egen rolle i behandlingen og brukermedvirkning. Universitetet i Tromsø ved institutt for helse- og omsorg er ansvarlig for dette prosjektet.

Hva innebærer studien?

Studien innebærer at en kontaktperson ved din DPS henvender seg til deg, og spør om du kan være interessert i å delta i en studie om brukermedvirkning. Kontaktpersonen vil informere deg om hva studien handler om, og det å delta i studien innebærer at vi ønsker å gjennomføre et intervju med deg hvor vi ønsker å spørre deg om spørsmål som har med behandling og brukermedvirkning å gjøre.

Vi tar deretter kontakt med deg for å avtale et intervju. Vi vil komme til deg/ stedet der du bor for å gjennomføre intervjuet. Intervjuet planlegges å ha en varighet på inntil 1- 1,5 timer, og krever ingen forberedelser fra din side.

Mulige fordeler og ulemper

Utover den tiden som går med til selve intervjuet, vil ikke deltakelsen innebære noen direkte ulemper for deg. Det kan oppleves som ubehagelig å snakke om slike forhold fordi det er personlig, men husk at det er du som setter grenser for hva du ønsker å fortelle og hva du ikke vil snakke om. Dine grenser vil bli respektert.

Fordelen med å delta er at dine erfaringer kan bidra til økt kunnskap som på sikt kan medvirke til at praksis kan forbedres.

Hva skjer med informasjonen om deg?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Når studien avsluttes, i 2015, vil navnelistene slettes. Informasjonen vil lagres i anonymisert form med tanke på eventuell oppfølgingsstudie.

Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for din videre behandling. Dersom du ønsker å delta,

undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte Rita K. Klausen på telefon 776 60713 og e-post : rita.k.klausen@uit.no.

Ytterligere informasjon om studien finnes i kapittel *A – utdypende forklaring av hva studien innebærer.*
Ytterligere informasjon om personvern og forsikring finnes i kapittel B *– Personvern, økonomi og forsikring.*

Samtykkeerklæring følger etter kapittel B.

Kapittel A- utdypende forklaring av hva studien innebærer

Bakgrunn for studien

Hensikten med denne studien er å undersøke brukernes forståelse av egen helse og behandling. Studien ønsker å bidra til å gi et språk som omhandler hva dette kan være for brukeren, og hvordan det kan henge sammen med måten brukeren beskriver seg selv på i sammenheng med behandlingsapparatet. Prosjektet vil arbeide med å ved å vektlegge kommunikasjon som griper fatt i brukerens kompetanse på seg selv og sin helse. Relevansen er å fokusere på hvordan innsikt kan fremmes for den enkelte bruker i hverdagen.

I dag er det enighet om en brukerorientert praksis. Likevel erfarer brukere generelt å ha liten innflytelse, de ønsker å medvirke, men blir lite inkludert. Norske forskningsprosjekt viser at brukere som opplevde medvirkning mente dette styrket selvrespekt og mestringsstrategi. Forskning viser også at det generelt var en kritisk holdning til brukermedvirkning blant brukerne. Andre studier viser at pasienter opplevde at anerkjennelse og delaktighet i behandling i sykehusavdelinger var mangelfull og at informasjon om sykdom, fremtidsutsikter og rettigheter i psykisk helsetjeneste ikke er tilstrekkelig.

Helsemyndighetene gir klare føringer for en forbedring av tjenestetilbudet til mennesker med psykiske lidelser. Et sentralt mål for forbedring er å styrke brukernes rettighet til å medvirke i utforming og utøvelse av tjenestetilbudet. Dette skal fremme en meningsfull rolle for brukerne hvor man selv kan fatte valg vedrørende egen situasjon. Brukermedvirkning styrker kvaliteten på behandlingstilbudet som blir tilpasset den enkelte brukers behov og mulighet.

Forskning viser også at et vellykket behandlingsutfall forutsetter at tilbudet skreddersys til individuelle behov og at brukere involveres i planlegging av helsetilbud, samt at det tilbudet er tilgjengelig ved behov, fleksibelt og kulturelt relevant. Det forutsetter derfor at helsepersonell kommer i en konstruktiv relasjon til brukerne uavhengig av symptombildet. Det brukerne har å fortelle om seg selv, sin situasjon og sin helse, er viktig for å forstå behovene, erfaringene og livsmålene. Fortellinger er personlige beretninger som blir fortalt til andre. De har lenge spilt en viktig rolle innenfor flere deler av helsevesenet, og da særlig i psykisk helsearbeid. Fortellingen utgjør terapi, og en kilde til å forstå seg selv og andre.

Målsettingen med denne studien er å

Øke kunnskapen om forhold som kan vanskeliggjøre brukermedvirkning innen psykisk helsearbeid innen kommune og spesialisthelsetjenesten og beskrive, analysere og forbedre rutiner, begrep og handlinger som påvirker brukermedvirkning. Vi har følgende spørsmålsstillinger:

1. Hvilke erfaringer har brukeren av å bli forstått/misforstått i forhold til egen livssituasjon? Hvilke sider ved egen livssituasjon mener brukeren det er viktig at andre forstår?
2. Hvilke erfaringer har brukere med samspill og medvirkning? Hvordan tolker man de situasjonene der man fikk/ ikke fikk medvirke?
3. Hva betyr det lokale stedet for måten brukeren opplever samhandling på?
4. Hva vil det si å ha eller mangle innsikt i egen livssituasjon eller sykdom?

Kriterier for deltakelse
For å delta i studien må du være mellom 18 og 65 år og motta behandling/ oppfølging fra et distriktspsykiatrisk senter i Troms eller Finnmark.

Tidsskjema – hva skjer og når skjer det?

Intervjuene vil finne sted i løpet av høsten 2011. De vil bli analysert og presentert i et antall ulike forskningsartikler i løpet av årene frem til 2015. Studiedeltakeren vil bli orientert så raskt som mulig dersom ny informasjon blir tilgjengelig som kan påvirke deltakerens villighet til å delta i studien.

Mulige fordeler

Fordelen med å delta er at dine erfaringer vil bli hørt og dokumentert som en del av et forskningsprosjekt. Dette kan bidra til økt kunnskap om brukerens rolle i helsevesenet.

Kapittel B - Personvern,økonomi og forsikring

Personvern

Opplysninger som registreres om deg er kun basert på de svarene du gir på spørsmålene under intervjuet. Vi kommer til å spørre deg om ditt syn på din egen helse og behandlinga du får, samt om brukermedvirkning. Vi vil også spørre deg om hva du tenker om stedet du mottar behandlingen på. Du setter selv grenser for hva du er villig til å fortelle. Dine grenser vil bli respektert av intervjuer.

Universitetet i Tromsø ved administrerende direktør er databehandlingsansvarlig.

Rett til innsyn og sletting av opplysninger om deg

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi

Studien utgjør et PhD- studium, og er en del av utdanningen til Rita K. Klausen. Det er et selvstendig prosjekt, og det foreligger ingen interessekonflikter. Studien er finansiert gjennom forskningsmidler fra Universitetet i Tromsø, institutt for helse- og omsorgsfag.

Informasjon om utfallet av studien

Når prosjektet avsluttes, vil deltakerne, dersom de ønsker det, få tilsendt en kort oppsummering av funn og et antall eksemplarer av avhandlingen til det aktuelle distriktspsykiatriske senteret etter disputas.

Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

Appendix 4

Interview guide

Interview guide

The interview is about your perception of your everyday life and the treatment you receive here at .... (name of CMHC). I'd like to talk to you about what happened to you when you came here. I would also like to hear a bit about your thoughts on how this stay (or something with the experience gained here) will change your life going forward or whether it will change your life.

This project deals with what is referred to as user involvement, i.e., how you are able to influence what happens to you when you are in need of help from mental health services.

We want to hear about your experience as a mental health service user (MHSU) in the community mental health center (CMHC). In this way, we hope our contribution will allow the voices of the MHSUs to clearly be conveyed in research.

Participation in the study is voluntary, and you may withdraw from the project at any time. You do not need to explain why. We want you to participate because *you* want to and you think that you have something to say about your own experience as an MHSU.

Topics	Proposed questions
1. Thoughts regarding own life situation	- Can you tell me how you got here (the name of CMHC)? Or something about the decision that was made before you came here? Was it your desire or need? Others, who? How did you react to the fact that you were here? Happy, relieved, confused? What did your significant others think? (Have you experienced losing control over your own situation? Have you been hospitalized? What do you think about that?[1]) (What do you think about your diagnosis (if mentioned)? What does this diagnosis mean to you?) - What do you think about the treatment you get here? - Do you get the help you need? - Do you think you can influence the help you get here? - Do you feel you are getting too much or too little help? - Do you feel that you are being listened to? Tell me about a situation where you felt that you were listened to. What do you think was the reason for being listened to?

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[1] The questions in parentheses are follow-up questions.

	- Can you tell me about a situation where you have not been listened to? - What was the reason you were not listened to? - Are there aspects of your life situation you think should be better taken into account while you are here?
2. User involvement	- Tell me about a situation where you had a say in an important decision about your treatment. - Who was present during this decision? - What do you think was essential if you were present for the decision? - Tell me about a situation where you were not present for an important decision about your treatment. - Who was present during this decision? - What do you think was essential if you did not participate in the decision? - What was needed to change the situation: What could have been done differently?

3. Meaning of contexts	▪ What do you think about the place you are now? ▪ (Is it better to stay here than other places you have lived?) ▪ Who do you contact in 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 enjoy it here? Do you feel at home? ▪ Do you take part in activities in the community? ▪ Who is closest to you? Family, friends? What role do they play in your everyday life?
4. Finishing the interview, comments	▪ Is there anything I have not asked you that you think is important? ▪ Do you want to talk about it?

OVERSIKT OVER TIDLIGERE DOKTORGRADSAVHANDLINGER - PHD I HELSEVITENSKAP - VED AVDELING FOR SYKEPLEIE OG HELSEFAG/ INSTITUTT FOR KLINISK MEDISIN) VED UIT I PERIODEN 01.01.2007 TIL 01.08.2009

Sissel Lisa Storli – (2007)
Living with experiences and memories from being in intensive care. A lifeworld perspective.

Åshild Fause – (2007)
Forpleiningen tilfredsstillende. Prisen ligesaa.

Gunn Kristin Øberg – (2008)
Fysioterapi til for tidlig fødte barn. Om sensitivitet, samhandling og bevegelse.

Cathrine Arntzen – (2008)
"Jeg får ikke hendene til å gjøre det de skal gjøre". Å leve med apraksi etter hjerneslag.

Aud-Mari Soini Fjelltun – (2009)
Waiting for nursing home placement: A study of the life situation of frail elderly and their carer.

Liv Wergeland Sørbye – (2009)
Frail homebound elderly: basic nursing challenges of home care. A comprehensive study across 11 sites in Europe.

Gudrun Nilsen – (2009)
Smerter under Nordlyset. Den vanlige lidelsen. Det uvanlige livet.

OVERSIKT OVER TIDLIGERE DOKTORGRADSAVHANDLINGER - PHD I HELSEVITENSKAP - VED INSTITUTT FOR HELSE- OG OMSORGSFAG VED UIT I PERIODEN 01.08.2009 – 31.08.2013

Elin Damsgård – (2010)
Activity related pain in patients with musculoskeletal disorders. An explorative study.

Kirsti Torjuul – (2010)
Living with ethical dilemmas. The ethical reasoning of surgeons and nurses in surgical units.

Mari Wolff Skaalvik – (2010)
Nursing homes as learning environments: A study of experiences and perceptions of nursing students and supervising nurses.

Eivind Berthelsen – (2010)
Farvel. En fortolkning av et pleiepersonales erfaringer med å pleie døende og å stelle døde.

Randi Inger Johanne Nymo – (2011)
Helseomsorgssystemer i samiske markebygder i Nordre Nordland og Sør-Troms. Praksiser i hverdagslivet. En skal ikkje gje sæ over og en ska ta tida til hjelp.

Kitt Irene Berg Austgard – (2012)
Omsorgserfaring i tradisjon og moderne omsorgsfilosofi - en hermeneutisk studie av den sykepleiefaglige omsorgserfaringen i lys av Kari Martinsens og Ulrikke E. Nissens forfatterskap.

Gabriele Elfriede Kitzmüller – (2012)
Long-term experiences of living with stroke in a family context.

Bente Ervik – (2012)
Everyday life with prostate cancer: A qualitative study of men`s and spouses` experiences.

Berit Andersdatter Bongo – (2012)
Samer snakker ikke om helse og sykdom - Samisk forståelseshorisont og kommunikasjon om helse og sykdom. En kvalitativ undersøkelse i samisk kultur.

Grete Mehus – (2012)
Ungdom, risiko og snøscooterkjøring: En studie av ungdoms forhold til snøscooterkjøring, risikotaking, ulykker og uhell med foreslåtte forebyggingsstrategier.

Rannveig Lind – (2013)
Family members' experiences of decision-making processes in the context of withholding or withdrawing treatment in the ICU. A qualitative interview study.

Britt Normann – (2013)
Physiotherapy and professional clinical guidance in an out-patient clinic for people with multiple sclerosis. Body and movement in sense making and professional development.

Bodil Blix – (2014)
The construction of Sami identity, health, and old age in policy documents and life stories. A discourse analysis and a narrative study.