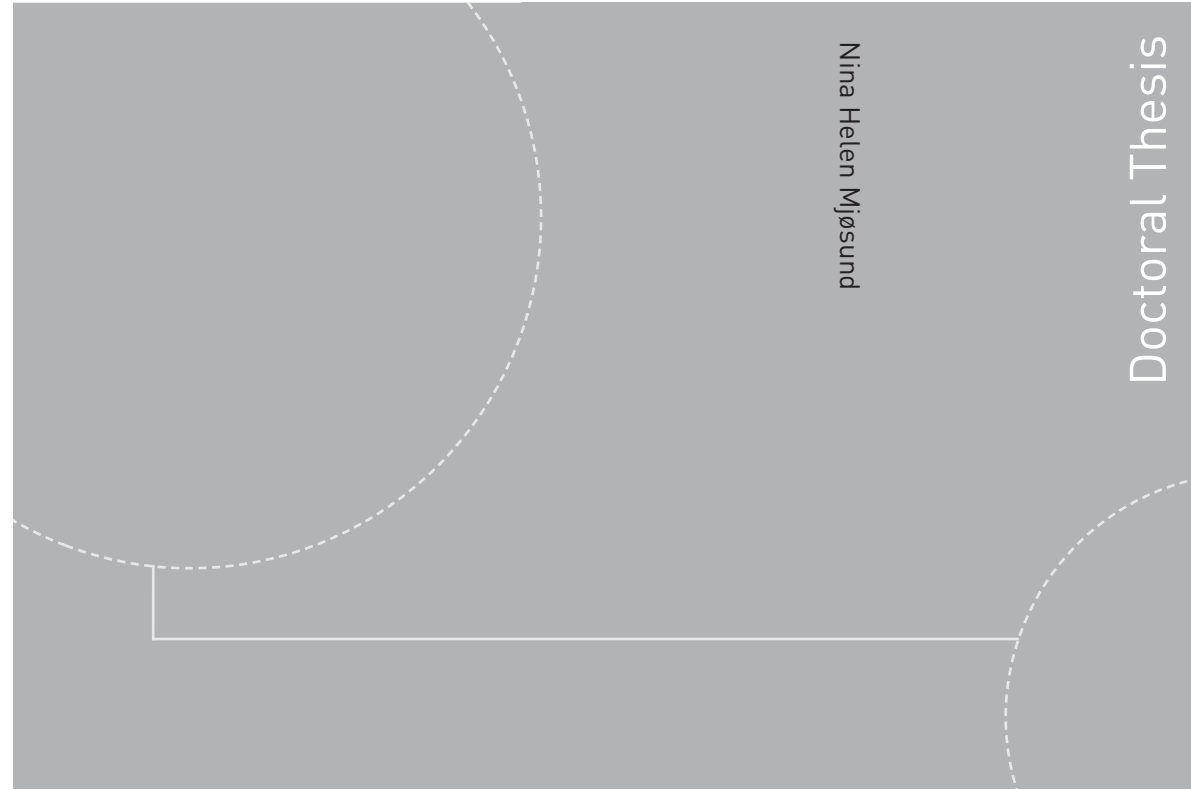


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Nina Helen Mjøsund

**Positive mental health
- from what to how**

A study in the specialized
mental healthcare service

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Science and Technology
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A study in the specialized
mental healthcare service

Thesis for the degree of Philosophiae Doctor

Lier, June 2017

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 **VESTRE VIKEN**
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Division of Mental Health and
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“Psykisk helsefremming – det er å styrke individets iboende oppdrift.”

Rådgivningsgruppa, 2012

“Mental health promotion – strengthening the individual’s inherent buoyancy.”

The advisory team, 2012

Sammendrag

Levde erfaringer hos personer med alvorlig psykisk lidelse kan være en rik og viktig kilde til kunnskap om helsefremming. Tidligere innlagte personer ble intervjuet om hvordan de erfarte psykisk helse og helsefremming. Psykisk helse blir opplevd alltid tilstedeværende i livet, en pågående bevegelse eller prosess, beskrevet som å bevege seg opp eller ned en trapp.

Erfaringer knyttet til psykiske, sosiale, åndelige og fysiske sider av livet påvirker bevegelsen, som samtidig blir ledsaget av en opplevelse av energi. Erfaringer fra opphold i psykisk helsevern viste at læringsprosessene som foregår under innleggelse er helsefremmende.

Deltakerne hadde en appetitt for kunnskap. Læringen var motivert av et ønske om å takle hverdagen med en psykisk lidelse, samt få bedre psykisk helse og økt velvære.

Den anvendte brukermedvirkningen i forskningsprosjektet ble også undersøkt. Erfaringene til fem personer med brukererfaring, forskjellig fra de intervjuede deltakerne, viste at nivået av involvering varierte gjennom forskningsprosessen, fra konsultasjon til samarbeid. Seks kjennetegn ble opplevd å legge til rette for bidrag fra brukerne; a) avklart forståelse av rollene, b) forutsigbar møtstruktur, c) tydelig ledelse, d) fokus på muligheter og løsninger, e) å være en av et team, og f) å bli sett og behandlet som hele mennesker med erfaringer fra helse, sykdom og livet for øvrig. Disse særtrekkene ved samarbeidet ble trukket frem som viktig for en trygg og støttende atmosfære som ga brukerne en følelse av å være kompetente og at deres erfaringer var verdifulle for forskningen. De ulike perspektivene brukerne brakte inn i studien var en styrke. Mangfoldet i erfaringskompetanse og perspektiv bidro til mer innsiktsfulle fortolkninger av nyansene, tvetydigheten og kompleksiteten i de intervjuede deltakernes erfaringer. Brukermedvirkning bidro til økt forskningskvalitet.

Siden helsefremming ble lansert i Ottawa charteret i 1986, har helsetjenestene blitt oppfordret til å fokusere mer på helsefremming og forebygging. Denne studien har hentet inspirasjon fra klinisk praksis i et helseforetak som tilbyr spesialisthelsetjenester innen psykisk helsevern.

Salutogenese benyttes om et teoretisk rammeverk for helsefremming, her forstått som å fremme mental helse som noe positiv tilstede, noe kvalitativt annet enn fravær av psykisk sykdom. Fortolkende fenomenologisk analyse (IPA) ble benyttet for kvalitativt å undersøke levde erfaringer hos tolv deltakere og fem brukere. Forskningsdata ble samlet ved hjelp av dybdeintervju, fler-steps fokusgruppeintervju, fra lydopptak av analytiske og fra dokumenter produsert under samarbeidsprosessen. Viktige meninger og forståelser ble fortolket til funn formulert gjennom tekst og illustrasjoner.

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Abstract

Background: The reorientation of the health services in a health promotion direction has been requested since 1986 when the Ottawa charter (WHO) was launched. A theoretical framework based on salutogenesis is recommended for health promotion development. This study emanated from a mental health hospital, where it was relevant to know how people with mental disorders perceive positive mental health and mental health promotion. Service user involvement in health research has been argued to hold the potential to make research more relevant to clinical practice, and further that it might result in effective improvements in the healthcare services.

Aims: The purpose of the study ‘Positive mental health – from what to how’ was to contribute to the knowledge base of health promotion by exploring experiences of persons with mental health disorders. The present study evolved into two parts. The first aim was to explore how mental health and mental health promotion are experienced by adults affected by severe mental disorders. The next aim was to explore former inpatients’ experiences of mental health promotion in a mental healthcare hospital setting. In the second part of the study, the aim was to explore the applied process of involving mental healthcare service users in the entire research process of the study, in our case as part of an advisory team. Thereafter, how service user involvement may contribute to the development of the methodology Interpretative Phenomenological Analysis (IPA), and in turn enhance the research quality, was examined.

Methodology: In the first part of the study, IPA was used to explore lived experiences of twelve participants. These former inpatients with mental disorders were interviewed in-depth. Analysis of the data was case focussed and then cross case focussed. As part of the study design service user involvement was applied in all stages of the research process. In the second part of the study, a case study design was used to explore the process of collaboration between five members of the advisory team and the researcher. Research data was collected from documentation, by multi-stage focus group interviews, and participant-observations. Important concepts, insights and common opinions were identified by the advisory team and the researcher in analytical discussions, and further developed into understandings formulated in texts and illustrations that helped display and present our findings.

Findings: The first of four papers included in this thesis shows how mental health is perceived as a dynamic phenomenon and an ever-present aspect of life. Mental health is perceived as a process, a constantly ongoing movement, like walking up or down a staircase

and expressed through body language and everyday spoken language. The movement is nourished by experiences in the emotional, physical, social and spiritual domains of life, and accompanied by a sense of energy. The second paper focuses on the prominent finding of an appetite for learning. The participants perceive the learning processes that occur in the healthcare settings as health promoting. They are craving knowledge in order to cope with the mental disorder and to increase their mental health and wellbeing in daily life. The third paper discusses the applied service user involvement process. The level of involvement was dynamic and six features facilitated contributions from service users; role clarification, a predictable meeting structure, a safe and supportive setting through leadership, focus on possibilities, being a team member and being seen and treated as a whole person. These features helped the service users see themselves as valuable and competent. The fourth paper argues that the multiple perspectives of service users and researchers gave more insightful interpretations of nuances, complexity, richness and ambiguity in the participants' accounts. The power of multiple perspectives in service user involvement reinforced the IPA methodology and vice versa.

Conclusions: This thesis shows that lived experiences by persons with severe mental disorders, constitute a rich and important source of knowledge to the field of health promotion. According to the participants, mental health is a dynamic, ever present aspect of life, with improvement or deterioration in their condition being likened to moving up or down a staircase. The learning processes that occurred in the hospital, including both salutogenic and pathogenic knowledge, were perceived as mental health promoting. The participants support the development of educational activities to complement the curative focus in mental healthcare hospitals. When it comes to service user involvement in the present study, the levels of involvement were dynamic and varied throughout the research process. The research advisors experienced certain features of the collaboration process as essential to facilitating their contributions to the research and to seeing themselves as competent. The power of multiple perspectives came across in the collaboration process and this gave us more insightful interpretations of nuances, complexity, richness or ambiguity in the interviewed participants' accounts. The advisory team became 'the researcher's helping hand'.

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Foreword

The idea behind this thesis originated several years ago at a clinical practice in the Division of Psychiatry at Buskerud Hospital Trust in Norway. At that time, I was as head of the Unit of Mental Health Research and Development (R&D) and a member of the management group at the Division. From 2005, I was involved in the development and implementation of ‘The strategy towards 2010’. The aim of the strategy plan was to guide us in future improvements of the services provided by our division. In Norwegian legislation and policy documents, focus was increasingly being directed towards the involvement of patients and relatives in planning, designing and evaluating our healthcare services. Personally, I had positive experiences from involving persons with service user experience in several project groups and steering committees launched at the R&D unit.

A plan of actions, based on up to date, evidence based knowledge, was put in place. Two themes were pinpointed to improve the services in line with policies and governmental guidelines. We decided to strengthen our services for the patients under the headings of ‘Family and network’ and ‘Coping’. In short, we wanted to develop the services in a direction where the working processes would systematically include collaboration with patients and their relatives. We carried out a literature search for experiences from improvements in hospitals and we explored research, theories, policies and strategies to find more knowledge on ‘Coping’. This process was assumed to help the Division’s management with the development of an action plan to strengthen and improve the services. We further initiated collaboration with the Health Promotion Research Centre at Folkhälsan, Helsinki, Finland, and in 2007 an inspiring collaboration started. In the collaboration we were introduced to health promotion, Salutogenesis and the Ottawa charter (WHO, 1986). On the way towards a starting point of the present study, a structural decision on the system level of healthcare services was taken by the Norwegian government. The Buskerud Hospital Trust was merged with three other hospital trusts. The Vestre Viken Hospital Trust was established on July 1st 2009 and a new Division of Mental Health and Addiction was born.

In this setting evolved the ideas which I formulated in a PhD research plan. Before a PhD research study was established, in the planning phase, I got advice from experienced persons in academia on how to deal with the different aspects of managing a research study. They advised me to set up the study in such a way that I had necessary support and not end up being too much alone. During the same period, I had several informal dialogues with former

patients, relatives and health professionals about my study plans. They often shared opinions and suggestions to strengthen the study which inspired me to plan for service user involvement. I decided to include a team of service users in the study, a team with similar experiences as the participants, which I could gather support from, discuss with and get input from. The advisory team became more important than I had imagined, as will be described below.

List of papers

Paper 1

Mjøsund, N. H., Eriksson, M., Norheim, I., Keyes, C. L. M., Espnes, G. A. & Vinje, H. F. (2015) Mental Health as perceived by Persons with Mental Disorders – an Interpretative Phenomenological Study. *International Journal of Mental Health Promotion*, 17(4), 215-233. Doi: <http://dx.doi.org/10.1080/14623730.2015.1039329>.

Paper 2

Mjøsund, N. H., Eriksson, M., Espnes, G. A. and Vinje, H. F. (2016) Reorienting Norwegian healthcare services: listening to patients' craving for learning. *In review*.

Paper 3

Mjøsund, N. H., Vinje, H. F., Eriksson, M., Haaland-Øverby, M., Jensen, S. L., Kjus, S., Norheim, I., Portaasen, I.-L., and Espnes, G. A. (2016) Salutogenic service user involvement: experiences from collaboration in a mental health research project. *In review*.

Paper 4

Mjøsund, N. H., Eriksson, M., Haaland-Øverby, M., Jensen, S. L., Kjus, S. H. H., Norheim, I., Portaasen, I.-L., Espnes, G. A. & Vinje, H. F. (2017) Service user involvement enhanced the research quality in a study using interpretative phenomenological analysis: the power of multiple perspectives. *Journal of Advanced Nursing*. Volum 73(1), 265-278. Doi: <http://dx.doi.org/10.1111/jan.13093>.

Abbreviations

DSM	Diagnostic and statistical manual of mental disorders
GRDs	Generalized Resistance Deficits
GRRs	Generalized Resistance Resources
GRRs-RDs	Generalized Resistance Resources – Resistance Deficits.
IPA	Interpretative Phenomenological Analysis
MHC	Mental Health Continuum
NTNU	Norwegian University of Science and Technology
PAR	Participatory Action Research
SOC	Sense of Coherence
SRDs	Specific Resistance Deficits
SRRs	Specific Resistance Resources
WHO	World Health Organization

1 Introduction

This thesis is based on a qualitative research process influenced by my philosophical assumptions, the adoption of an interpretative lens, and the procedures involved in exploring the human phenomenon of mental health and mental health promotion, as well as the process and outcome of the service user involvement applied in the study. In the foreword, my experiences leading to the research topic, and the relevance, context and inspiration for the study were presented. In the forthcoming chapters background and theoretical perspectives are outlined, before philosophical assumptions including my personal beliefs built into the study, are described. Thereafter, the methodology and the steps and procedures of conducting the study, are explained. A summary of the findings in the four papers included in the thesis are presented, before I discuss some implications of the findings and make some suggestions for clinical practice and further research.

1.1 The focus of the thesis

Mental health and mental health promotion as experienced by persons with mental disorders is the focus of this thesis. The purpose was to study mental health and mental health promotion from the first-person perspective; lived experiences from daily life and from hospitalization. The idea was that if one could understand how former patients' perceive mental health, one might be able to suggest better ways to reorient the healthcare services in a health promotion direction. Additionally, the aim was to explore how the processes of service user involvement in research could be employed and how involvement of service users might influence research quality.

The literature reviews described in my papers showed there was an inadequacy in the current body of knowledge concerning how persons with mental disorders understand mental health and mental health promotion. Persons affected by severe mental disorders seem to be overlooked as sources of credible and useful knowledge on mental health and wellbeing (Lal, Ungar, Malla, Frankish, & Suto, 2014). Likewise, my literature review showed there was a scarcity of detailed and in-depth investigation into the processes of involving service users in research. I was not able to find studies scrutinizing the influence of multiple service user perspectives on interview analysis in studies using IPA.

1.2 The story of what I set out to do and what I ended up doing

In the development of a thesis, there has to be some linear structure which I present to the reader. However, the reflections, recognitions and processes underpinning this thesis may be

characterized by a hermeneutical spiral. One common characteristic of qualitative research is that the initial plan cannot be too tightly prescribed (Creswell, 2012). Hence there are opportunities to adapt and make adjustments in accordance with what occurs in the process. My initial design included a methodological approach IPA to answer the research questions. The findings were to be published in three papers. The first tentative paper aimed to report on the findings on how mental health was perceived; the second aimed to scrutinize the findings on mental health promotion experiences; the third aimed to focus on the findings of how mental health promotion was experienced during hospitalisation, as well as improvements suggested by the participants. However, during analysis of the participants' stories which led to the findings presented in paper 1, interpretations came to the surface that required closer consideration. We realized that movement, development and dynamics were core features of how the participants understand the phenomenon of mental health. The participants described experiences of mental health promotion when responding to the questions on how they perceive mental health. Their perceptions of mental health as dynamic and 'in movement' effectively meant that our findings answered two research questions. Therefore, these were both included in one paper. Consequently, the initial publication plan was reconsidered.

Coincidentally, after nearly three years of working on my study, another issue required reconsiderations: the issue of service user involvement. The collaboration with the advisory team evolved and became more significant than considered possible. Interest and curiosity from other researchers, service users and policy makers made us realize and appreciate that our experiences were important, and needed to be described, documented and communicated. The central authorities guiding research in Norway had begun to set requirements for service user involvement in health research. Therefore, many researchers were looking for experiences on how to do it. We realized that the sharing of our experiences had the potential to extend the knowledge base of service user involvement.

The significance of going deep into the detailed step-by-step guide to conducting an IPA study was recognized. At first I cautiously adopted tested strategies, but as my confidence grew I became more aware of the process and my developing skills. The guidelines worked as recommendations for getting started, rather than permanent prescriptions. The underlying philosophy of IPA is just as important as matters of procedure and methodology, according to Smith, Flowers and Larkin (2009). For me, the theoretical underpinnings of IPA were compatible with using case study design to explore the process of service user involvement.

1.3 Overview of the two parts of the study

I ended up doing an IPA study to explore the understanding of mental health and mental health promotion among persons with mental disorders, and how they experienced mental health promotion while hospitalized, as well as what improvements they suggested in order to promote mental health in this setting. Further, a case study was conducted to examine the processes and outcome of the applied service user involvement in my study. See a presentation of the study in Table 1.

Table 1: Overview of the objectives, design and the source of data

Interpretative Phenomenological Analysis Methodology		Objective (O)	Design	Source
		First part	<p><u>O1</u>: To explore the understanding of mental health and mental health promotion among persons with severe mental disorders</p>	<p>Twelve in-depth interviews, case-focused and cross-case focused analysed. Service user involvement in all stages of the research process.</p>
Second part	<p><u>O2</u>: To examine the process and outcome of the applied service user involvement in the present study</p>	<p>Case study design of the service user involvement process in the first part of the study. Research data collected from documentation, by multi-stage focus group interviews, and participant-observations.</p>	<p>Lived experiences of the advisory team members, and documents (transcripts from analytical discussions, posters, manuscript, notes and minutes of meetings)</p>	

2 Background

The focus of this thesis is twofold; firstly how persons with mental disorders experience mental health and mental health promotion and secondly it focuses on the involvement of mental healthcare service users in the research process. The study emanated from a mental healthcare setting; a hospital aiming to reorient their services towards more mental health promotion. Central concepts of this thesis will be discussed below.

2.1 Health

Health is a contested concept and tension often emerges when attempting to define it. Difficulties are encountered when attempting to provide precise assumptions about health, because health is one of those subjective and abstract concepts, like love and beauty, which mean different things to different people (Green & Tones, 2010). Perceptions of the concept of health among patients in mental health nursing included that they perceived autonomy, meaningfulness, and community as important to achieving health (Svedberg, Jormfeldt, Fridlund, & Arvidsson, 2004). There is a range of definitions. Should we emphasize disease or wellbeing, holistic or atomistic, the individual or the collective, lay or professional, or the subjective or objective interpretations (Green & Tones, 2010)? Huber et al. (2011) suggest describing health as an ability to adapt and self-manage in the face of social, physical, and emotional challenges. Boorse (1977) argues that the medical conception of health as the absence of disease is a value-free theoretical notion, with elements of biological function and statistical normality. At the same historical time, Antonovsky (1979) challenged the conventional pathogenic paradigm and its dichotomous classification of persons as being either diseased or healthy. Antonovsky (1979) saw health as a movement along a continuum between ease and dis/ease¹, and rejected the dualism of the health - disease dichotomy.

In this thesis the understanding of health is embedded in the positive orientation of the Ottawa charter: “Health is a positive concept emphasizing social and personal resources, as well as physical capacities” (WHO, 1986, p. 1). Initiating my study, I brought with me an understanding of health as a continuous phenomenon and assumed health to be something positively present. I wanted to pursue health in its self, as opposed to seeing health in

¹ In Antonovsky’s original writings he consequently used an hyphen between dis and ease describing the health continuum as ease – dis-ease, however according to programs of automatically correct misspelled words the hyphen often disappears (see example in the published paper 1), therefore, in this thesis I will use a slash; ease-dis/ease).

connection with disease. Additionally, I wanted to allow for contributions from the participants in my study in discussing and formulating an understanding of mental health.

2.2 Mental health and mental health promotion

World Health Organisation (WHO)'s (1948) famous definition of health as a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity, included mental health. From WHO's definition follows that mental health is much broader than the absence of mental disorders, that there is no health without mental health, and that mental health is connected to behaviour and physical health (Herrman, Saxena, & Moodie, 2005). Defining health and mental health was important, although the differences in values across countries, cultures, classes and genders were recognized. WHO has published a definition aiming to capture a core common sense meaning without culturally restricting its interpretations (Herrman et al., 2005). Mental health was defined as a state of wellbeing in which the individual realizes their abilities, can cope with normal stress of life, can work productively and fruitfully, and is able to make contributions to society (WHO, 2014). The focus on positive mental health and mental health promotion has increased in the last decades (Barry, 2009; Barry & Jenkins, 2007; Cattán & Tilford, 2006; Herrman et al., 2005; Jané-Llopis, 2007; Kovess-Masfety, Murray, & Gureje, 2005; Manderscheid et al., 2010). Mental health promotion is essentially concerned with promoting optimal mental health rather than reducing symptoms and deficits (WHO, 2002, 2004a). The aim of mental health promotion is to elevate the levels of positive mental health and protect against its deterioration (Keyes, 2007, 2014; Secker, 1998). In this thesis mental health and mental health promotion encompasses an understanding of mental health as a resource, as a value on its own and as a basic human right, and essential to social and economic development. This is in accordance with the understanding of WHO (2004a).

2.3 Health promotion and the Ottawa charter

The field of health promotion is located in the multidisciplinary context of public health (Green & Tones, 2010). The WHO has been central in the development of the social movement and ideology of health promotion. In the basic document for health promotion, the Ottawa charter (WHO) from 1986, health promotion was defined as the process of enabling people to increase their control over, and improve their health. The first contours of health promotion however, were seen in the strategy; Health for All by the year 2000 (WHO, 1981). The vision here was not only 'adding years to life' but also 'life to years'. Lindström & Eriksson (2010, p. 26.) interpreted this as the following: the outcome of health promotion

activities is wellbeing and quality of life. Their understanding indicates for me a positive outcome of the promotion of health. However, health promotion is still often reduced to disease-oriented prevention approaches according to International Union of Health Promotion and Education (IUHPE, 2016).

Reorienting the healthcare services in a health promotion direction was stated as one of the five key action areas in the Ottawa charter (WHO, 1986). This seem to be the least systematically developed, implemented and evaluated key action area (Wise & Nutbeam, 2007). It has been, and still is, urgent to find new and unorthodox ways to reorient the health services towards the promotion of health (Catford, 2014; de Leeuw, 2009). The recently launched Shanghai Declaration on promoting health (WHO, 2016) confirmed the enduring relevance of the Ottawa charter. The prevention and treatment of mental illness will not necessarily result in a more mentally healthy population (Keyes, 2002). This is forcing politicians to emphasize health promotion as a means to prevent further rises of expenditure in mental healthcare services. Legislation (The Health Personnel Act, 1999; The Patients' Rights Act, 1999), The Coordination Reform in Norway (2009), as well as national (Klepp, 2010) and international policies (Canadian Institute for Health, 2009; Commission of the European Communities, 2005; Regional office for Europe WHO, 2005; WHO, 2004a) and theoretical recommendations (Jané-Llopis, 2007; Magyary, 2002; Slade, 2010), all focus on the need to complement the traditional curative orientation with a health promotion orientation. Patients with mental disorders need and should be offered the same health promotion interventions as any other patient group (Tønnesen, 2013a). Persons with mental disorders deserve a major effort to promote their mental health as the presence of something positive (Keyes, 2013b). To approach the problem of mental illness only through treatment of mental disorders seems insufficient. However, experiences from reorienting initiatives towards more health promotion in the specialized mental healthcare services were hard to find in the literature review.

2.4 Mental illness, mental disorder and prevention of mental disorders

The present study was launched in a setting traditionally dominated by a biomedical and pathogenic orientation with focus on diseases. The use of terminology associated with disease is complicated and contested both in Norwegian and in English (Hofmann & Wilkinson, 2016; Schramme, 2013; Zachar & Kendler, 2007). In a hospital setting, diagnoses have relevance and reasons for terms used in this thesis will be presented. Two diagnostic systems exist in the field of psychiatry. The ICD-10 (WHO, 2009) uses classification of diseases and the DSM-5 (American Psychiatric Association, 2013) uses classifications of disorders. To

avoid confusion with Antonovsky's ease-dis/ease terminology, I will not use the word disease. To denote a diagnosed condition, I will use the term 'mental disorder'. When focusing on the individual experiences of struggling with mental problems or living with a diagnosed condition, the term 'mental illness' will be used.

Mental disorders are common and affect many people. An EU survey, consistent with earlier international studies, shows that one third of the population suffers from mental, neurological or substance abuse diagnoses (prevalence) (Wittchen et al., 2011). About half of the Norwegian population will experience a mental disorder during their lifetime, and similar trends are seen in the rest of the western world (incidence) (Mykletun, Knudsen, & Mathiesen, 2009). In a study of the Norwegian disability pension registry mental disorders were responsible for the most working years lost. Of those rewarded disability benefit individuals with mental disorders were given this at a younger age than individuals with other diagnoses (Knudsen, Øverland, Hotopf, & Mykletun, 2012). According to Wahlbeck, Westman, Nordentoft, Gissler, & Laursen (2011), Nordic patients with severe mental disorders have 15-20 years shorter life expectancy than the general population. This is largely due to lifestyle related non-communicable diseases (Wahlbeck et al., 2011).

Mental disorders span from mild to severe conditions. The latter would often broadly include disorders in the bipolar and schizophrenia spectrums, and also complex comorbid conditions with substance abuse disorders. Severe mental disorders tend to have a prolonged course with a correspondingly lengthy need for healthcare services. Mangalore and Knapp (2007) estimated costs associated to schizophrenia; because of the range of health needs the health cost of treating and supporting people with severe mental disorders were huge. Mental disorders also affect those who are close to the patients. Severe mental disorders were stressful not only for the patients, but also family members might experience moderately high levels of burden (Saunders, 2003).

Prevention of mental disorders in public health is concerned with reducing the incidence, prevalence, duration, recurrence and the prognosis of the disorder, and improving the prognosis (WHO, 2004a). In a mental hospital setting the treatment and care may have several intended purposes. Petersen (2010) argues that promoting mental health reduces the incidence of mental disorders, as positive mental health is protective against mental disorder, and the prevention of mental disorders may use mental health strategies. In clinical practice we face the difficulty with similarities and boundaries between the concepts of mental health

and mental illness and between prevention and promotion (WHO, 2004a). Mental disorders and mental health are interrelated concepts. However, in this thesis they are treated as separate.

2.5 The study context

In 2016, Vestre Viken Hospital Trust had a total catchment area of 470 000 inhabitants spread over 26 municipalities. This constitutes nearly 10 % of the population in Norway. The Division of mental health and addiction operates with approximately 1800 man-labour years and is composed of two Hospital Departments and five Community Mental Health Centres for adults. In addition, there is the ‘Department for Child and Adolescent Psychiatry’, the ‘Department for Substance Abuse and Addiction’, and the ‘Department for Mental Health Research and Development’. The departments have about 35 wards spread over a relatively large geographical area.

All Norwegian citizens have the right to government provided healthcare services (Specialized Health Services Act, 1999; The Mental Health Care Act, 1999; The Patients' Rights Act, 1999). A desired development has been towards increasing the proportion of healthcare services offered in the municipalities and a decrease in the number of hospital bedposts. Another service development has been towards democratization and user orientation, where the relationship between healthcare providers and users is based on partnership and cooperation (Klepp, 2010; The Coordination Reform, 2009; The Health Personnel Act, 1999). Patients' participation in decision making and shared responsibility is seen as a condition of efficient treatment (The Patients' Rights Act, 1999). The relatives' rights and the children's needs as relatives are emphasized in specific guidelines (Children as relatives, 2010; Relatives' Rights, 2014), and in amendments in The Health Personnel Act (1999). The Mental Health Care Act (1999) defines the term mental healthcare as the examination and treatment by specialized healthcare services and the nursing and care that persons suffering from mental illness require. Examination and treatment must be in accordance with professionally recognized psychiatric methods and clinical practice.

2.6 Service users and service user involvement in health promotion

In this thesis, the term ‘service users’ is used to denote persons receiving any kind of services from the specialized mental healthcare services, in accordance with the Specialized Health Services Act (1999). As a consequence, patients as well as their relatives and family members are considered to be service users. In related literature service users involved in research have

been described using a numbers of terms, including ‘peer specialists’, ‘experts by experience’, ‘service user researchers’, ‘co-researchers’ and ‘academic user researchers’, with slightly differing conceptual content (Wallcraft, Schrank, & Amering, 2009). In this thesis the members of the advisory team, who were involved in the research process of the study, are entitled ‘research advisors’ – a term they themselves decided on. The term ‘service user involvement’ is used about the activity and processes between the researcher and the members of the advisory team, all of whom are or have been users of the mental healthcare services, either as patients or relatives.

3 Theoretical perspectives

Initiating the study a salutogenic theoretical framework was chosen, influenced by the topic, positive mental health, and the context of the specialized mental healthcare hospital. To some degree, the theoretical perspectives influenced my collection of data, analysis and the forming of an understanding, which was developed in further data collection. The process grows out of a hermeneutical spiral-like movement. As Alvesson and Sköldbberg put it, the researcher: "...eats into the empirical matter with the help of theoretical preconceptions, and also keeps developing and elaborating the theory" (2009, p. 7.). This thesis is positioned in the phenomenological hermeneutical research tradition which involves the integration of parallel, but interacting processes; on the one hand studying the existing literature and its theoretical models, and on the other conducting one's research.

3.1 A salutogenic orientation

Salutogenesis provides a theoretical approach to the origin of health including meanings, resources, motivation and action competences with an active and conscious focus on strengths and resources in individuals, families, and groups (Mittelmark, Sagy, et al., 2016). A salutogenic orientation to the study of health focuses on the movement towards health, with emphasis on resources and strengths that promote health as a positive outcome (Lindström & Eriksson, 2010). The concept salutogenesis stems from the Latin word *salus* (meaning health) and the Greek word *genesis* (meaning origin). The medical sociologist Aaron Antonovsky introduced the concept of salutogenesis and formed a theoretical framework for health (Antonovsky, 1979, 1987). Antonovsky (1996) suggested the salutogenic orientation as a theoretical framework for health promotion, later recognized to be a core theory to guide health promotion (IUHPE, 2016; Lindström & Eriksson, 2010; Mittelmark & Bull, 2013). In a salutogenic interpretation of the Ottawa charter; the core document of health promotion, Lindström & Eriksson (2010) argue for four core elements integrated in health promotion; First, making it a rule to value the individual as a participating subject, second; an understanding of health promotion based on the Ottawa charter; third, salutogenesis as the process towards health, and fourth; the quality of life as the outcome of the process. The Declaration of Human Rights provides the ethical foundation both for health promotion and salutogenesis (Lindström & Eriksson, 2010). Salutogenesis is today described as an umbrella concept including several theories and approaches aimed at strengthening people's resources and skills for improving their health and wellbeing (Lindström & Eriksson, 2015). Being introduced to the sociologist Corey Keyes and his model of mental health made a significant

contribution to my understanding of mental health. Based on a salutogenic perspective (Keyes, 2014), he defined mental health as the presence of a positive state of human capacities and functioning in cognition, affect, and behaviour (not the absence of disability or pathology). Keyes has developed the two continua model of mental health, that includes the presence of human capacities and functioning as well as the assessment of disease or infirmity (Keyes, 2005, 2014).

3.2 Antonovsky’s salutogenic model of health

For Antonovsky the most important research question was what creates health; what are the origins of health? According to him, the answer was to be found in a sense of coherence (SOC). The question and the answer together make up the salutogenic model of health (Antonovsky, 1979). Antonovsky’s model elucidates the subjective dimensions of health, and this became an important inspiration for my study.

3.2.1 Health and mental health as a continuum

Antonovsky (1979, 1987) rejected the dichotomous understanding of sick and well and argued for a health ease-dis/ease continuum. Antonovsky (1987) saw the two orientations - pathogenesis and salutogenesis - as complementary. In his lectures Antonovsky showed the health continuum graphically on a horizontal line between total health (H+) and total absence of health (H-), and explained that we are all positioned somewhere on this line (Lindström & Eriksson, 2010), see Figure 1 (used by permission). Antonovsky assumed that life can never be completely controlled (Lindström & Eriksson, 2010). We will face challenges and adversities in life and we need to deal with stressful life situations and events, which he refers to as stressors of living (Antonovsky, 1987).

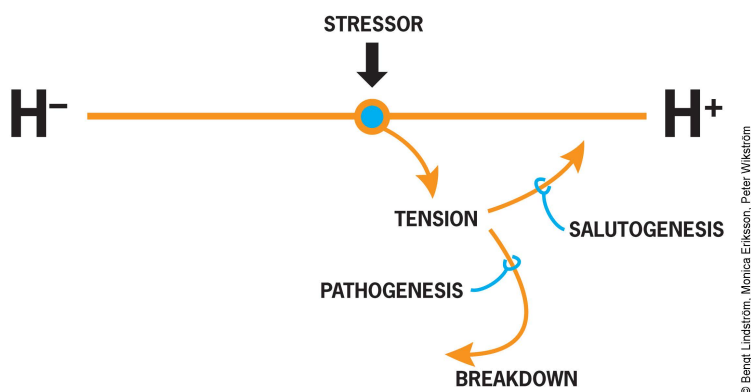


Figure 1: The health continuum “ease/dis-ease”, from Lindström & Eriksson (2010).

Rather than emphasising the end points of the continuum, the salutogenic orientation is primarily concerned with the actual movement along the line (Vinje, Langeland, & Bull, 2016). In the study context an understanding of health as moveable represented a hope for enhanced situation in the future for the patients struggling with mental disorder.

Antonovsky (1979) understood health as the absence of four characteristics. Two were related to the subjective judgment of pain and functional limitations, and two to the medically defined condition and associated treatment based on the health authorities' judgment. Vinje et al. (2016) interpret Antonovsky's writings on the health continuum as encompassing physiological health only, due to his warnings about the dangers of classifying mental and social wellbeing as elements of health. They concluded that Antonovsky's message was that health is one part of the larger realm of wellbeing, and that health should be narrowly defined in order to facilitate empirical research and avoid value-based definitions that might open up for abuse of power (Vinje et al., 2016). Antonovsky also described 'mental health' as a continuum, with good mental health being more than the absence of something negative, and the concept of wellbeing was used.

Mental health, as I conceive it, refers to the location, at any point in the life cycle, of a person on a *continuum* which ranges from excruciating emotional pain and total psychological malfunctioning at one extreme to a full, vibrant sense of psychological wellbeing at the other (Antonovsky, 1985, p. 274).

A salutogenic orientation focuses on the achievement of successful coping, which facilitates movement toward that end of the mental health continuum which is a vibrant sense of psychological wellbeing. Antonovsky (1979) described wellbeing as something wider than health, health was only one dimension.

3.2.2 Tension management and Generalized Resistance Resources

Stressors are omnipresent in human existence. Being confronted with stressors, ranging from the microbiological to the socio-cultural level, results in a state of tension which one must deal with (Antonovsky, 1987). These stressors or challenges, by Antonovsky's definition (1979), place a load on people, resulting in a tension. Stress is the strain that remains when tension is not successfully overcome. Tension management is the process of dealing with tension and overcoming the stressors. "In other words, tension, the state of psychophysiological response of the organism to the challenge, is not at all necessarily pathogenic" (Antonovsky, 1985, p. 274). Tension may have negative or neutral consequences, or even be salutary (1979).

To promote a salutary tension management, we need resources at our disposal. The generalized resistance resources (GRRs) are defined as any characteristic of the person, the group, or the environment that can facilitate effective tension management (Antonovsky, 1979). Specific resistance resources (SRRs) were defined as resources often useful in particular situations of tension and in coping with individual stressors (Antonovsky, 1979). The absence of GRR or SRR could become a stressor in itself, a situation described as Generalized / Specific Resistance Deficit (GRD/SRD)(Antonovsky, 1987). Mittelmark, Bull, Daniel, & Urke (2016) argue that differences between GRRs and SRRs are important in health promotion research and practice, because the means by which these resources are strengthened are dissimilar. Both GRRs and SRRs can provide relevant focus in the development of interventions aiming at mental health promotion for persons with mental disorders. The GRRs include psychological, physical, biochemical, social and cultural factors such as knowledge, experiences, intelligence, coping styles, social support, traditions, close friends and relatives, money, shelter and clothing (Antonovsky, 1979). Even more crucial than the resources themselves is the ability to use them. Strengthening existing GRRs and SRRs or developing new resources, as well as elaborating on how to use or to take advantage of existing RRs, can be a core issue for collaboration between patients and health providers.

3.2.3 Sense of Coherence - SOC

Sense of coherence (SOC) is one of the key concepts in the salutogenic health model.

Antonovsky defined SOC in his first book from 1979, but redefined it in the 1987 version:

“The sense of coherence is a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one’s internal and external environments in the course of living are structured, predictable and explicable; (2) the resources are available to one to meet demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement.” (Antonovsky, 1987, p. 19)

According to Antonovsky (1987), the SOC is mainly formed in the first three decades of life, and is a deeply rooted, stable dispositional orientation to life. However, SOC is not immutable or rigidly fixed; SOC is developed throughout life until death (Eriksson & Mittelmark, 2016). In the context of healthcare services, it is important that SOC is perceived as flexible and able to be strengthened by interventions. Antonovsky made the dynamics of the SOC in adult life important: “...particularly the question of planned modification and utilization of the theory by practitioners” (Antonovsky, 1987, p. xvi). SOC is seen as a dispositional orientation rather than a personality trait. The strength of the SOC is a decisive

variable in determining the extent to which an individual will successfully cope with the challenges posed in the course of life, and hence in determining movement toward the health pole of the continuum (Antonovsky, 1985).

The core components of SOC, comprehensibility, manageability and meaningfulness, are involved when individuals are in interaction with the environment as they constantly go through challenging situations (Antonovsky, 1987). A person who perceives the stimuli confronting him as making cognitive sense, as information that is ordered, consistent, structured, and clear, rather than as noise – chaotic, disordered, random, accidental, and inexplicable – is a person with a high level of comprehensibility. This person expects that stimuli he or she will encounter in the future will be predictable or if they come as surprises, that they will be orderable and explicable (Antonovsky, 1987). The comprehensibility component is also described as the cognitive component, a capacity to judge reality, to understand what is happening. The second component manageability, is defined as the extent to which one perceives that the resources which are at one's disposal are adequate to meet the demands posed by the stimuli that bombard one (Antonovsky, 1987). When things happen in life, one will be able to cope and sort it out. Manageability is described as the instrumental or behavioural component, a capacity to practically manage the situation. The third component is meaningfulness, which Antonovsky saw as representing the motivational element. Meaningfulness refers to the extent to which one feels that life makes sense emotionally, that the challenges we meet in life are worth investing energy in, and are worth our commitment and engagement (Antonovsky, 1987). The challenges are classified as important for us in an emotional and a cognitive way; life events that affect us. More recent research shows that the three components in the SOC are closely intertwined, meaning that the different dimensions have different importance depending on the situation (Bergman, Årestedt, Fridlund, Karlsson, & Malm, 2012). A strong SOC will make the person feel that the world makes sense, that the challenges posed by living can be handled reasonably well and that one cares about engaging in these challenges (Antonovsky, 1985). The Orientation to Life Questionnaire for measuring SOC was developed by Antonovsky (1987), the instrument consists of 29 items or a shorter version with 13 items.

3.3 Keyes' Two-Continua Model

The research of Keyes (2014), focuses on subjective experiences of mental health. Inspired by salutogenesis he views mental health as the presence of positive states of human capacities and functioning in cognition, affect and behaviour. He questioned the commonly accepted

definition of mental health as the absence of psychopathology. He developed the Two-Continua model of mental health and mental illness, showing how the absence of mental illness does not equal the presence of mental health, and revealing that the causes of mental health are often distinct processes from those understood as the risks for mental illness (Keyes, Dhingra, & Simoes, 2010). The Two-Continua model includes related but distinct dimensions of mental health and mental illness, (Keyes, 2007, 2010; Keyes et al., 2010; Westerhof & Keyes, 2010), as illustrated in Figure 2 (used by permission).

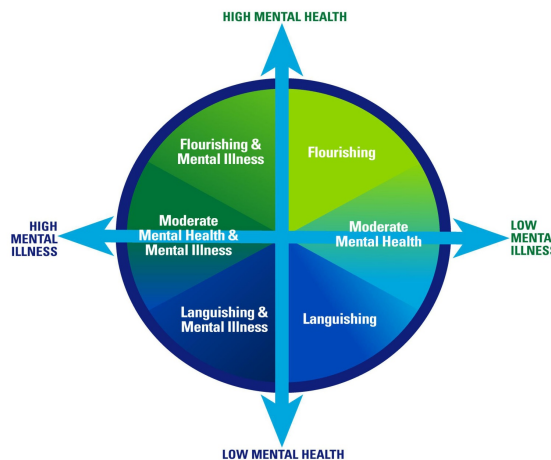


Figure 2: The Two-Continua model from Keyes (2013).

Patients and healthcare providers in mental healthcare services may utilize this framework to focus on the mental illness status, as well as the persons level of mental health (Keyes, 2010). Keyes’ conceptual framework maps on to themes emerging from narratives about recovery from mental illness (Slade, 2010), and can be a model to bridge mental illness with positive mental health in processes of recovery (Provencher & Keyes, 2011).

3.3.1 Mental health as feelings and functioning

Keyes has suggested an operationalization of mental health as a syndrome of symptoms of positive feelings and positive functioning in life (Keyes, 2002). The DSM-3 (American Psychiatric Association, 1987) approach to the diagnosis of major depression was employed as a theoretical guide for the conceptualization and the determination of the mental health categories and the diagnosis of mental health (Keyes, 2002). The terms used derived from the pathogenic paradigm more often used to describe mental disorders and illness rather than

health. However, Keyes chooses to utilize DSM-3 as a tool aiming to place the domain of mental health on equal footing with mental illness (Keyes, 2002). The concepts (syndromes, symptoms and diagnosis) are familiar and easy to comprehend for the multidisciplinary professionals in healthcare services. Using a familiar language can be a pedagogic advantage when new models and theories are implemented to guide interventions in clinical practice.

Keyes (2002) conceptualizes mental health along a continuum subdivided into three conditions; languishing, moderate mental health and flourishing. A state of mental health is indicated when a set of symptoms at a specific level are present or absent for a specified duration and they coincide with distinctive cognitive and social functioning (Keyes, 2002). The self-administered questionnaire Mental Health Continuum was developed to assess mental health based on individuals' responses to structured scales measuring the presence or absence of positive affects (happy, interested in life, and satisfied), and functioning in life, which includes the measurement of two facets; psychological wellbeing and social wellbeing (Keyes, 2002, 2009). The three factor structure; emotional, psychological and social wellbeing has been confirmed in a representative sample of US adults (Gallagher, Lopez, & Preacher, 2009), college students (Robitschek & Keyes, 2009), across a lifespan (Westerhof & Keyes, 2010), and in a national representative sample of adolescents (Keyes, 2006), as well as in South Africa (Keyes et al., 2008), and the Netherlands (Lamers, Westerhof, Bohlmeijer, ten Klooster, & Keyes, 2011). Moreover, the MHC has been used to measure mental health as outcome in intervention research (Fledderus, Bohlmeijer, Smit, & Westerhof, 2010). Similarly to mental illness, the level of mental health seems to be dynamic over time (Keyes, 2010).

To be flourishing is to be filled with positive emotions and to be functioning well psychologically and socially. Languishing is experienced as emptiness and stagnation, the feeling of a quiet despair that parallels accounts of life as hollow, empty, a shell and a void (Keyes, 2002). Individuals neither diagnosed as flourishing nor languishing are diagnosed to have moderate mental health. Mental health is operationalized as an individual's subjective wellbeing; the individuals' perceptions and evaluations of their own lives in terms of their affective state, and their psychological and social functioning (Keyes, 2002).

Psychological wellbeing represents private and personal criteria for evaluation of how we view ourselves functioning as "I" and "Me" (Keyes et al., 2008). Psychological wellbeing may be characterized by the presence of intrapersonal reflections of one's adjustment to and outlook on life, and consists of six dimensions; self-acceptance, positive relations with others,

personal growth, purpose in life, environmental mastery, and autonomy. Social wellbeing epitomizes the more public and social criteria whereby people evaluate their functioning in life as “We” and “Us”, and consist of social coherence, social actualization, social integration, social acceptance and social contribution (Keyes et al., 2008). Applying this framework makes it meaningful to protect a positive mental health status for those flourishing as well as promoting mental health for those with a status of moderate or languishing mental health (Keyes, 2007, 2013b).

3.4 Service user involvement in research

The field of mental health has a longer history of engagement with service users in research than many other areas of research (Boote, Wong, & Booth, 2012; Cossar & Neil, 2015; Pollard & Evans, 2013; Telford & Faulkner, 2004; Wallcraft et al., 2009). The UK has been at the forefront and established INVOLVE in 1996 to develop and promote involvement of patients and public in research (National Institute for Health Research, 2015). The Mental Health Research Network (2013) considers that involvement in research to take place when research is carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. Taking part in a study as a participant does not necessarily constitute involvement. Regardless of the research methodology applied service user involvement is desired and justified for several reasons; moral / ethical; ideological / political; and methodological / usefulness (Bryant et al., 2012; Ives, Damery, & Redwod, 2013).

Another motivation for service user involvement has been to increase the likelihood that the knowledge produced might result in more effective initiatives to improvements in the healthcare services, since these have the support of the people concerned (Secker, 1998). This may reduce the time from knowledge production to implementation of improvements. Incorporating knowledge that originates from lived experiences into research has gradually become more documented and evaluated (Barber, Beresford, Boote, Cooper, & Faulkner, 2011; Beresford, 2005; Boote et al., 2012; Brett et al., 2012; Clark, Glasby, & Lester, 2004; Staley, 2012). There has been focus on the impact of involvement on the research process and the production of knowledge (Cotterell, 2008; Gillard et al., 2010; Gillard, Simons, Turner, Lucock, & Edwards, 2012). A literature review (Brett et al., 2012) identified influence on quality and appropriateness of research. To be challenged and exposed to different languages, attitudes and beliefs from persons with a patient’s perspective can open up for a more comprehensive understanding (Clark et al., 2004; Hewlett et al., 2006), from which professionals can learn (Secker, 1998). Service users are seen to ‘know what they are talking

about' because they have directly experienced it. Shorter distance between direct experiences and their interpretations may reduce the risk of producing knowledge that is inaccurate, unreliable and distorted (Beresford, 2005). Partnering with service users and citizens in evaluation and research is strongly recommended in the New Haven Recommendations (International Health Promotion Hospitals and Health services, 2016) as a mean to enhancing performance and quality in health promoting services. Making research findings accessible and understandable to patients, by using 'normal language' in abstracts, leaflets and other publications is encouraged and seen as a way to break down the silos between healthcare stakeholders (International Health Promotion Hospitals and Health services, 2016). A plurality of approaches to involvement of service users in mental health research exists. However, there seems to be a paucity of detailed accounts of the process of involvement, as well as the benefits, challenges and learning throughout the process that could guide researchers and service users in their collaboration (Barber et al., 2011; Sims et al., 2013).

3.4.1 The levels of involvement

User involvement in research can take place at different levels or positions along a continuum from low to high involvement (Hickey & Kipping, 1998), or at different stages as in Arnstein's (1969) ladder of participation. These frameworks have been developed further, taking into account changes in policy and thinking, practical and theoretical improvements and the strengthening of the patients' rights. Sweeney and Morgan (2009) contribute to a clarification by introducing four levels of involvement in research; consultation, contribution, collaboration, and control, in addition to no involvement. These levels have been used to describe the type of user involvement in my study. A prominent feature of the involvement, also experienced in our collaboration, was that the level of involvement varied from stage to stage in the research process (Wallcraft et al., 2009).

4 Aims and research questions

The following aims and research questions guide the research presented in this thesis.

The first aim was to explore how mental health and mental health promotion are experienced by adults affected by mental disorders and with in-patient experiences.

Research question 1: How is mental health experienced and described?

Research question 2: How is mental health promotion experienced and described?

The findings are presented in Paper 1.

The second aim was to explore former in-patients' experiences of mental health promotion in a mental healthcare setting.

Research question 3: What experiences from hospitalization in mental healthcare do former patients experience and describe as promoting their mental health?

Research question 4: What improvements in mental healthcare are suggested by former patients in order to promote mental health?

The findings are presented in Paper 2.

The third aim was to explore the applied process of involving mental healthcare service users in the study.

Research question 5: How do the service users experience and describe their involvement in the research process?

Research question 6: In what ways have service users experienced that their involvement has been encouraged and been of importance?

The findings are presented in Paper 3.

The fourth aim was to examine how service user involvement may contribute to the development of Interpretative Phenomenological Analysis methodology and in turn enhance the research quality.

Research question 7: In what ways may service user involvement strengthen research quality in an IPA study?

The findings are presented in Paper 4.

5 Methodology

Methodology refers to the theoretically informed framework for the various rational and procedural principles and processes guiding the scientific inquiry (Delanty & Strydom, 2003; Smith, 2015). Methodology is together with ontology and epistemology interconnected generic activities defining the qualitative research process (Denzin & Lincoln, 2013c). It is the answer to how I can go about finding out what can be known. How can I understand and interpret, or recognize and explain the phenomenon of my interest? All research is guided by a set of beliefs about the world and how it should be studied (Denzin & Lincoln, 2013a), also called a paradigm (Denzin & Lincoln, 2013c), or a worldview (Creswell, 2009). To make the research in this thesis transparent and available for critical examination, which is a premise for the development of scientific knowledge (Creswell, 2012), I want to articulate my assumptions as accurately as possible. My values influence the nature of my study, as well as how I approach the “other”. This is also relevant for the assessment of the inner consistency of the thesis. Information found in Foreword, Introduction and Attachments give the reader some impression of who the knowers are in this thesis. The term positional validity is used about this form of self-disclosure (Pillow, 2003).

Answering the ontological questions “what is the form and nature of reality?” and “what can be known?” my worldview is mostly consistent with constructivism. Reality exists in the form of multiple mental constructions, socially and experientially based, dependent on the persons who hold them (Creswell, 2012; Denzin & Lincoln, 2013b). It is socially co-constructed through interactions between individuals using symbols and language to interpret their perceptions of the world and their experiences (Bowling, 2009; Delanty & Strydom, 2003). Human beings are physical and psychological entities (Smith et al., 2009). To me human beings are biological, psychological, cultural and social beings with existential dimensions, in constant interactions with each other and their environment. Human beings are sense-making creatures and therefore the accounts provided by the participants reflect their attempts at making sense of their experiences. This is an assumption that is also built into IPA methodology (Smith et al., 2009). I believe human beings are more than and different from the sum of their parts. They have the capacity to become consciously aware of the understanding they attach to their experiences in such a way that they are able to make choices influencing their own situation.

Of relevance in epistemology is the connection between the researcher and that being researched, the relationship between the knower and what can be known (Lincoln, Lynham, & Guba, 2013). I cannot separate myself from what I know. Qualitative research, I believe, is therefore shaped by the researcher's values and experiences. Constructivists believe the inquirer and inquired are fused into a single entity and the findings are co-created (Lincoln et al., 2013). The researcher is the key instrument, and his/her own background shapes their interpretations (Creswell, 2012). My understandings are influenced by social interaction, language, my socio-cultural context and my perspectival situatedness in the historical (time) and cultural norms of the Norwegian society (place). We are shaped by our lived experiences, and these will always come out in the research data generated by the participants and the members of the advisory team, as well as in my interpretations.

My assumptions are embedded in constructivism, loosely defined. I agree with Lincoln et al. (2013), believing that criteria for judging either reality or validity are not absolute, rather they are derived from community consensus regarding what is 'real'. The criteria should be chosen according to what is useful and what has meaning within that community, as well as in the context of a particular study. I also find the participatory position resonating with my worldview and with some aspects of my study. In the second part of the study, which examined the process and outcome of the applied service user involvement my constructivist approach became more influenced by the participatory paradigm. Is it possible to blend the elements of one paradigm into another, so that one is engaging in research that represents the best of both worldview, ask Lincoln et al. (2013). They answer cautiously yes, and presume that the integrated philosophical systems need to share axiomatic elements that are similar or that resonate strongly, and therefore they claim that elements of constructivist and participative inquiry fit comfortably together (Lincoln et al., 2013). Commensurability is an issue only if the researcher wants to pick and choose among the positivist and interpretivist models because these axioms are contradictory and mutually exclusive (Lincoln et al., 2013).

Ontology of constructivism sees realities existing in the form of multiple mental constructs, socially and experientially based, which are local and specific, dependent on the individuals who form them. In the participatory paradigm reality is participative, a subjective-objective reality, co-created by the mind and the surrounding cosmos (Lincoln et al., 2013). In the participatory paradigm it is not rationality that is assumed to be means of improving our knowledge, but experiential subjectivity and practical knowing (Lincoln et al., 2013). In my study influence from the participatory paradigm is primarily seen in the collaboration between

me and the advisory team. I believed lived experiences within the same culture and historical context, expressed in the same language as the participants, would provide the study with relevant perspectives. When it comes to meaning-making process between me and the advisory team, it was co-created, coloured by the team members' experiential and practical knowledge. This is in line with the participatory paradigm with its emphasis on the practical, and the use of a language grounded in a shared experiential context (Lincoln et al., 2013). In a participatory position, researchers prepare to conduct inquiry by initiating co-researchers into the inquiry process, facilitated by the researcher, and learning happens through active engagement in the process (Lincoln et al., 2013). In this spirit the advisory team members were actively engaged in analytical discussion on the transcripts of the twelve interviews, as well as in the part exploring the process and outcome of the service user involvement. They were engaged in the collection and analysing data from our collaboration process, and to closure this process by composing papers as co-authors.

Some researchers embedded in the participatory paradigm claim that constructivists do not go far enough in advocating action to help individuals (Creswell, 2012). However, my present study does not contain an action agenda. I initiated service user involvement in my study based on my assumption that the members of the advisory team hold experiential and practical knowledge, which might help me produce research with a potential beyond knowledge creation and theory building; research with a prospect to more directly benefit clinical practice. Both the constructive and participatory positions require a researcher or facilitator employing an emotional competence, democratic personality and skills (Lincoln et al., 2013), which I strive to achieve. In the following chapter of methodology I will, demonstrate how I “live” my position and assumptions in my research activity.

6 Interpretative phenomenological analysis methodology

This thesis is based on a qualitative experiential study guided by IPA methodology (Smith, 2015; Smith et al., 2009). IPA methodology refers to a theoretically informed framework, a package of elements; guiding theoretical assumptions; recommendations for particular kinds of research questions; ideal methods for data collection; guidelines for data analysis and report writing (Smith, 2015). When I chose the IPA methodology I chose some ontological and epistemological assumptions built into the research. I will try to make these assumptions clear by sharing some practical aspects of my research. To discuss the three theoretical underpinnings of IPA; phenomenology; hermeneutics, and; ideography, I lean mainly towards the book *Interpretative Phenomenological Analysis* by Smith et al. (2009), and the chapters by Ashworth (2015) and Smith & Osborn (2015) in the book *Qualitative Psychology* edited by Smith (2015). The IPA methodology harmonises well with the participatory paradigm and constructivism in most respects. However, I encountered some discrepancies that will be considered.

IPA is a research approach developed and described in the last twenty years, originating in the field of health psychology, to help us better understand human experiences of specified phenomena (Smith et al., 2009). The purpose of IPA research is to understand in detail how people make sense of significant happenings in their lives (Smith et al., 2009). I am interested in what happens when the everyday flow of lived experiences takes on a particular significance and becomes ‘an experience’ of mental health or mental health promotion for persons with mental disorders. Further, what is happening when the members of the advisory team experience that their contribution in the research process is encouraged and of importance? Experience is a complex and challenging concept. Experience may be understood in different levels in a hierarchy, according to Smith et al. (2009). Most elementary, we are constantly caught up in the everyday flow of experiencing, unselfconsciously. When we become aware of what is happening, we begin to step into what can be called ‘an experience’ (NO: en erfaring) as opposed to simply experiencing (NO: å oppleve). This is the smallest unit of an experience in the flow of time according to its unitary meaning. Further, separated by interrupting events, or time, more comprehensive units made up of parts of a life, linked by a common meaning are also called an experience (Smith et al., 2009). Experiences of major significance in the person’s life are often the subject for IPA research. I assumed that mental health and mental health promotion were of significance for persons with mental disorders. The fact that all persons invited accepted participation in the

study supported my assumption. Further, some of the participants told me it was the topic of the study, positive mental health, which made them make the effort to participate in the interview. I believe support for the significance of mental health can also be found in the rich, detailed and various accounts conveyed in an effortless, easy and plausible way in the interview dialogues. The significance of mental health was also seen in the enthusiasm, the engagement and the explicitly spoken support to the topic from the advisory team members.

IPA's first underpinning draws on the work of phenomenological philosophers when it comes to ideas about how to examine and understand lived experiences. The founder of phenomenology, Edmund Husserl (1859-1938), established the importance and relevance of focus on experience. He proposed that the phenomenological method should involve careful examination of experience in the way that it occurred, and in its own terms (Smith et al., 2009). From this came an attention to a return to the things themselves, as experienced. The 'thing' was the experiential content of consciousness (Smith et al., 2009). Husserl rejected anything underlying or more fundamental than the experience and he was particularly interested in identifying the essential qualities of the experience (Smith et al., 2009). Here I can sense a discrepancy between how Husserl understands an essence of a given experience and my assumptions influenced by the constructivists' acceptance of the world as constructed. To me, the knowledge of mental health and mental health promotion might be found in what is experienced in daily life. However, what is accessible to me are the constructed meanings the participants ascribe to their experiences and express to me in the interview.

IPA studies utilize small, purposively selected (rather than through probability methods) and carefully situated samples, based on the epistemological stance that experiences are uniquely embodied, situated and perspectival (Smith et al., 2009). The research questions need to be meaningful to the participant (Smith et al., 2009; Weiss, 1995). In my study, health professionals in our hospital helped me recruit former patients to whom the topic and the questions were relevant and meaningful; in turn their experiences were of interest to me. Smith (1996) claims that the aim of IPA research is to get close to the participants personal world, to explore the 'insider's perspective' of the phenomena we are studying. However, access to the insider's perspective is both dependent on, and complicated by, the researcher's own perceptions which are required in order to make sense of the participants' accounts through a process of interpretative inquiry (Smith, 1996). I endeavoured to come close to the insider's perspective by meeting the participants face to face, I aimed to create a calm and peaceful atmosphere where they felt good about describing their experiences, and keeping my

attention and curiosity focussed on their interpretation of their experiences. An explorative dialogue was required, along with sufficient time for them to express their understanding as freely as possible. I followed up the exploratory questioning with in-depth questions. I tried to scrutinise details with questions such as; “how do you feel this inside, in your stomach?”, “was it followed by something?”, “did you see anyone nearby?”, “what happened afterwards?”, and so on. The participants were given the opportunity to choose the interview location themselves, in order to facilitate data collection in environments that they experienced as comfortable.

In order to be able to examine everyday experience Husserl suggested, according to Smith et al. (2009), a phenomenological attitude which involved and required a reflexive move from our gaze at objects in the world, directed inward, towards our perception of those objects. Husserl invoked the term intentionality to give attention to experience or consciousness as always consciousness of something. To achieve a phenomenological attitude Husserl developed the phenomenological method aiming to identify the core structure of human experience. With my assumptions rooted in constructivism it is not meaningful for me to search for a core structure. However, I sought to arrive as close as possible to a conscious experience by adapting a phenomenological method, putting to one side the taken-for-granted world in order to concentrate on our perception of the world. Included in the phenomenological method is ‘bracketing’, which means the idea of treating separately (Smith et al., 2009). I tried to start the participants’ reflections in advance of the interviews by giving them an information letter about the research topic. In the interview I encouraged the participants become aware of and reflect on how they perceived mental health and mental health promotion. In initial analytical steps I tried to put my knowledge and assumptions to side. I aimed to understand the participants’ accounts through different lenses; I focused on the use of language and the ways in which the content and meaning were presented. I tried to capture objects of concern for the participants, and to understand what relationships, places, happenings, or particular experiences meant to them.

IPA also draws on Martin Heidegger’s (1889-1976) concerns with the conceptual basis of existence, where human being is always a worldly ‘person-in-context’, meaning the person is embodied, intentional actor with a range of physically-grounded (what is possible) and intersubjectively-grounded (what is meaningful) options (Smith et al., 2009). Heidegger emphasized the situated (worldliness) and the interpretative quality of our knowledge. This was also supported by Maurice Merleau-Ponty (1908-1961); a phenomenologist describing

the embodied nature of our own individually situated perspective on the world. Our perception of the 'other' always develops from our embodied perspective, meaning we can never share entirely the other's experience, because their experience belongs to their own embodied position in the world (Smith et al., 2009). Another phenomenologist Jean-Paul Sartre (1905-1980); stresses an action-oriented, meaning-making self-consciousness, which engages with the world. His expression 'existence before essence' indicates that human nature is more about becoming than being. In IPA research the person is viewed as embedded in a world of objects and relationships, language and culture, projects and concerns. In my study, persons previously hospitalized at the Division of mental health and addiction, representing what Patton (2002) calls information-rich cases, were asked to join the study. "Studying information-rich cases yields insights and in-depth understanding rather than empirical generalization" (Patton, 2002, p. 273). I aimed to uncover the meanings the information-rich participants brought to their life experiences. I looked for the complexity of views and equally valid realities, rather than narrowing the meanings into categories. In line with an orientation influenced by the constructivist and participatory paradigm, I believe our understandings are constructed through our lived experiences and through our interactions with other individuals in our environment. I aimed to collaborate with my participants in the interview situation to ensure we were producing knowledge that was reflective of their constructed reality. I was interested in the meaning they attached to what was happening to them; their lived experiences, which I acknowledge as a source of what can be known about reality. However, I saw the outcome of the analytical processes, the co-created knowledge, as one of multiple mental constructs. The creation of knowledge was influenced by the meaning the participants ascribed to their experiences, the advisory team members' experiential subjectivity and practical knowledge from the same culture and historical context, as well as my own background.

IPA's second underpinning is rooted in the hermeneutics; the theory of interpretation. This influence gives the methodology an interpretative position aiming to understand the perspectival involvement in the lived world. Sharing some ground with the person being interpreted, the intersubjectivity, makes us able to communicate with each other, and make sense of each other's accounts (Smith et al., 2009). Friedrich Schleiermacher (1768-1834), according to Smith et al. (2009), argued that everyone carries a minimum of everyone else within themselves. Schleiermacher work was further developed by Heidegger to include complementary hermeneutical activities to those involved in phenomenology (Smith et al.,

2009). The primary aim is to examine ‘the thing itself’ as it appears to us (the phenomenon), a primarily perceptual activity. Building on this, the analytical thinking helps us to facilitate, and grasp, this showing (Smith et al., 2009). Heidegger argues that an interpretation of something is never free of pre-supposition (Smith et al., 2009). In the interviews and in the early stages of the analytical processes I endeavoured to give priority to the participants’ experiences and the meaning-making dialogue they share with me in the interviews. Later in the analysis I included more of my own preconceptions, prior experiences, assumptions and fore-understanding rooted in my personal experiences, education and clinical practice. For me, the aim was to consciously and intentionally focus on the participant’s meaning-making process. Smith et al. (2009) also claim that the complex and dynamic notion of fore-understanding may help us to see a more enlivened form of Husserl’s bracketing, which include both a cyclical process and as something which can only partially be achieved.

The philosopher Hans Georg Gadamer (1900-2002) contributed to the interpretative aspect of IPA through his emphasis on the importance of history and the effect of tradition; interpretation is a dialogue between past and present, aiming not to relive the past, but to learn from the past in the light of the present. The work of Gadamer on the hermeneutical circle of interpretation, including a dynamic iterative process with focus on the relationship between the part and the whole, gives IPA researchers a useful way of thinking about the method of interpretation, claim Smith et al. (2009). In day to day research activities such as reading literature or discussing parts of the study with others, and in the analytical processes, I experienced ‘living’ the hermeneutical circle. For me it was in fact more of a hermeneutic spiral. Smith (2015) claims a double hermeneutics is involved when I am attempting to make sense of the participants making sense of their mental health experiences.

In line with an inductive stance, IPA studies draw meaning from the participants’ accounts rather than imposing a priori constructs on them (Smith et al., 2009). This guided me to approach the topic and the participants with self-consciousness. Before collecting any data, I reflected on the ways in which the theoretical framework, my pre-understanding and assumptions could influence and predispose me to interpret the participants’ accounts. A preliminary literature review rather than an extensive review offered a framework for understanding of the topic area (Creswell, 2009; Snelgrove, 2014). The interviews had been conducted and the analysis process had gone through several stages when a strategy of ongoing, broadening literature searches was made during the process of writing up the findings in papers. Working with data this way; conducting a comprehensive literature review

after analysing the data, is described by Snelgrove (2014) to be an inductive technique. In line with Snelgrove's (2014) experiences, my initial observations produced some tentative interpretations, which in turn led me to create new questions which were then nuanced, confirmed or rejected during further interviews, as well as in dialogue with the advisory team.

IPA's third underpinning, the ideographic commitment to the 'particular' rather than the 'universal', operated on two levels in my IPA research. First, there is commitment to particularity in terms of details. From this follows a thorough and systematic in-depth interviewing and analysis. Second, IPA is devoted to understanding how a particular experiential phenomenon has been understood from the perspective of a particular individual in a particular setting. As a consequence of the ideographical commitment in my study the analytical approach justified a detailed and elaborative investigation of the particular cases.

6.1 The first part – designing an IPA study involving service users

An IPA study was designed to explore the understanding of mental health and mental health promotion by persons with severe mental disorders. I have carefully followed the guidelines presented by IPA experts (Smith et al., 2009; Smith & Osborn, 2015), however, works of other qualitative scientists have also inspired me and influenced my work on this thesis; Kvale & Brinkman (2009) on how to collect data, Graneheim & Lundman (2004) on qualitative content analysis, and Weiss (1995) on the art of qualitative interview studies, as well as Malterud (2011) on qualitative methods and on systematic text condensation (Malterud, 2012), and finally Alvesson & Sköldberg (2009) on reflexive methodology.

At the planning stage of the study, I decided to involve an advisory team of service users in the research process. The recruitment of the team members and our initial collaborations will be presented below. Based on my knowledge of group dynamics, I aimed to have an advisory team of six research advisors. The members of the advisory team are not to be confused with the participants (see section 6.1.2) interviewed as part of my study. Two colleagues were asked to join the advisory team because of their positive attitude to the research topic, their personality, competencies, and their experience with project management. Both of them happen to have family members living with mental disorders. Together we hold extensive experience from collaboration with patients' organizations and from projects, workshops and seminars with individuals living with mental disorders. One of the team members, the manager of psycho-educational family interventions at our Division of Mental Health and Addiction, has a large network of people living with mental disorders, as

well as those close to someone with a mental disorder. The next four team members were purposely selected from this network. I wanted to have both genders, experiences of in-patient treatment, and the perspectives of next of kin represented. An information letter (see Attachments) was given to four individuals and all agreed to become a team member. One advisor decided to leave the team after two years because of a heavy educational workload.

I facilitated meetings between the team and me approximately once a month. The meetings were 2-3 hours in length and organized in two parts. First, we shared orientations and operational matters, while the second part was organized as a workshop. The team's working environment and the structure of collaboration are described in more detail in paper 3 and 4. During our meetings I gave small lectures and we discussed research ethics, the theoretical framework and qualitative methodology. Later in the process we discussed interpretations of research data and worked on drafts of papers. The first assignment we did together proved to fill several purposes. Aiming to provide me with verified information each member was asked to make a personal presentation (see Attachments), that I could make reference to when describing the advisory team in various situations throughout the study. Working on this assignment also turned out to be a systematic process to get to know each other, which increased confidence and predictability in the team. The development of these presentations became a team building tool. The process contributed to the transformation from being individual service users to being a team. My goal was to achieve reflexivity; that we engaged in an explicit, self-aware analysis of our respective roles in the study. This working process also promoted reflections and discussion on important ethical issues (see section 6.4). The presentations were completed after 9 months, although with an understanding of their dynamic character. During the same period we also worked on other topics. My own presentation was discussed first, with a special focus on creating a meaningful structure of the content that all members felt familiar with. The working process included homework done by each member, who would bring back drafts of their presentations to be shared with the team. Information included interests, relevant experiences, perspectives and motivations for participating in the study. The presentations were not exhaustive; in order to avoid stigmatizing personal information we chose to exclude certain relevant experiences such as medication and coercive treatments. These presentations of each member aimed to increase the transparency of the study by giving information about who the advisory team members are. I will argue that this increased the trustworthiness of the entire thesis.

The advisory team gave substantial input to the various stages of the research process associated with their own experience. As a result of the team's input, the wording of the information letter and consent forms was reshaped and clarified in order to be more accessible to the participants. The length of the information letter was discussed and the order of sections was restructured. The team helped me enhance the interview schedule by rephrasing questions and guiding me in use of language. The team emphasised the importance of mastery in mental health, and wanted to add more sub-questions about coping in daily life. Another question was added to the schedule, dealing with situations where the patients are offered resources but are unable to use them due to an adverse situation or increased symptoms of the mental disorder. They pointed to the need for a break during the interview and also introduced the option for the participants to give the interview in two parts. The advisory team's experience proved to enhance my understanding of important aspects of the participants' daily life.

6.1.1 The sample

How could I find the most appropriate and suitable individuals, those who would be able to give rich and detailed accounts of their experience of mental health and mental health promotion? To find these participants, I turned to skilled healthcare providers, mental health nurses and other health professionals working at four in-patient units. Recruitment was organized step by step. After approval from the head of each department I invited myself to a meeting at the unit. I presented the theoretical framework, the study aims and the research questions. We discussed the inclusion criteria and I asked the healthcare providers to think of former patients who would be able to answer the research questions. Before the end of my presentation suggestions for individuals came up. After my visit the healthcare providers identified potential participants, contacted them, described the study and sent them the information letter. All individuals contacted agreed to participate. Thereafter, I got their names and contacted them by telephone to decide on a time and place for the interviews. The participants:

- had had an experience of in-patient care lasting at least two weeks during the preceding two years
- considered themselves as being in recovery
- considered that their lives had improved with the help of mental healthcare services
- were adults and able to narrate their experiences and speak Norwegian fluently

The stepwise recruitment of participants went on without obstacles. The recruitment process aimed to identify the optimal number of participants. In terms of sample size, Weiss (1995) advises that recruitment stops when one encounters diminishing returns and the

participants' experiences are assessed as redundant or peripheral. Further, he suggests ending the recruitment process when the learning outcome from a new participant's experiences adds too little to what one already knows to justify the time and cost of further interviewing (Weiss, 1995). Nearing the time I decided to stop further recruitment I recognized what Malterud (2011) discusses; the experience of a data collection becoming more chaotic and thereby increasing the risk of superficial analysis. I reflected upon my capacity to hold an overview of twelve distinct dialogues present in mind. According to Malterud (2011) the analysis process requires that the researcher has a thorough overview in order to promote knowledge about the breadth, depth, totality and coherence of the data so that it becomes clear what elements are relevant and useful in different contexts. Together with my supervisors we considered the sample after nine interviews and associated case-analyses. We discussed what kind of experiences could contribute to a richer variation. We decided I should try to find individuals over 60 years of age in order to have an older age perspective represented. Furthermore, I was specifically looking for individuals who were in full time work at the time, preferably men. So the sample was expanded with three.

The participants had some common characteristics; they had a severe mental disorder and they have been in-patients at the same mental healthcare hospital, they lived in the same geographical area, within Norwegian society and culture. In a reasonably homogeneous sample it is possible to examine convergence and divergence in some level of detail (Smith et al., 2009). At the same time I wanted to ensure that the sample included variation in terms of gender, age, family situation, whether they were living in rural or urban areas, and whether their income was from work or disability pensions. The participants' age spanned almost every decade: three in their twenties, one in their thirties, two in their forties, three in their fifties, one in their seventies and one in their eighties. All participants except one who worked full time, worked part time and / or received either disability or old age pension, or work assessment allowance from the Norwegian Labour and Welfare Administration.

6.1.2 Presentation of each participant

According to guidelines for IPA studies participants should be purposely selected among the population of interest (Smith et al., 2009). Experiences of hospitalization with a subsequent mental disorder diagnosis, together with experiences of helpful healthcare interventions are the defining characteristics that make my sample homogeneous. Their individual experiences and views will be unique and varied but should form a thematic coherence, like Smith et al. (2009) request. The participants shared generously and talked freely in a straightforward

manner about their experiences. Mental health seems to be an important part of their lives, significant in their situation. Their accounts were relevant to the research questions and they talked about experiences from daily life and from hospitalization. The participants were genuinely interested in the research questions, and enthusiastic about positive mental health and mental health promotion. The participants told me that they felt honoured to have been given the opportunity to put this issue on the agenda, both in research and hopefully in improvements of clinical practice in the hospital. They appreciated the chance to give something back to the healthcare services and knowing that sharing their experiences might contribute towards improvements of healthcare services for other patients. The participants appeared to be free of reservations and did not seem to hold back. The youngest participant came across as exceptionally mature, conscious and more perceptive than other young adults I know at the same age; especially considering the length of her in-patient hospital stays. What strikes me after conducting this study is the potential to be found in all humans. These participants represent an enormous amount of wisdom and prudence about health despite, or because of, their struggles with mental illness. All names are fictive to care for anonymity.

Anna lived with her husband in an apartment building in a rural area. She was a mother of two adult children. Anna loved parties and wrote poems and speeches. She was diagnosed with a bipolar disorder in her early twenties. Since then, she had been hospitalized more than fifty times. She was now heavily medicated prescribed by her psychiatrist. After high school, she has been working part-time on and off. She had lately been engaged to share her service user experiences on educational programmes for people recently diagnosed with a mental illness.

Ruth lived in a house with her husband, one son and a dog. In total, she had three children and five grandchildren. Several of her grandchildren lived in the neighbourhood and they saw each other often. Ruth loved to travel. She and her husband were friends with several couples. She also had a close relationship with one particularly good friend. Ruth was diagnosed with a schizoaffective disorder in her early thirties and she had also struggled with anxiety for many years. She had been hospitalized several times and at the time of the interview Ruth was taking antipsychotic medicine.

Jon lived in an apartment with his girlfriend and her young daughter. Jon loved summer and being outdoors. He had been addicted to alcohol for forty years. He was drunk for the first time in his childhood. He had been sober the last five years and was not on any

medication when I met him. Previous to successful treatment Jon had been strongly affected by his social anxiety; he had lived alone, far from other people. In his twenties, he was in full-time employment. However, his alcohol consumption along with his social anxiety made it impossible to keep working. Jon had been hospitalized and thus received in-patient treatment a total of four times. He was thankful to his girlfriend, appreciated normal everyday life and enjoyed a close relationship with nature.

Guro had struggled with mental illness since she was a teenager. After high school she had been living alone in a small apartment. She had a passion for pets. Three years ago, she was diagnosed with a bipolar disorder. In addition, she had struggled with drug abuse and has been receiving out-patient therapy for five years. When Guro and I met, she had just completed her second in-patient stay and was very satisfied with the treatment she had received. She had learned a lot about how to live with long-term illness. At the time of our meeting she was not using any medication. She had several friends and enjoyed a close relationship with both her mother and her sister. Her brother also had a mental disorder as well as a drug problem. Her dream was to study and one day become a teacher.

Hilde lived alone in an apartment in a city. She loved jazz. She had been struggling with mental illness for several years. She was diagnosed with a bipolar disorder when she was seventeen. In addition, she had other diagnoses; a personality disorder, anxiety, and drug abuse. When I met her she was on antipsychotic medication. Hilde was very shy and had few friends. However, she had some contact with her parents and her siblings in addition to some online friendships. Hilde had received in-patient care several times, both in mental healthcare and in institutions for people with drug addiction. She came across as an optimistic young woman with dreams for the future; she displayed a dedication to and interest in, her own recovery process.

Roar lived on his own in a rented apartment in his father's house, in an urban area. He had several interests such as fishing and outdoor camping, as well as football. At the time of our interview Roar was feeling optimistic about life. He had made up for the many mistakes he made earlier in life. After breaking up with his girlfriend he turned to drugs. He both used and sold drugs, and went to prison for dealing a couple of times. In addition to this, he struggled with mental illness. Over the years, diagnoses of depression, personality disorder, and anxiety had been discussed. He had post-traumatic stress disorder due to his experiences with drugs - a milieu often involving fighting and violence. He experienced this diagnosis as

meaningful. He was now drug-free and sober after successful in-patient treatment for drug addiction. He was not using any medication at the time of our interview. Roar had nearly finished a degree in economics and dreamed of working for an accounting firm in the future.

Marit lived alone in an apartment in an urban area. She had a boyfriend who lived only a bus ride away. Marit had passions for scrapbooking and baking cakes. She volunteered three days a week at a publicly supported centre. Her mental illness had affected her since she was about fifteen years old; she was now diagnosed with schizophrenia and was also working on controlling her bulimia. Marit used antipsychotic drugs and had received in-patient care in a mental health hospital many times. Since finishing secondary school, she had - in her own words - been attending the school of life. Marit had a good relationship with her family, especially her mother and her brother. She was enthusiastic about being involved in a psycho-educational multifamily group together with her mother.

Irene lived with her boyfriend in an apartment in a small village. She had been struggling with mental health problems since she was twelve. She was diagnosed with bipolar disorder when she was twenty. Irene took mood stabilizing medication and she had been hospitalized more than 15 times, often due to depression. She had close ties to her father and her grandmother, in addition to five close girlfriends. After secondary school she got a part-time job in a kindergarten. Irene was interested in culture; music and theatre. She also promoted anti-stigma initiatives through blogging, newspapers and radio.

Paul lived alone in a small apartment. He had a nine year old son, but up until now they had only had occasional contact. Paul loved the weekends when his son came to stay with him. He was also interested in migration birds. Paul has no education beyond primary school. Early in life he became addicted to pills and narcotics. His abuse had impacted on his entire life and he had also been struggling with severe anxiety. Paul had been institutionalized for substance abuse and his latest in-patient stay was a couple of months before we met. The last few years he had been receiving methadone therapy.

Erik was a divorcé who lived in a house by himself. Every other week, his nine year old son came to stay with him. He had a close friendship with the boy's mother, his former wife. He was also close to his parents, his siblings and their children. Erik had always been passionate about sport; he used to be a football player and was now training regularly. Erik completed a year and a half of high school and since then he had run his own business. A couple of years before our meeting he had been in a situation where he was working more and

more and suffered from high levels of stress. When his marriage ended he became severely depressed and suicidal. After a short period in out-patient therapy he said yes to an in-patient stay in the hospital. He was diagnosed with bipolar disorder and started a process focussing on his mind set and values in life. At the time of our interview Erik was working full time as an entrepreneur in a new company. He was focused on trying to find a balance between his enthusiasm for work, his family life and his own needs for rest and recreation.

Kari was a widow, living alone in a small village, in an apartment designed for elderly people. Kari had worked as a chef for 25 years. Her husband died some years ago. She had a close relationship with her two daughters and their families. She would also regularly visit a few friends in the neighbourhood. Kari had a great passion for romantic and historical novels. Late in life, her husband started drinking and had a severe alcohol problem for several years. Approximately 15 years before our meeting she suffered from her first depression. Since then, she had been hospitalized several times, most recently at a unit for the elderly. She started to experience recovery as a result of electroconvulsive therapy. She viewed this treatment as absolutely essential to her recovery process and felt that this treatment was what made it possible for her to lead a normal life again and generally enjoy life. At the time of our meeting Kari was on electroconvulsive maintenance therapy, consisting of one treatment a month.

Dag lived with his wife in a villa on the outskirts of a city. They had one son, as well as several friends they would regularly visit. Dag had spent his entire career working within the public railways system. He was also interested in politics and had a passion for history. He suffered his first depression when his son was born; he was hospitalized and recovered after a year. He had been very active throughout his life and had always been in great shape. He loved cross-country skiing, running in the forest, and riding his bicycle. Recently, he had his second severe depression. After a long period of hospitalization without any positive effects of medication or other treatments, he was offered electroconvulsive therapy. After a few treatments he was back home. Dag was still in recovery, but he now had more energy; his interests in life were back, his mood was better and he was enjoying life again.

6.1.3 The processes of data collection

Qualitative in-depth face-to-face interviews were conducted. This was in line with IPAs idiographic commitment to the detailed examination of a particular case, to be able to know in detail what the experience of *this* person was like, how *this* person was making sense of what was happening to him (Smith et al., 2009). I aimed to get first-person accounts of rich and

detailed descriptions, many variants of lived experiences from daily life and in-patient stays, including thoughts, feeling and stories about mental health and mental health promotion.

Interview schedule: The interviews were guided by a semi structured interview schedule (Smith et al., 2009). The schedule (see Attachments) evolved inspired by the theoretical framework, experiential knowledge from the advisory team, guidance from my supervisors and not at least my own clinical experiences and professional training in nursing science, psychiatric nursing, along with my enthusiasm for positive mental health and health promotion. However, the main input to the development of the schedule included topics corresponding to the research questions and each topic had potential follow-up questions. I experienced that thorough work with the research questions and the interview schedule enabled me to facilitate a comfortable interaction, aiming to come as close as possible to the richness of the lived experiences held by the participants. Working on the schedule helped me become familiar with expansive and open questions, encouraging the participant to talk at length.

Interviewing: The day before each interview appointment I called the participant to confirm our meeting. For the interview I brought with me the information letter, the informed consent form, the audiotape recorder, the interview schedule printed on paper and a ceramic cup. People feel more comfortable when they are in locations they are familiar with (Smith & Osborn, 2015). The participants were allowed to choose themselves where the interviews would take place. Four chose their own home, and three participants met me at the research department at the somatic hospital. Two participants were interviewed at my office, one in a room at the hospital and one at a café. One of the twelve participants had a desire to conduct the interview while we were walking in a recreation area in the city. This idea came up after the third interview. All participants were asked to talk about the experience of being interviewed. One of the participants experienced no difficulty with our dialogue, but he disliked sitting by a table in a room with me. It took him back to the therapy sessions with his therapist. We discussed the possibility of conducting an interview outdoors, walking in nature. He appreciated the idea. This was discussed with the advisory team, who supported it. As a result, the other participants were all given this opportunity. One of the next participants was happy to have the interview conducted outdoors.

IPA requires verbatim recording of the interview situation (Smith et al., 2009). The dialogue in my interviews was captured on a small audiotape recorder. The microphone was

excellent, and the sound on the tape was very good. Having audio recordings made it possible to get my supervisors' feedback on the interviewing itself, and also to share audio excerpts with a supervisor in the process of analysis. Using a video camera was considered not to add any more information in this study, taking into account the use of individual interviews and not a focus on interaction between persons. At the end of the interview the participant was informed about the proceeding research process and the thesis. Four of the participants wanted to be contacted after the study and to receive the published thesis.

In order to get close to the participants personal world, to get access to the insider's perspective, it was my responsibility to facilitate a good interviewing partnership and promote a supportive, safe atmosphere. I tried to meet each person with warmth and positive curiosity, and to express my belief that the interview would bring unique information and knowledge. The purpose was to enable the participants to relax and feel comfortable, to promote what Smith et al. (2009) request; a movement from the descriptive to the affective, from the general to the specific in the dialogue. This endeavour aligns my practice with IPA's commitment to seeing the person as a cognitive, linguistic, affective and physical being, and assuming a chain of connection between their verbal expression and their thoughts and feelings (Smith & Osborn, 2015).

One of the interviews conducted in the participant's own home was done with the spouse present. For me coming as a visitor into their home, there was no option but to include her. The participant wanted her to be present, and I saw this situation as providing more information about him and his context. He was defined as participant, and the dialogue was primarily between him and me. However, he was seeking support for several of his statements from his wife. This gave me additional data, which according to Smith et al. (2009), might contextualize the interview.

Transcription: IPA analysis aims to interpret the meaning of the content of the participants' account. It requires a semantic record of the interview, meaning that all words spoken by everyone present must be included in the transcript (Smith et al., 2009). The first interview was transcribed from the audio tape by me. I could not find that this procedure added anything substantial to the analysis process. It was time consuming, and all my focus was on the accuracy of the transcript. I couldn't at the same time manage to listen to the content of the dialogue. From there on the interviews were transcribed verbatim by a skilled typist. This required a quality check by me to validate the transcript by adding missing words

and correcting misinterpreted phrases or words. The level of details in the transcription is inspired by phenomenological spirit of turning back ‘to the things themselves’, and to preserve the semantic content (Smith & Osborn, 2015). As a consequence the dialogue was transcribed verbatim, using the same words that were spoken, including “hm-s”, pauses, and repetitions.

6.1.4 The analysis – individual cases and patterns across cases

The analysis was mainly motivated by an IPA approach (Smith et al., 2009), which involves a combination of phenomenological and hermeneutical insight, guided by an idiographic sensibility toward particular instances of lived experiences. Moreover, the work of Weiss (1995), Vinje (2007) and Malterud (2012) inspired the analysis. The IPA methodology guides researchers to come as close as possible to the participants’ perceptual experiences as they appear to them and with help of analytical thinking, facilitate and grasp the phenomenon. As such, analysis inevitably becomes interpretative (Smith et al., 2009). The IPA approach helped me direct an analytical attention towards the participants’ attempt at making sense of their experiences.

The analytic process of IPA is characterized by a healthy flexibility, rather than a prescription of a single method for working with qualitative research data. However, Smith, et.al (2009) present a step by step unidirectional guide to conduct IPA analysis, aiming to promote a sense of manageability and order, which may be useful for novice qualitative researchers. The analytical approach in the present study included two different levels. First, a case focused analysis of each of the twelve interviews was carried out, secondly an issue focused analysis. The purpose of the case focused analysis was to gain knowledge about mental health and mental health promotion by understanding how each participant makes sense of his/her lived experiences, both in daily life and during hospitalization. The purpose of the issued focused analysis was to find patterns of recurrence across cases, as described by Smith et al. (2009). These two levels of analysis will be described below, as will strategies for an inductive and iterative analytical process presented by Smith et al. (2009).

Analysis of individual cases: The ideographic focus of IPA made me focus my attention on the particular experiences of each participant. The analytical process begins with a detailed examination of each case (Smith et al., 2009). A stepwise analysis during data collection was used, as described by Malterud (2012) and Smith (2009). I conducted the analysis (as described below) of the interview data from my first participant, after which I was ready to

collaborate with the next participant. The same process was repeated before I contacted the third participant, and so on. One interview informed the next. The case focused analysis process might end up with new questions, which can be elaborated further in the up-coming interviews. This improved my overview of the interview data and became a mean to increase the possibility to focus on the aim and the research questions, like Malterud (2012) suggests. This strategy can prevent the “1000-pages problem”, conceptualized by Kvale & Brinkman (2009) where a huge amount of data, sometimes irrelevant data, can hide important knowledge. Such a situation could overload the researcher with text, making it difficult to achieve a thorough, transparent and responsible analysis.

The case focused analysis proceeded as a hermeneutical process, going back and forth. The process of analysis starts as soon as there is data (Weiss, 1995). In these first stages of the analysis the emphasis is on eliciting the views of the participants, while the views of the researchers are of secondary concern. Like Biggerstaff & Thomson (2008) recommend, I tried to suspend my presuppositions and to focus on what was actually presented by the participant in the dialogue. To promote a reader-friendly presentation each step of the case focused analysis is marked by bold font.

First, in the interview dialogue I developed insight, some new questions and probably some pre-cognitive ideas which I brought with me to the analysis. **Second**, immediately after the interview was conducted, I wrote down my thoughts, ideas or aspects that made me curious. **Third**, I turned to the audiotape. I proceeded by listening to the dialogue again and again, at least five times for each interview and for some up to nine times. This became an important way for me to ‘turn to the things themselves’, as prescribed in phenomenology. I listened to the audiotapes while jogging or cross country skiing, and I found this very valuable. Revisiting the dialogue in these calm and pleasant surroundings helped me gain a sense of internal ‘dialogue-singing’ that gave me a coherent overview of the interview. I became familiar with the tone, the pronunciation, the pauses, the small linguistic details, intonation and how the syntax changed through the conversation. Listening to the audiotape again and again helped me re-capture the emotions, mood and atmosphere, and I could see before my inner eye the participant’s body language. I ended up knowing the conversation very well, which made validating the transcript from the typist easy. Repeated listening promoted an ongoing analytical process in my mind, with insights arriving throughout the day. Being occupied with other tasks in the study was helpful in creating distance to the material and giving my thoughts time to crystallize, as described by Hale et al. (2008).

Fourth, the transcribed text of the interview dialogue was transferred into a table with three columns; see paper 1 for an illustration. The column in the middle contained the transcript. The column to the left was for my exploratory notes. The column to the right was for notes about emergent themes that were the outcome of a process of description and interpretation, aiming to capture and reflect an understanding. I went through the written transcript, line by line, still with the dialogue clearly and prominently present in my memory. Based on this close reading I wrote down my immediate reflections and comments aiming to produce a comprehensive and detailed set of exploratory comments on the text. IPA distinguishes between ‘descriptive comments’, ‘linguistic comments’ and ‘*conceptual comments*’, the second type marked with underlined letters and the third with cursive in the table text. The descriptive comments aimed to describe content; they summarised what the participant told me; the content of what was said. The linguistic comments were about the use of language and the ways in which the content and meaning were presented. The use of pauses, laughter, repetition and tone was noticed, and functional aspects of language reflected on; for instance, was it ironic? The use of metaphors was commented on, which seems to be a helpful linguistic device when describing experiences hard to explain with everyday language. The conceptual comments written in a questioning style, opened up for reflection. The descriptive, linguistic and conceptual comments I made on the transcript were examples of IPA’s phenomenological attitude. The comments had a descriptive clear phenomenological focus on staying close to the participant’s meaning. I committed myself to put aside my assumptions, and adopting a phenomenological attitude of ‘going back to the things themselves’. The data collection and my exploratory comments were participant oriented. In this fourth step, I gave myself a more central role in organizing and interpreting the data.

In the **fifth** stage, I turned to the research data set that had grown substantially, extended by my comments and annotations. This large data set informed the process of developing emergent themes. The more questioning and abstract style of thinking moved the analysis beyond the superficial and purely descriptive, and brought interpretative elements to the analysis. Each step of the analysis took me further away from the participant and included more of me and later also the perspectives of the advisory team members. Looking for emergent themes involved a shift to work primarily with my notes and comments, rather than the transcript itself. Identifying emergent themes included a recall of what was learned from the process of listening and initial note taking. The narrative flow of the interview was broken up and the original whole of the interview became parts of the participant’s experiences; these

would sometimes, however, come together in another new whole further along the analysis; a manifestation of the hermeneutic spiral.

At the end of the **fifth** stage, I applied the software NVivo 10²; a tool to organize, classify, sort and arrange texts. NVivo 10 made it possible to link transcript excerpts from the interview dialogue to nodes, as illustrated in Figure 3.

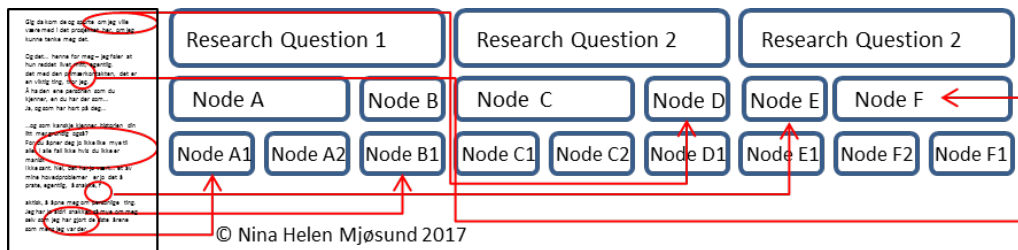


Figure 3: Excerpts from transcripts were organized into nodes in NVivo

A node is a collection of references, like transcript excerpts about a specific theme or area of interest. I gathered the references by “coding” sources; the twelve interviews. Coding was a way to link excerpts from the transcript to different nodes. The nodes were labelled by me and reflected what I thought was essential in each node. Under these “mother” nodes were “child” nodes created. I like the metaphor of a chest of drawers used by Malterud (2012). Each drawer or node got a preliminary label indicating what was in it. Different materials that dealt with the same issue were brought together, regardless of where in the interviews the excerpts originated. NVivo made an active link to the full transcript so that an excerpt easily could be tracked back to its original context. The same excerpt could be stored in several drawers or nodes if appropriate.

In the **sixth** stage, still working with the transcript, I went into the coding and took advantage of the use of NVivo. I created, organized and labelled the nodes inspired by the research questions, theoretical framework, my training, clinical experience and my collaboration with the advisory team and supervisors. Several of the nodes were relabelled, some were merged together or new child nodes created, throughout the analysis of the twelve cases. The sorting and organizing of the transcript excerpts in this coding process facilitated the next analysis level: the issue focused analysis. Transcript excerpts from several participants concerning the same issue were stored in the same drawer, under the same node.

² NVivo; computer software for qualitative data analysis designed for researcher by QRS International 2012

Analysis of patterns across cases: The next level of analysis involved looking for patterns and recurrence across cases (Smith et al., 2009). This level involved a recall of what was learned through the process of case focused analysis conducted on all twelve cases. I shifted from reading, coding and annotating on transcripts to reading and coding on excerpts from twelve participants on specific issues. The process was illustrated more in details in paper 1.

First, identifying emergent themes across the cases required a focus on the excerpts together with the exploratory notes. The emergent themes could consist of statements of what was important in the excerpts or in attached comments, a concise and pithy statement as Smith et al. (2009) put it. The theme usually expressed some of the content of the excerpts and contained enough particularity to be grounded and enough abstraction to be conceptual (Smith et al., 2009). The emergent themes reflected not only the participants' original words but also my interpretations of them, as I aimed to capture and reflect an understanding of the meanings expressed. The outcome of the analysis so far was a set of emergent themes ordered chronologically in the order they came up, first by participant A, then participant B and so on.

In the **second** step of the issued focused analysis I took advantages of the Mindjet MindManager 2012 to develop charts (see Figure 4), to display visually the patterns of themes and emergent themes independent of chronology. MindManager helped me make figures, mind maps, point out connections and interrelationships. Figure 4 is an illustration taken from the analytical process towards the findings presented in paper 1. Smith et al. (2009) encouraged researchers to be innovative in terms of organizing the analysis, as well as in graphic representation of the structure of emergent themes. Illustrations showing my interpretations were useful for collaboration with supervisors and the advisory team.

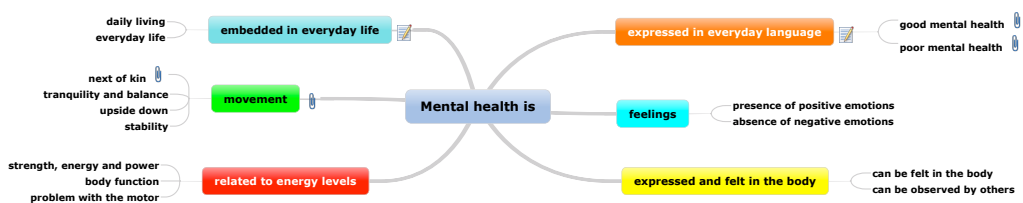


Figure 4: Example from the analytical process with the use of MindManager

The guiding principles of Smith et al. (2009) to develop what they labelled superordinate theme were adapted. In my study the superordinate theme were called theme.

The theme were evolving as a result of putting like with like and look for patterns and connections to develop a new name for this cluster, a process called abstraction (Smith et al., 2009). In the NVivo language the child nodes could be abstracted and become mother nodes. Subsumption was a principle used to identify emergent themes that themselves acquired a superordinate status. The emergent theme became a theme as it helped bring together several related emergent themes. In NVivo language I merged a node into another node, the content of at least two drawers were put together, and the new node kept the label of one of them. To look for oppositional relationships between emergent themes the focus was upon differences instead of similarities, a principle called polarization by Smith et al. (2009). An example from my study was the understanding of close relationships to family members as mental health promoting for the majority of the participants. However, some experienced these relationships as devastating for them. I also used the principle of contextualization. I looked for connections between emergent themes by identifying contextual or narrative elements. Emergent themes, which relate to particular narrative moments or key life events, were studied together. This presupposes knowledge of the participants' context and of the whole interview transcript. I looked for connections and patterns related to each participant's special interests, their passion in life. Numeration can be one way of indicating the relative importance of some emergent themes (Smith et al., 2009). Numeration guided me to take account of the frequency with which a theme was supported. An example can be the presence of joy and happiness as an important factor in perceived positive mental health. These emotions were described by all the participants several times. Another guiding principle used was function. Emergent themes can be examined for their specific function. In my analysis the need for social support can also be interpreted as an opportunity to give or fulfil the role of being a significant other.

6.1.5 Involving the advisory team in parts of the analysis

Multiple perspectives were brought into the analysis by including the interpretations of the advisory team members. The aim of bringing several perspectives into the process of analysis was to create a wider analytical space, rather than consensus and validation as explained by Malterud (2012). Our collaboration revealed that the capacity to understand the participants' experiences was increased when several people were conducting the interpretations together. The advisory team members hold useful experiences from struggling with similar illnesses, living in the same geographical area and receiving healthcare services from the same Hospital Trust at the same time period as the participants. Their experiential knowledge was of

significance for our IPA inspired analysis, with roots in descriptive and interpretative philosophies that emphasise understanding experiences ‘what is’ as temporal (time) and contextual (place) (Smith et al., 2009).

After nearly three years (35 months) of collaboration we became aware of the fact that our experiences had the potential to extend the knowledge base on service user involvement. In turn, while conducting my study, the second objective of this thesis (see Table 1) came to the surface. The objective led us to find a research design and analytical techniques that could help us document and disseminate our experiences. We found the method in case study research.

6.2 The second part – designing a case study

Qualitative research procedures are inductive, emerging and shaped by the researcher’s experience of collecting and analysing data (Creswell, 2012), a phenomenon also experienced in the present study. After discussions with my supervisors, I decided to include a second part of my study. Here the purpose was to explore the process and outcome of the applied service user involvement in the first part of the study. The tentative publication plan required consideration, as outlined in the introduction (see section 1.2). I had a desire to understand the complex process of collaboration within the advisory team, as well as between me and the team, as it was occurring. Case study research would be the preferred method in contemporary (as opposed to historical) real-world situations when the objectives are posed by ‘how’ or ‘why’ questions (Yin, 2014). Case study research begins with the identification of a case. This might be an individual or a small group which is involved in a specific process or projects (Creswell, 2012). I wanted to perform participatory research involving service users in order to collect, present and analyse data of our collaboration process thoroughly, and to end the case study by publishing papers. In doing so, Yin’s guiding principles (2014) were helpful for me.

6.2.1 The case

In case study design, the case or the unit of analysis is of utmost importance (Yin, 2014). Our case was defined to be the collaboration process between the advisory team and me from the start until the end of the research process of the study presented in this PhD thesis. Case studies present an in-depth understanding of the case, which is described within certain parameters such as a specific time and place, sometimes called ‘bounding’ the case (Creswell, 2012; Yin, 2014). Case study research is preferred when investigating a contemporary event

(our collaboration process) and relevant behaviours are not manipulated as in an experiment (Yin, 2014). The bounding of the case's social group (the advisory team and me), the organization (Vestre Viken Hospital Trust), and geographical area (Norway) helped us to recognize the priorities for, and scope of our data collection. We were collecting data produced along the collaboration process so far retrospectively, as well as exploring our own experiences of this process. Research data were developed further and analysed while we proceeded throughout the case study towards the publication of our experiences.

6.2.2 Who are the researchers?

In this part of my study I was still the principle researcher, the one who initiated and facilitated the working processes, decided what to do and when to do different operations. However, to me it was important to continue the service user involvement and to bring the advisory team actively into this part of my study too. We collaborated both on data collection and in the analysis. The role of the supervisors was more traditional; they oversaw the design, advised me in my choices and gave guidance throughout, until they more actively participated in writing the papers. I was also fortunate to receive a grant that made it possible to employ a member of the advisory team in a 20 % position for six months. She was then able to contribute more actively in searching and collecting data, and together with me she prepared the data for analysis.

6.2.3 Data collection

The use of multiple sources of evidence for an extensive data collection is recommended in case study research (Creswell, 2012; Yin, 2014). Case studies explore current, real-life cases that are in progress so that researchers can gather accurate information not lost by time (Creswell, 2012). In our case study we identified several sources of evidence, both retrospective sources already recorded, as well as sources of data deliberately created, which enabled us to describe how we formed our collaboration and how service user involvement influenced the outcome. The shifts between historical, current and future data creation facilitate the construction of an understanding. Multiple forms of qualitative data are suggested, such as interviews, documentations, direct observation and participant-observations, audio-visual material and physical artefacts (Creswell, 2012; Yin, 2014).

In our study, interviews, participant-observation and documents were sources of evidence. I had taken care to write announcement and minutes of meetings, notes from sessions with supervisors and abstracts of discussions from workshops with the advisory

team, which now came in handy. These documents constituted three sources: First, two notes from supervisors meetings including my reflections, representing an out-side perspective on the collaboration process. The second source was the minutes of meetings and abstracts from workshops with the advisory team, representing an inside-perspective of the collaboration process. Minutes of eight meetings from 2012, seven in 2013, nine in 2014 and eleven in 2015 were approved by the advisory team members and analysed for the writing of the papers. However, the collaboration continued in 2016. Altogether 43 meetings have been conducted. The collaboration process will reach a natural end when the thesis is submitted for review at NTNU. Third, we collected a paper written by the advisory team in a journal (Portaasen, Haaland-Øverby, Jensen, Kjus, & Norheim, 2015), a note published by a journalist on a website about our collaboration (Fleiner, 2014), three posters, as well as the manuscript of three oral presentations from international and national conferences.

I facilitated and chaired four multi-stage focus group interviews (Hummelvoll, 2008), with the advisory team, more thoroughly described in paper 3. The interviews were guided conversations with a consistent line of inquiry with focus on ‘why’ questions instead of ‘how’, emphasizing reflection to promote comprehensive arguments. In the focus group interviews we created research data based on the insider’s perspective; participant-observations of the collaborations process with special attention to values, atmosphere, actions, and working style. We became investigators in a case study of our own process. Like Yin (2014) elaborate on, we assumed a variety of roles within a fieldwork situation and participated in the actions being studied. There may be no other way to produce an accurate portrayal of the case study phenomenon, according to Yin (2014).

We collected evidence through participant-observation to obtain the inside viewpoint of service user involvement and how the users themselves perceived how they were strengthened and encouraged to make significant contribution to the research process. As displayed in details in paper 4, we also gathered data from our analytical discussions in the first part of the study. The advisory team collaborated with me on transcripts from interviews with the participants to analyse preliminary themes more in depth. These discussions were audiotaped and transcribed. One advisory team member listened to the audiotape and identified part of the discussions which could illustrate how the advisory team contributed to the analysis. These transcribed paragraphs were interpreted together with me and later discussed with the rest of the advisory team and the supervisors.

The data collection and the analysis presented below were inspired by our salutogenic orientation, as well as by Appreciative Inquiry (Ludema & Fry, 2008; Zandee & Cooperrider, 2008). An appreciative stance aimed to counterbalance the perceived predominance of a deficit discourse as manifested in a focus on problem-solving, human pathology and negative organizational performance (Zandee & Cooperrider, 2008). To take an appreciative stance in our inquiry for us means utilizing a strength-based approach with focus on possibilities. We challenged ourselves to value the full spectrum of our experiences to overcome our tendencies towards reductionist thinking in either/or dichotomies, and to be biased towards the good, the better, the exceptional, and the possible, as Zandee and Cooperrider (2008) put it. A constructionist worldview is embraced and the reality is seen as limitless potential. Appreciative Inquiry emphasizes that organisations and social structures (in our case the structure of our team) are products of human imagination and interactions, and that the truth is multifaceted and impermanent (Zandee & Cooperrider, 2008).

6.2.4 Analysis

According to Creswell (2012), a description of the case is a key to understand the analysis. In our study the minutes of meetings, abstract, notes and manuscripts were mainly the sources for the description of our collaborations process, primarily presented in paper 3. The techniques in analysing case study evidence have not been well defined, however we took inspiration from some general strategies suggested by Yin (2014). We also took advantage of computer-assisted tools such as NVivo and MindManager to assist us in the analytical discussions. We started to play with our data and search for important concepts, insights and common meanings. The advisory team members were asked to put upcoming memos in writing in between workshops to aid the reflections and discussions when we were gathered. Identified themes or issues or specific situations uncovered should be organized into a chronology, claims Creswell (2012). As such, we tried to review our data chronologically, as well as that related to specific events or specific processes as the development of a poster for a conference. We analysed from the ground up; we categorized, examined and recombined data to develop our insight. Sketching and drawing to suggest connections and express our meanings became very helpful for us in displaying and presenting the findings. The results of this process can be seen in several illustrations in paper 3 and 4. This inductive strategy had similarities with the IPA analysis conducted in the first part of the study. We applied an overall analytical strategy where we turned our attention to analysing the causes of moments we considered to be successful (Ludema & Fry, 2008). We searched for things that worked

for us, experiences of high points or positive moments in the collaboration. We were not preoccupied with failures, obstacles and problems. We actively and deliberately used our salutogenic orientation to discover strengths, assets, values, capacities and principles that promoted positive influences on us as individuals and as a team. Appreciative Inquiry invites stakeholders “to inquire into the-best-of-what-is-and-can-be” (Ludema & Fry, 2008, p. 294). We requested views from each other that could broaden and extend our understanding, as opposed to a more reductionist approach to the data. The analytical strategies complemented each other; the work on data from the ground up together with looking at our data through salutogenic glasses became the analytical path, which promoted insight and understanding. This combination of strategies can yield appreciable benefits; by giving a voice to both to individuals experienced in salutogenesis and to individuals less familiar with this approach. Also in these analytical endeavours the power of multiple perspectives was experienced.

6.3 Reflexivity - in relationships and in meaning-making processes

Reflexivity contributes to knowledge production, provides insight into how the knowledge is produced, and is based on the human ability to reflect on the past and the future and to transcend the present (Pillow, 2003). Reflexivity in the form of clear and specific considerations of how the researcher is likely to affect the study is an important part of the transparency of research (Yardley, 2015). The distinction between ‘reflective’ and ‘reflexive’ is important; to be reflective does not demand an ‘other’, while to be reflexive demands both an ‘other’ and some self-conscious awareness (Pillow, 2003). Reflexivity is applied in different ways; in some studies as more of a ‘box ticking’ technique, while in others as a coherent, all-encompassing presence - an operating mode. I wanted to use it as the latter, in other words, as described by Pillow (2003) as a methodological tool to produce more accurate research and to represent, legitimize or call into questions the findings.

Writing the thesis gave me the opportunity to examine how my presence and my attitudes influence the subject, a practice termed ‘reflexive writing’ by Pelias (2013). Used in writing, reflexive strategies may include discussions on how the researcher emerged as a contaminator, or how the researcher’s insider status was revelatory or blinding (Pelias, 2013). Working with my study, I have several times wondered how my own enthusiasm for a salutogenic approach could influence the research. My assumptions are grounded in the theoretical framework and resonate with events and lived experiences from my life. How do these assumptions, mostly unconsciously, contaminate or colour the relationships, the

dialogues, what I hear and see, and what I choose to put into writings? While interviewing the participants, I tried to confirm their initiative to articulate their understanding by nodding, smiling, giving positive response, and not rush the next question. Throughout the research process I have acknowledged the influence I may have on the participants' meaning-making process, and worked in the direction to make it explicit in this thesis. As Pelias (2013) explains, I have thereby tried to convince the reader to trust my sensitivity to these issues. However, I argue for a salutogenic orientation as an adequate and necessary way to help me obtain access to how the participants try to make sense of their experiences. My positive and affirmative attitude was significant, as one of the participants conveyed to me.

Hilde: *I'm not a person who tends to talk. I'm shy. I can't verbalize at all. I just feel silly.*

Nina: *How wrong you can be about yourself!*

Hilde: (laughs) *However, I choose to listen to you. I see that you smile, and that helps.*

Another strategy in reflexive writing, according to Pelias (2013), is to claim that the researcher's insider status indicates that he/she shares cultural membership with the group being studied. In this thesis, I revealed in the presentation of myself my clinical practice over many years with people struggling with mental disorders, as well as my personal experiences as a relative of someone with mental illness. I described some characteristics of me and my life story assuming the information would give the reader confidence that I am able to grasp the participants' attempts at understanding their experiences of mental health and mental health promotion. Understanding another person's point of view or situation involves finding commonalities; as such reflexivity was used to situate myself closer to my study participants.

I have also explained and justified the selection of the advisory team members based on their experiences of living with similar mental illnesses, within a time frame and context similar to the participants', assuming they could help me understand the participants' interpretations of their experiences. The shared cultural membership with the participants was assumed to be a methodological tool to enhance transparency, insight and understanding of the participants' experiences. Research collaboration with service users has been described as a valuable way to stay open and aware, as an aid in reflexivity (Veseth, Binder, Borg, & Davidson, 2017). Further, I organized the examination of the service user involvement together with the advisory team, a process described in paper 3 and 4. Studying our own experiences involved several discussions including individual reflection on our own perspectives and our relationship to each other. I experienced self-reflexivity growing out of these discussions, motivated and strengthened by the upcoming co-authorship in papers 3 and

4. I facilitated the co-authorship of the advisory team members in these papers, inspired by the trend described by Pillow (2003) of ‘multivocal’ texts and letting the members speak for themselves. However, these actions are also to be reflected upon. Reflexivity has limitations and I cannot be free from the consequences of my positions by talking about them.

Reflexivity is also a contested methodological concept, subjected to deconstruction (St.Pierre, 2013). Pillow (2003) identifies and discusses problems in four common trends in reflexivity: reflexivity as recognition of self and as recognition of the other, reflexivity as truth and reflexivity as transcendence. These strategies are dependent on each other and work together to provide the researcher with a form of self-awareness; ‘researcher know thyself’ (Pillow, 2003). For me, reflexivity was a way to increase my attention to subjectivity and self-reflexivity, which helped me recognize an otherness of self and the self of others. Whose story is it – the researcher or the researched, asks Pillow (2003). For me, influenced by the postmodern constructivist understanding of both myself and the participants as multiple, unknowable and shifting, I am not sure about how reflexivity influences my knowledge of the subjects. However, if reflexivity increase the ability to recognise where the attempts of the participants to make meaning of their experiences end, and where interpretations of them begin, then it is worthwhile to actively become more self-reflexive. I see the claims in my study as a joint product of the participants and me together with the advisory team. In the collaboration with the advisory team it is of relevance to be reflexive on where the members end and where I begin. Embedded in the collaboration with the advisory team are relationships of power; who sets the agenda. Is it possible to create an atmosphere where multiple views and different perspectives have the same value?

Reflexivity as recognition of the other is a form of reflexivity on how I am able to know and understand the other. It may be used to point to the limits of representation of the other. I asked myself how I could be able to understand my study participants and the advisory team members. Was it possible to let them speak for themselves through me and my interpretations? One validated strategy to approach this problem described by Pillow (2003) and used in my study, is to make it evident how the advisory team members participated in making their own stories and images together with me. In the case of the latter, they co-created models and illustrations and they co-authored paper 3 and 4. However, their conditions to speak for themselves are limited by my primary author position where I lead the writing process and therefore necessarily coloured the wording of claims and illustrations in the papers. Another issue is about how power is distributed in our collaboration; the normative expectations are about giving the service users more power. However, in my study

we tried to be open about how power is distributed in the various stages of the research process; from no contribution from the team to complete control by the team in the individual essay writing sharing their experiences (Portaasen et al., 2015). I would argue that we experienced what Veseth et al. (2017) claimed; service user involvement can enhance a reflexive practice in research, and that reflexivity can help maximize the potential of the collaboration.

‘Reflexivity as truth’ supports the idea that the researcher can ‘get it right’ says Pillow (2003). Underpinning this is an assumption that in the spoken word we know what we mean, mean what we say, say what we mean and know what we have said (Pillow, 2003). I will argue that my reflexivity can make me more self-reflexive, my research more valid, more truthful and increase the transparency of how I have tried to capture the voices of my participants. However, reflexivity will not make me able to grasp the truth, simply because I believe in multiple mental constructs of the reality and thus there are several truths.

‘Reflexivity as transcendence’ is a common strategy based on an assumption that the researcher through reflexivity can transcend her own subjectivity and cultural context in a way that releases her from (mis)representations (Pillow, 2003). We should rather engage in an uncomfortable reflexivity – a reflexivity that seeks to know, yet at the same time considers this knowing tenuous, according to Pillow (2003). My aim has been to use reflexivity while I acknowledge its limits. If I have succeeded the transparency has improved, and therefore the quality of my study.

6.4 Ethical considerations

Ethics are described as standards of conduct or social norms that prescribe behaviour (Resnik, 1998). The ethics of science are, like all standards of conduct, relative to the particular society or culture that happens to accept these standards (Resnik, 1998). Similarly, the Norwegian Health Research Act (2008) provided the legal framework for my research. As an authorized nurse I am obliged to follow the codes of ethics relevant to my profession in nursing and in research (Norsk Sykepleierforbund, 2001). In this study I comply with the guidelines drawn by The Norwegian National Research Ethics Committee for medical and health research (NEM, 2014). The ethical approval (2012/566 B) for this study was obtained from the Norwegian Regional Committees for Medical and Health Research Ethics (REK). Throughout the qualitative research process reflection on and review of the ethical practices are important (Creswell, 2009). For me, this involved adopting reflexivity as an ethical practice, as Hem (2015) requests. Reflexivity is a helpful conceptual tool for understanding both the nature of

ethics and how ethical practice in research can be achieved (Guillemin & Gillam, 2004). My eagerness for discussion around ethical issues was part of my ambition to make my research as transparent as possible. Therefore this section is closely linked to my discussion on reflexivity (6.3) and validity (6.5). Ethical concerns or dilemmas, called ‘ethically important moments’ by Guillemin and Gillam (2004, p. 262), arose throughout the research process of my study, in addition to those I had already identified in the research plan. I discuss some of the day-to-day ethical issues here; first those related to the part of my study exploring mental health and mental health promotion through the interviews of twelve people with mental disorders. Second those ethical issues relevant to the part of my study exploring the process and outcome of service user involvement. Discussing my ‘ethics in practice’ (Guillemin & Gillam, 2004, p. 263) is one way to make my ethical competence transparent in this thesis.

6.4.1 Ethical reflections associated with the participants

An information letter (see Attachments) addressing the study’s aim, design, and procedures for publication were given to potential participants by health providers who knew them. The purpose of the letter was to provide information that would make potential participants able to give informed consent. This is seen as a cornerstone in ethically acceptable mental health research (Hem, Heggen, & Ruyter, 2007). The study’s purpose was described in this letter, and the wording was developed together with the advisory team. The aim was to avoid what Creswell (2009) describes as deception, and therefore tried to present the purpose of the study in a way that would ensure it was understood as intended. Further, the information letter provided information on how the participants’ anonymity would be protected in the data analysis, interpretation and in dissemination of the research in papers and presentations. Verbatim extracts of the participants’ contributions have been published but edited for anonymity. I did not offer confidentiality in the sense that no one else would see the transcripts. In this study, both the advisory team and the supervisors saw parts of the transcripts, however always anonymised. Anonymity is all that qualitative researchers can offer (Smith et al., 2009). In the process of writing this thesis I have considered whether or not to present the participants using what Kvale and Brinkmann (2009, p. 263) call ‘thick description’. Generalization relates to an analysis of the similarities and the differences between the original research and future application of it; the attributes compared need to be relevant, which presupposes rich, dense, and detailed descriptions of the participants (Kvale & Brinkmann, 2009). I chose to use ‘thick descriptions’ of the participants. However, in order to

enhance confidentiality I used fictive names and omitted the age of the participants in the presentation (see section 6.1.2).

People living with a mental disorder are in several ways considered to be vulnerable (De Nasjonale Forskningsetiske Komiteer, 2005), which requires considerations from me. According to Hem (2015) the vulnerability might be a disqualifying factor or it might constitute a potential, it depends on the situation and the context. The participants purposively selected for my study were living with a mental disorder and therefore might be seen as vulnerable. However, their experiences are of importance in research, precisely because it is from these that new knowledge can be gained about my topic. To me it was therefore imperative to be cautious, and conscious of safeguarding the participants' interest. Each participant's decision-making capacity was assessed by their therapist at the time of recruitment. The participants were given the information letter by their healthcare provider in advance, before my first contact with them. This was a deliberate time delay to facilitate a process of consent, as recommended by Hem (2015). On the day of the interview, several days after they got the information letter in writing, I started the interview by orally going through the information letter, and then informed consent in writing was collected. The participants were informed of their opportunity to withdraw from the study up to the point of publication. After the interview, before we parted, I asked them how the interview situation had been experienced, and once again explained the process forward, giving them another opportunity to reflect on the decision to participate. This included an opportunity to consider whether they felt they had revealed very personal matters or too much of themselves, which is a potential risk discussed by Guillemin and Gillam (2004).

The collection of research data through an in-depth interview required me to reflect on a few issues. First of all, I considered the potential for putting my participants at risk in terms of psychological, social, economic or legal harm. Smith et al. (2009) say researchers need to consider to what extent talking about sensitive issues might constitute harm. I considered the topic of my study, mental health and mental health promotion, not to be a sensitive issue to talk about. In the information letter the distinction between therapy and a research interview was outlined, and the potential for risk in any dialogue was elaborated on; the risk of reactivating earlier upsetting experiences or sensitive issues. If this should happen, my training as a mental health nurse and my working position at the hospital meant I could handle such a situation. In case of a minor problem I would be able to offer a conversation about this issue after the research interview. In case a more severe problem occurred I was able to make

an appointment for the participant with his/her therapist at the hospital. However, such a situation was not experienced during the twelve interviews. The participants were offered travel expenses in accordance with public tariffs. However, none of the participants had any expenses covered in this study. All participants got a gift after the interview was conducted, a ceramic cup made by an artist, as a way to show them my gratitude and give them positive memories of their participation.

6.4.2 Ethical reflections associated with the advisory team members

Ethical dilemmas need to be considered when involving service users (McLaughlin, 2006), and ethical issues may emerge at any point of a collaboration process (Frankham, 2009). People with mental disorders are seen as a vulnerable group because the disorder can make informed consent hard to achieve, and therefore, they are in danger of being exploited (Hummelvoll, 2009). I tried to be careful not to do anything inconsiderate, in line with the arguments surrounding informed consent and ethically acceptable mental health research (Hem et al., 2007). I tried to 'live' the principle of 'process consent', described by Hem (2015), in my collaboration with the advisory team. This process required an ongoing sensitivity and reflexive attitude, slightly different from more traditional ethical issues discussed earlier in relation to the participants. The members of the advisory team had specific needs in some situations, which required a solution-oriented attitude, as well as a caring and facilitating approach from me, as Hummelvoll (2009) elaborate on. An example of an unforeseen ethical dilemma was a situation of ongoing treatment and an in-patient admission at the hospital for one member of the advisory team. This person very much wanted to participate in our workshop, because he/she associated this with his/her healthy identity rather than his/her illness. After a dialogue with the team member and his/her therapist, we resolved the situation by organizing for a health professional to accompany the team member to the meeting. Bringing the needs of all the individuals involved, the participants, the advisory team members and myself into the ethical reflections helped us shed light on critical, positive and constructive aspects of our collaboration. The first workshops were devoted to comprehensive discussions about several ethical aspects and practical dilemmas in relation to how we understood and might apply confidentiality in different everyday situations. Together we developed voluntary guidelines which continued to evolve throughout the research process. Confidentiality was about protecting the privacy of the participants, but in this case it was also about protecting the privacy of the advisory team members. The members did not know the identity of the participants. The team members

signed written consent to participate in the advisory team, and this also included a declaration aimed to protect the participants (see Attachments). Working with transcripts from the interviews all identifiers such as names, places, names of wards and place of living were replaced with fictive names by me. However, there were always risks of identifying the participants, and recognizing this promoted an ongoing reflection and discussion on the duties of confidentiality. Information from the interview transcripts shared in the workshops should be handled with care, especially in contact with others outside the team.

Experiences of living with a mental disorder might increase the ability to produce reliable knowledge in mental health research (Beresford, 2005). Hence, it was desirable that the advisory team members' individual experiences were shared and actively applied. Accounts shared in the meeting room should be considered as belonging within the advisory team, and were not to be shared with others without explicit agreement from the person concerned. Making personal presentations (see Attachments) made the members consciously introspective and reflecting on what they wanted to disclose about their own situation and this provided ethical clarifications. According to Hem (2015) a different kind of dilemma may arise when participants, in this case the advisory team members, do not wish to be anonymous. In some cases the service users were eager to promote an issue they thought was important; for example by the wish to be co-authors, or to join in presentations (Mattingly 2005). In my study the advisory team members were not actively introducing themselves as co-authors; they were invited by me after discussions with my supervisors. Before they said yes to become co-authors, we had comprehensive discussions on potential consequences and tentative ethical dilemmas.

The ethical principle of vulnerability elaborated on by Hem (2015), was also subject to our discussions. We recognized the dilemma considering who is 'vulnerable', but also how over-protection of the 'vulnerable' risks silencing important voices in research. Another ethical dilemma was identified in finding the balance between protecting the individual and his/her desire to fight against stigmatization. Our discussions centred on assessment of consequences, or in Hem's (2015) words: about the risk and benefit considerations. I presented possible ethical issues as well as current and real dilemmas for consideration in workshops. Potential consequences were discussed and each member got the opportunity to consider different options. Examples of such dilemmas were: authorship using individual names or name of the team on posters or in papers; giving a blog interview anonymously or with name and photograph; being exposed in a local newspaper as individuals with severe

mental illness. We always came back to the advice we got from an experienced journalist; if you are in the slightest doubt, don't do it. As a consequence each member chose their own solutions regardless of the rest. Through our discussions and active reflections the advisory team and I tried to promote what Guillemin & Gillam (2004) describe as ethical mindfulness.

6.4.3 Ethical reflections on the empirical data material

The first part of the present study explored research data from interviews with twelve participants. Their accounts were analysed in line with the IPA methodology. Two papers were written from this empirical data. Due to the ideographic stance of IPA, the number of participants is higher than recommended for the scope of a PhD study (Smith et al., 2009). Preparing for and conducting in-depth interviews, case-focus analysis of twelve transcripts and cross-case analysis of research data from twelve sources is time-consuming. Close to 500 pages of transcribed texts are annotated with my and the advisory team members' exploratory comments. Throughout the analysis process choices had to be made about what parts of the data the study should focus on and what needed to be left behind. I believe the full set of transcripts contain more data to be scrutinized, and potential findings for future publications. Analysing the transcripts based on other research questions could present possibilities. IPA studies utilize small homogeneous samples; five of my participants were diagnosed with a bipolar disorder. These participants could form a sample for a study of balance and mental health in those struggling with bipolar disorder, which might include fluctuating symptoms and instability. Another option could be to continue the ongoing analytical discussions with the advisory team to explore emotions experienced in good mental health, in other words while being high up on the staircase of mental health. I feel obliged to delve into these issues after finishing this thesis to honour the time and effort put in by the participants, and the advisory team during the present study. This is also in line with the message conveyed by Knut W. Ruyter the leader of the Regional Research Ethics committee³. He questioned the tradition in the qualitative research community of not storing interview data long term and argued for the potential benefits of being able to look at interview data again, from a different perspective, to answer other research questions in the future.

6.5 Demonstrating validity

The validity of the research is determined by the degree to which it is accepted as sound, legitimate and authoritative by those interested in it, such as other researchers, policy makers,

³ Lecture about research ethics given 6th January 2011 at Buskerud Hospital Trust, Drammen.

practitioners who use the research, and the lay public (Yardley, 2015). In the first part of the study, IPA methodology including service user involvement was used to explore mental health and mental health promotion. IPA research should be evaluated in accordance with criteria recognized as appropriate to IPA methodology and with a pluralistic stance, according to Smith et al. (2009). They recommend four broad principles for assessing quality in IPA studies, presented by Yardley (2000, 2015). Smith (2011a, 2011b) further discusses a guide to evaluate IPA research and he provides quality markers for IPA studies. In addition to the issues of validity provided in paper 1 and 2, below I will discuss how these four principles have been addressed in my study and in this thesis. The service user involvement applied in the IPA study was in the second part explored through a case study design. These two parts of my study are intertwined, and the principles for assessing IPA studies are also relevant to the validation of the case study. However, in relation to the case study design, I will discuss some specific perspectives on validation in line with Yin's (2014) criteria for judging the quality of research design.

6.5.1 Sensitivity to context

Good IPA research will demonstrate sensitivity to the socio-cultural milieu, the existing literature and the research data obtained from the participants (Smith et al., 2009; Yardley, 2015). My choice of topic was influenced by my dedication to people struggling with mental illness and their families. Awareness of a study's socio-cultural context; the normative, ideological, historical, linguistic and socioeconomic influences on the beliefs, objectives and expectations of all persons involved, is important (Yardley, 2000). I recognize that my position and my understanding both limited and made me sensitive to the participants' context; the Norwegian society and culture and the organizational structure of the local healthcare system available to my participants and the advisory team members. Having local knowledge made it easier for me to find and carefully select suitable participants and research advisors. The relationship between the participants and the investigators is crucial (Yardley, 2000). My dedication to put the participants and the research advisors at ease manifested in awareness of, and sensitivity to, the interactional nature of data collection, both in the interview situation and in the collaboration with the advisory team. Through an empathetic approach I facilitated an atmosphere where they could feel free to be the experiential experts that they were. The following example illustrates this sensitivity. The interview location chosen by one of the participants happened to be an outdoor café. After a few minutes I noticed that the participant often looked over his shoulder towards the entrance to the local

pharmacy. I asked him gently if he was looking for someone. He told me he was afraid that some of his less friendly acquaintances could be picking up medicine from the pharmacy and then come up behind him without him noticing. We agreed to switch places at the table so he got a better overview. The rest of the interview was then calm and peaceful.

A good IPA study should demonstrate sensitivity to the raw material by putting forward a considerable number of verbatim extracts from the participants' accounts to support arguments being made (Smith, 2011a; Smith et al., 2009). Having found myself with an abundance of such quotations, it became a challenge having to exclude many good and illustrative examples from my papers in my attempts to adhere to the journals' word count limitations. The nature of my relationship with the participants and the advisory team members also requires careful consideration. Closeness increases the risk of exploitation, and can complicate the preservation of anonymity and the confidentiality of the advisors' views, according to (Yardley, 2000). I elaborate on this dilemma under the section of ethical considerations (see section 6.4). Sensitivity to context is also about awareness of the existing literature, which can be either substantive, related to the study topic, or theoretical, related to the underpinnings of the research method itself, according to Smith et al. (2009). Yardley argues (2015) there is almost always some previous relevant theoretical or empirical qualitative research. For me, sensitivity to the literature also means acknowledging my lack of capacity and time to search, read and adopt the huge amount of literature accessible. The helpful assistance from skilled librarians was priceless, but countless times I have come across important literature quite by coincidence. Therefore I cannot be sure I have found all the relevant literature. Additionally, I have chosen not to read the original works of the central philosophers in phenomenology and hermeneutics which underpin IPA methodology. Reading IPA experts' interpretations of these theoretical underpinnings (Ashworth, 2015; Smith et al., 2009; Smith & Osborn, 2015) has been meaningful to me, and inspired further study, such as several chapters in the books of Denzin and Lincoln (2013a, 2013b, 2013c).

6.5.2 Commitment and rigour

Commitment encompasses prolonged engagement with the topic (Yardley, 2000). In my case my work as a mental health nurse for over 20 years, and my personal interest in and compassion for people struggling with mental illness, both serve to illustrate the strength of my commitment to the topic as well as to the people. Additionally, all this has helped me to develop competence to research qualitatively their lived experience. Rigour refers to the completeness or thoroughness of the study; the quality of the collection and the analysis of

data from an appropriate sample (Smith et al., 2009; Yardley, 2000). For me, interviewing was a journey where I tried to balance closeness and separateness to my participants and research advisors while attempting to pick up important clues and digging deeper into subjects relevant to my research. The purpose was to come close to the participants' experiences. I made use of my training and long clinical experience as a mental health nurse in the interview situations. The analysis in IPA studies must also be sufficiently interpretative; "moving beyond a simple description of what is there to an interpretation of what it means" (Smith et al., 2009, p. 181). The step from interesting case analysis of each of the twelve participant's accounts to grasping something important about themes they shared was a challenging exercise for me. To address all of the variation and complexity into understandable themes required all my intuition and imagination, as well as my ability to work systematically and logically. I was helped by several levels of analysis; drawing, reflecting and discussing with the advisory team and supervisors.

6.5.3 Transparency and coherence

Yardley's third broad principle of validity is about transparency and coherence (Yardley, 2000, 2015). It relates to the clarity and cogency of the description of the research process and the write-up of the study (Smith et al., 2009). Aiming to provide the reader with clear, relevant and sufficient information I have elaborated on the selection of participants and research advisors, and how the interview schedule was constructed and used. Further, I described how the interviews with the participants were conducted, as well as the focus group interviews with the advisory team. Finally, I have explained the steps in the analytical process. Additionally, Yardley (2000) underlines reflexivity to achieve transparency, which I have elaborated on (see section 6.3).

6.5.4 Impact and importance

Yardley's last principle by which a qualitative study might be judged, draws attentions to the utility of the findings (Smith et al., 2009). It is not sufficient to make a sensitive, thorough and plausible analysis if the topics and the ideas of the researcher have no influence on the beliefs or actions of other researchers, policy makers or practitioners (Yardley, 2000) or, as in my case, benefitting those living with mental illness. The usefulness of my study needs to be assessed in relation to the community it was intended for; the mental healthcare services. I discuss some practical implications of my research in the discussion chapter (see chapter 8). The collaboration with the advisory team has given me opportunities for reflection on utility and application in practice. Bringing new understanding to clinical practice may represent a

step from interpretation to construction; from research which seeks to explain existing phenomena to research which creates new solutions (Yardley, 2000). Smith et al. (2009) suggest an independent audit as a powerful way of assessing validity in IPA studies. In my study the sharing of material and data from the various stages of the research process with one or two of my supervisors could be compared to an audit, or a “mini audit” in the word of Smith et al. (2009, p.184) . The interview schedule was subject to discussions and one of the supervisors listened to two interview audiotapes and gave feedback on my style of interviewing. Further, several excerpts from the transcripts with annotations, tables of themes, mind map drawings and preliminary illustrations were reflected on together with the supervisors. All this helped me, a novice, to see good practice in action, which helped me to develop my own skills and to produce a credible study. However, the aim of the supervision or audit is not to produce a report which claims to represent the truth, rather it is to focus on how systematically and transparently the study has been undertaken (Smith et al., 2009).

6.5.5 Validation of the case study

Criteria for judging the quality of research design have been applied to case study research under different headings (Creswell, 2012; Yin, 2014). Guided by Yin’s (2014) framework of validity (construct, internal, external) and reliability, relevant aspects of our case study design will be considered. To establish construct validity the use of multiple sources of evidence is recommended (Yin, 2014). We collected data from documents, interviews and participant-observation. Data triangulation helps to strengthen the validity (Yin, 2014). In our case an independent observation of our collaboration might have brought interesting additional data. A case study database is recommended to enhance construct validity (Yin, 2014). We took advantage of already stored documents, which formed a local database. Several of the sources, such as agendas, minutes, posters and manuscripts for oral presentations had previously been shared with the advisory team as part of our collaboration. Yin (2014) also recommends engaging key informants in reviewing drafts. In our case study these key informants were also co-authors and contributed to written documents and illustrations, as well as paper 3 and 4. To sum up, we used multiple sources of evidence (data triangulation) among six individuals (investigator triangulation) aiming to create the findings.

External validity in case studies is about whether the study findings are generalizable beyond the immediate study (Yin, 2014). The groundwork for establishing external validity started before the case study was launched, while we searched literature for appropriate theories. In helping us to understand our own process, we took advantage of Sweeney and

Morgan's (2009) 'levels and stages of involvement', a classification system of the potential levels of involvement at all stages of a research project. We developed an illustration inspired by this classification system, as a way to display our findings in the case study (see Figure 9). I would argue that our findings supported, expanded and generalized Sweeney and Morgan's (2009) classification system. Our findings could be discussed in light of theoretical propositions (analytic generalization). The findings presented in paper 3 included six facilitating features of the structure and the atmosphere surrounding the collaboration process. These features were interpreted to be consistent with the salutogenic orientation applied in my study and outlined in chapter 3, thereby a discussion of these findings constituted an analytical generalization.

To address reliability means that a later investigator follows the same procedures as described and arrives at the same findings (Yin, 2014). According to my constructivist position this is impossible. However, making our procedures and steps in data collection and analysis explicit increases the reliability, as in all research. Yin (2014) suggests using a case study protocol aiming both to safeguard the documentation of procedures and develop a case study database. In our collaboration we often discussed how to make every step in the research process as operational as possible, and to conduct them as if someone were looking over our shoulders.

7 Findings

The findings from the two parts of the empirical study, involving four papers, are summarized in this chapter.

Table 2: The research questions, aims, papers and main findings included in this thesis

	Research question (RQ)	Aim	Paper	Main findings
First part	RO 1: How is mental health experienced and described?	To explore how mental health and mental health promotion are experienced by adults affected by mental disorders and with inpatient experiences	Paper 1: Mental health as perceived by persons with mental disorders – an interpretative phenomenological analysis study	Mental health was experienced as a dynamic phenomenon and an aspect of life always present. Mental health was perceived as a movement that was nourished by experiences in the emotional, physical, social and spiritual domains of life, and accompanied by a sense of energy.
	RO 2: How is mental health promotion experienced and described?			
	RO 3: What experiences from hospitalization in mental healthcare do former patients experience and describe as promoting their mental health?	To explore former inpatients' experiences of mental health promotion in a mental healthcare setting	Paper 2: Reorienting Norwegian healthcare services: listening to patients' craving for learning	An appetite for learning was prominent, the participants perceived the learning processes which occurred in the healthcare settings as health promoting. They were craving knowledge to cope with the mental disorder and to increase their mental health and wellbeing in daily life.
	RO 4: What improvements in mental healthcare are suggested by former patients in order to promote mental health?			
Second part	RO 5: How do the service users experience and describe their involvement in the research process?	To explore the applied process of involving mental healthcare service users in the study	Paper 3: Salutogenic Service User Involvement Experiences from Collaboration between an Advisory Team and Researchers in a Mental Health Research Study	The level of involvement was dynamic, and six features facilitated contributions from service users; role clarification, predictable meeting structure, a safe and supportive setting by leadership, focus on possibilities, being a team member and seen and treated as a whole person were all perceived to help the service users to see themselves as valuable resources and to feel competent.
	RO 6: In what ways have service users experienced that their involvement has been encouraged and of importance?			
	RO 7: In what ways may service user involvement strengthen research quality in an IPA study?	To examine how service user involvement may contribute to the development of IPA methodology and in turn enhance the research quality	Paper 4: Service user involvement enhanced the research quality in a study using interpretative phenomenological analysis - the power of multiple perspectives	The multiple perspectives of service users and researchers gave more insightful interpretations of nuances, complexity, richness or ambiguity in the participants' accounts. The power of multiple perspectives in service user involvement and the IPA methodology mutually reinforced each other.

7.1 Paper 1

In paper 1, we wanted to illuminate how adult persons diagnosed with mental disorders perceived positive mental health and mental health promotion. Mental health was seen by the participants as an aspect of life that is always present and is experienced as a dynamic phenomenon; a process, a constantly ongoing movement, like walking up or down a staircase. This vertical movement is nourished by life experiences within four domains of life; emotional, physical, social, and spiritual. On the other hand, a person's position on the staircase at any given moment also influences feelings and functioning, expressed as more or

less wellbeing, within those same four domains of life, thus creating a bi-directional interaction between life experiences and perceived mental health. The constantly ongoing movement up and down the staircase is accompanied by what participants described as a fluctuating sense of energy, experienced both mentally and physically as vitality versus fatigue. The participants described energy as a potential to perform physical and mental activity, thus the fluctuation in energy influences the four domains of life. Perceived mental health was accessible to significant others through body language and everyday spoken language, rather than through more theoretical or professional language. To describe the extremities of the staircase the participants used metaphors.

7.2 Paper 2

Paper 2 presented the participants' health promotion experiences in an in-patient setting and their opinions about how a healthcare system should be improved for the future. These former patients shared of their wealth of experience and insight into what promoted their health and wellbeing. One prominent finding was presented in detail in paper 2; the appetite for learning. Ten of the twelve participants described the learning processes that occurred in the healthcare settings as health promoting. The participants had a yearning for knowledge that was thought to help them comprehend their own experiences and develop an understanding of their life events. This appetite for learning was motivated by a craving for change towards less illness and more health in daily life. Mental health promoting knowledge, as well as knowledge about their mental disorder was appreciated. However, their experiences did not demonstrate healthcare providers having a systematic focus on both pathogenesis and salutogenesis. The participants' accounts implied that there is an opportunity to complement the curative activity of the healthcare services with educational activities to promote their mental health.

7.3 Paper 3

In paper 3 we explored our applied process of service user involvement. We scrutinized experiences and documentation from four years of collaboration (2012 – 2015). We aimed to explore practical issues and discussed features of our collaboration which empowered and encouraged the service users to make significant contributions to the research process. The level of involvement was dynamic and varied throughout the research process. In the paper a figure illustrating the different levels of involvement in the stages of our research process is presented (also reproduced in this thesis, see Figure 9). The figure is designed with the intent of being adaptable for use in other projects, to facilitate an explicit and systematic plan for how to conduct service user involvement in different stages of various research processes. We

identified six significant features facilitating contributions from service users: A) clarification of roles among the partners, B) a predictable meeting structure and C) clear leadership promoted a safe and supportive setting. Additionally, D) the focus on possibilities to counterbalance a focus on obstacles, as well as E) being a member of a team was perceived to be important in increasing the contributions from the advisory team members. Finally, F) being seen and treated as a whole person, with a life story which included life events and experiences of both health and mental illness, helped the team members to see themselves as a valuable resource and to feel competent. These findings were also presented in an illustration (reproduced in this thesis, see Figure 10). These features of the structure and the atmosphere surrounding the collaboration process were interpreted to be consistent with a salutogenic approach to service user involvement.

7.4 Paper 4

In paper 4 we discussed how service user involvement may contribute to the development of the IPA methodology and in turn enhance the research quality. The paper was based on interpretations of documentation and the exploration of our own experiences from the collaboration process in the first part of the study where twelve persons diagnosed with severe mental disorders were interviewed. In paper 4 we examined and described the joint process between the advisory team and the researcher that involved analysing the empirical data from these interviews. Our analytical discussions were audiotaped, transcribed and subsequently interpreted following the guidelines for good qualitative analysis in IPA studies. The advisory team became ‘the researcher’s helping hand’. The power of multiple perspectives came across in the interpretation of interview transcripts. The variety of perspectives gave more insightful interpretations of nuances, complexity, richness or ambiguity in the interviewed participants’ accounts. The interpretative element of IPA was enhanced by the emergence of multiple perspectives in the analysis of the empirical data. Essential to increasing understanding of the participants’ experiences was the viewpoints of service users with similar experiences of struggling with mental disorders, from the same time and place as the participants.

8 Discussion

Based on the study presented in this thesis and findings from the four papers, I will here elaborate on some issues, which are not addressed in-depth in the discussion parts of the papers. First, I discuss some consequences of how persons with mental disorder perceive mental health for some contemporary theoretical definition of mental health. The participants perception of the sense of energy as a significant aspect of perceived mental health makes me discuss this in relation to Antonovsky's theory of health and the concept of SRD. Inspired from the participants' craving for knowledge I argue for a future development of the healthcare services by complementing the dominant perspective on diagnosis, risk factors and symptoms with health promotion knowledge based on salutogenesis. In turn concepts and language need to be developed towards clear and explicit terms. Further, I argue that nurses have an opportunity to be even more central in the mental health promotion agenda. Before I elaborate on some limitations of this thesis and an implication for practice, the significance of management of service user involvement is discussed.

8.1 Definition of mental health - contributions from persons with mental disorders

The exploration of the internal perspective of mental health creates a counterpart to the external point of view. The first-person perspective, the experiential knowledge of both health and illness, constitutes a type of knowledge that can complement observational data, which is more common in the field of health promotion and in the medicine dominated hospital setting. Secker (1998) claimed that mental health promotion revolved around skills and attributes identified by professional experts, and that more participatory methods were missing. Lived experience is a source of knowledge qualitatively different from the study of behaviour. Qualitative research could have the potential to inform mental health policy in several ways (Davidson, Ridgway, Kidd, Topor, & Borg, 2008). Keyes (2013b) argues it is not enough to see how people react, we also need to know how they feel and how they perceive their world.

Presented in paper 1, interpretations of the lived experiences of persons with mental disorders gave an understanding of mental health as a movement up or down a staircase. In the setting of mental healthcare services a range of different conceptualisations and definitions of health have relevance for the variety of activities going on there. Boorse (1977; 2014) argues for a value-free definition of health; the total absence of pathological conditions. This is a definition anchored in pathogenesis. The participants in this study were not at all talking about absence of illness or disorder symptoms when they described their perception of

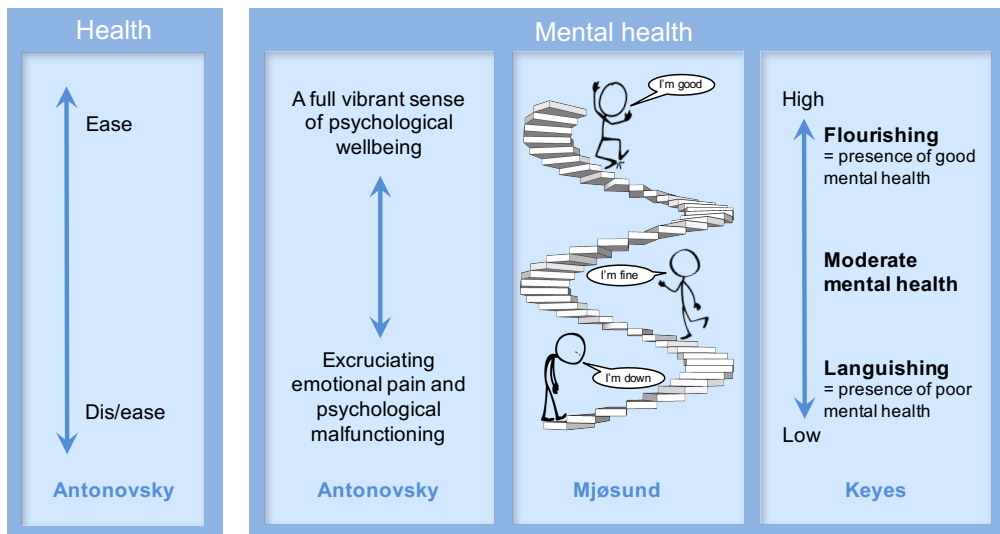
mental health and mental health promotion. Antonovsky studied health instead of disease (Antonovsky, 1979, 1987). He was preoccupied with the origin of health, and he described health as a horizontal continuum of ease-dis/ease. As elaborated on in this thesis' theoretical perspectives (see chapter 3), Antonovsky (1979) understood health as the absence of four characteristics; pain and functional limitations as subjectively assessed, medically defined conditions and associated treatments based on health professionals' judgements.

Antonovsky's definition of health has been said to be no more than the absence of disease and infirmity (Vinje et al., 2016). His understanding of health is somewhat dissimilar to his understanding of the continuum of mental health with a positive end representing "a full, vibrant sense of psychological wellbeing (Antonovsky, 1985, p. 274)". To me, this is the presence of a positive experience, not the absence of infirmity. Keyes (2014) followed this line, based in salutogenesis, with his view of mental health as the presence of positive feelings and functioning, a positive state of human capacities. Keyes (2002) too presented a continuum of mental health, a vertical continuum, divided into categories labelled 'languishing', 'moderate mental health' and 'flourishing'. Keyes (2002) described flourishing as the presence of mental health and languishing as absence of mental health. Later he described mental health as low or high (Keyes, 2013a) as illustrated in Figure 2.

The understanding of mental health as a continuum is confirmed by research on young people (Shucksmith, Spratt, Philip, & McNaughton, 2009), and by the findings presented in my paper 1; mental health was perceived as a dynamic phenomenon, a movement, like walking up or down a spiral staircase, equivalent to a continuum. Talking about the experiences of being in any position on the staircase, the participants used language and words indicating a vertical movement in accordance with Keyes' (2002) continuum of mental health. Benefitting from the use of lay language in order to break down barriers between stakeholders in health promotion and healthcare is encouraged (International Health Promotion Hospitals and Health services, 2016). The finding of mental health as a movement up or down leads me to suggest turning Antonovsky's horizontal continuum (see Figure 1) 90 degrees to a vertical one, in order to express visually the perceptions of the study participants.

Another finding was presented in paper 1; the perception of mental health as an ever present aspect of life, a part of being human. Mental health was perceived qualitatively, not characterized by quantitative entities such as numbers, but rather as good or bad, up or down, poor or strong. The finding of mental health being experienced as constantly present in life and a part of being is not in accordance with Keyes' (2002) definition of languishing as the

absence of mental health. Based on the participants’ way of speaking about the position low in the staircase, I would suggest revising the term ‘languishing’ to ‘be the presence of poor or low mental health’. The continuums in Antonovsky’s model of health and mental health, and in Keyes model of mental health, together with relevant findings from the present study, are illustrated together in Figure 5, including the suggestions discussed above.



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Figure 5: Mental health as moving up and down a staircase - equivalent to a continuum

8.2 A shaky engine and flat battery – a specific resistance deficit (SRD)?

Presented in Paper 1, the sense of energy was a salient marker of perceived mental health, and also it influenced experiences of mental health in all the four domains of life. The feeling of energy was proportional with the position on the staircase; low/down on the staircase the sense of energy was described as “like having a shaky start engine with a flat battery”. The participants described how this lack of mental and physical energy was associated with difficulties initiating and completing any activities. Describing the movement towards the positive end of the continuum of mental health, Antonovsky (1985) used the term “vibrant psychological wellbeing” and Keyes’ (2002) descriptions of flourishing included the presence of enthusiasm, aliveness, vitality and an interest in life, which give associations to a sense of energy. As discussed in paper 1, the sense of energy might be perceived as a GRR. According to Idan et al. (2016), Antonovsky merged the concept of GRRs with the concept of the stressors resulting in a combined concept; Generalized Resistance Resources – Resistance

Deficits (GRR-RDs). Consequently, GRRs might be understood as being on a continuum (Idan et al., 2016). Lack of energy and motivation as a result of mental disorders has been identified by patients as barriers to integrating healthy lifestyles (Verhaeghe, De Maeseneer, Maes, Van Heeringen, & Annemans, 2013). A lowered sense of personal energy has been associated with psychopathology (Ryan & Frederick, 1997). The sense of energy should be investigated in more depth and the relationship between mental health, mental disorders and sense of energy need further investigation in order to inform health promotion knowledge. In a salutogenic orientation to mental health promotion for persons with mental disorders we might take advantage of the salutogenic concepts of Specific Resistance Resources (SRRs) (Mittelmark, Bull, et al., 2016), and Specific Resistance Deficits (SRDs) (Vinje et al., 2016). Mapping SRRs and SRDs could play a central part in the development of person centred interventions, which could then be tailored to promote a movement up the staircase, in effect mental health promotion. Bringing a salutogenic approach to the idea of ‘the sense of energy’, I would suggest to viewing vitality as an SRR and the perceived fatigue as an SRD, in order to find a more individualized and specific means to strengthen the SRR, as suggested by Mittelmark et al. (2016). Bringing this salutogenic orientation together with the person centred model of nursing and care (McCormack & McCance, 2010) creates the potential to tailor personalized mental health promotion interventions, termed patient-centred health promotion or clinical health promotion by Tønnesen (2013b). In collaboration with the patient an assessment of the sense of energy might form the basis for interventions aiming to “push or pull” into an activity, or advising rest, both interventions described by Lerdal (1998).

8.3 The protection of mental health – a problematic term?

Means to strengthen GRRs and SRRs (Antonovsky, 1979, 1987) could be developed specifically with the aim to safeguard those aspects of life that encompass good mental health, in other words interventions that would seek to protect against a movement down the staircase, thus protecting the person’s mental health. Protection of mental health is not to be confused with protections against mental illness or disorders. In hospital settings where the focus of health service provision is primarily on reducing morbidity and the economic burden of care, as opposed to ensuring optimal functioning (Petersen, 2010), the concept of protection might give associations to the pathogenic paradigm. I would like to emphasize my differentiation between the protection of mental health (something positive) and the protection against mental disorders (something negative). I am aware that the perception of what is positive or negative is dependent on the context and culture and might differ from one person

to another, however in the above context the terms are used simply to illustrate the difference in purpose. Secker (1998) requested a health promotion agenda with a clearer position on the relationship between prevention and promotion and in particular its relevance for mental health promotion of services for people diagnosed with mental disorders. The present study was not focussed on the relationships between prevention and promotion but interpretation of the findings presented in this thesis gives support to the promotion and protection of mental health as described in the two-continua model (Keyes, 2013b). Bringing the continuum of mental illness and the continuum of mental health into the same picture (see Figure 2) corresponds to the experiences presented by the participants in this study. Interpretation of their accounts led to an understanding of an everyday life where experiences of illness and health are intertwined, but also dissimilar.

8.4 Emphasizing salutogenesis and pathogenesis equally - a complementary understanding of mental health

In paper 2, we described how former patients experienced mental health promotion in the inpatient setting. Mental healthcare services offer a range of treatments and care aiming to prevent the mental disorder itself, the severity of it or the associated disability (WHO, 2002). The focus on positive mental health was not common in the setting of my mental healthcare hospital when I initiated my study. Many health professionals would automatically make an association between the absence of mental disorders and being mentally healthy. Clinical daily life for health professionals in this setting was characterized by an explicit focus on symptoms, risk factors, treatments to reduce the severity and duration of mental illness, and to prevent upcoming episodes of the disorders, in line with governmental guidelines. However, it is expected of the specialised healthcare services to also promote health (Specialized Health Services Act, 1999), and standards for health promotion in hospitals have been developed (WHO, 2004b). Nearly three decades ago the health sector was requested to move towards health promotion, beyond its responsibility for providing clinical and curative services (WHO, 1986). Attempts have been considered unsuccessful so far (Catford, 2014; de Leeuw, 2009; Tønnesen, 2013b). Progress has been slow in making the health promotion the core business for the health services (Catford, 2014).

To succeed in our effort to reorient the health services I would suggest being more attentive to the patients. Understanding the environment, perspectives and situations of the people involved in the setting in which we are working has been deemed necessary in order to succeed in sustainable mental health promotion programmes (Petersen, 2010). The heading of

this section is inspired by a header in Antonovsky's book (1987, p. 12), "Pathogenesis and Salutogenesis: A Complementary Relationship", which draw attention to the participants' concern about both health and illness. As outlined in paper 2, the participants perceived the learning processes including personalized knowledge and skills acquired while hospitalized, as health promoting. An appetite for learning was a striking finding in the empirical data. Gaining knowledge from both the salutogenic and pathogenic paradigms was appreciated and motivated by a craving for change towards more health and less illness in daily life. The experiences from inpatients treatment and care did not demonstrate healthcare professionals having a systematic focus on both salutogenesis and pathogenesis. Keyes (2014) makes a case for promoting and protecting mental health to prevent against mental illness and to improve overall psychological functioning. Health promoters need to lead, deliver, research and educate on the adventure ahead, says Catford (2014). Mental health promotion in a mental healthcare hospital is my interest, supported by the findings in this study, I claim that a theoretical framework, to guide a reorienting process in this setting might be found in the complete model of mental health, also called the two-continua model (Keyes, 2005, 2014; Provencher & Keyes, 2011). The complete model of mental health accommodates both illness and health, and as such includes knowledge from both the paradigms of salutogenesis and pathogenesis.

The learning processes of the participants' during hospitalisation held the potential to help master daily life, and at the same time enhances mental health and wellbeing. This is in line with the core purpose of recovery - to enable people to live their lives - as opposed to a focus solely on reducing their symptoms (Davidson et al., 2008). A purpose which agrees with a salutogenic approach to recovery emphasizing living as well as possible with a mental illness and optimizing mental health (Provencher & Keyes, 2011). A Norwegian study shows recovery was promoted by supportive contexts and conversations with focus on everyday life, working with hope, and shared decision making (Andvig & Biong, 2014). Catford (2014) used the term 'sickness services' as a description of contemporary healthcare services dominated by pathogenic approach. I would argue that treatment and care, research, education and development in the hospital setting, based on a complementary understanding of mental health with equal emphasis on salutogenesis and pathogenesis, might help us speed up the reorientation from 'sickness services' to 'health services' in this regard. A mental healthcare hospital geared towards interventions equally based on the salutogenic and pathogenic paradigms is illustrated in Figure 6. Here, patients are offered interventions aiming to treat the

mental disorder, prevent recurring episodes and reduce their duration, severity and debilitating effect, as well as interventions aiming to bolster the patients' mental health and protect it from becoming worse.



Figure 6: Mental healthcare services based on complementary knowledge

Initiatives to combine these perspectives have been seen in research, among others in recovery research (Andvig & Biong, 2014; Langeland, Gjengedal, & Vinje, 2016; Langeland et al., 2006; Slade, 2010). Bolstering the reorientation requires a more explicit and apparent focus on salutogenic knowledge alongside the pathological focus embedded in the structures of the healthcare services. This involves changes on several levels among politicians, policy makers, bureaucrats, health professionals, the educational sector, and among management in healthcare services.

8.5 Nurses – heightening their role in health promotion?

Presented in paper 2, a dominant finding was the participants' perception of the learning processes which occurred in the hospital as mental health promoting. My education and training as a mental health nurse with a master's degree in nursing science (Cand.san.) make me interested in the potential in engaging with and mobilising the large number of nurses in mental healthcare services, a notion also recommended by others (Catford, 2014; Whitehead & Irvine, 2011). The knowledge bases of mental health promotion and mental health nursing might mutually reinforce each other. Additionally, the analysis in my study brought mental

health promotion experiences to the surface confirming existing knowledge on how to secure efficient treatment and care at mental healthcare hospitals, relevant to nursing.

First, the daily rhythm and the predictable structure of meals, meetings, silent periods and medication times throughout the day were highlighted by the participants. The health promoting effect of predictable routines is in line with the framework for social rhythm therapy developed for persons with bipolar disorders (Frank, 2005). However, a predictable structure seems to be an essential component in promoting mental health regardless of diagnosis, according to the participants.

Second, all twelve participants emphasized the health promotion significance of, and the supportive power within, the relationships between the patients and the healthcare providers, as well as the importance of continuity in these relationships. This has been confirmed by persons with severe mental illness also in other studies. Green et al. (2008) found that strong, positive and trusting relationships, long-term relational continuity and a caring, collaborative approach from healthcare providers facilitated recovery and improved quality of life among people with serious mental illness. Likewise, participants from another study remarked on how the interpersonal qualities of health professionals had facilitated their commitment to a health promotion program (Shiner, Whitley, Van Citters, Pratt, & Bartels, 2008). In a study from Norway, continuity of care was highlighted as an important element of a health system that worked (Ruud et al., 2016).

Many nurses view health promotion as an integral part of their role, although what they refer to as health promotion will often represent traditional preventative health education (Whitehead, 2005). Tønnesen (2013a) claims that patients with mental disorders are considered to be in great need of health promotion interventions. However, my interpretation of her arguments lead me to claim that she actually focuses on the important need for interventions aiming to prevent disorders based on knowledge from the pathological paradigm. This may be related to the insufficient perceptions and definitions of health. A study of nurses working in mental health services found that the nurses understood health as the absence of disorder, yet simultaneously also as more than the absence of disorder (Jormfeldt, Svedberg, Fridlund, & Arvidsson, 2007). The traditional focus on initiatives to change unhealthy lifestyle behaviour, such as reducing smoking or hazardous alcohol or drug abuse, making dietary modifications towards healthier eating or increasing physical activity, is important in the fight against reduced life expectancy for persons with mental disorders

(Wahlbeck et al., 2011). However, taking a more complete approach with knowledge from both salutogenesis and pathogenesis, the focus on prevention of somatic disorders would be complemented by the promotion of mental health as the presence of feelings and functioning. Giving attention to the human feelings that follow movement of the body is of significance. The joy, happiness, resistance, aches and pains and other feelings that come from being active is important to be aware of, in order to continue being physically active. A salutogenic focus might bring about more sustainable lifestyle changes motivated by the presence of positive experiences and not just the prevention of disorder.

The vast majority of the global nursing workforce practices within a hospital or institutional setting, and this workforce is claimed to be a sleeping giant in health promotion (Whitehead & Irvine, 2011). I claim that nurses are in position to work health promoting due to their constant presence night and day, and the continuous and close relationships with patients. The timing for health promotion seems to be good during hospitalization when the awareness of health is heightened (Latter, 2001). One of the participants described the inpatient situation as a 'window of opportunity' for choosing a healthier way of living, with the help of all the (human) resources available on the ward. The relationship between the patient and health provider has been described, also by patients with serious mental disorders, as essential to achieving successful outcomes of health promotion programmes (Shiner et al., 2008). A review of the nurses' role in health promotion practice shows that their activities were guided by an individualistic and holistic approach to help patients and families make health decisions and support them in health promotion activities (Kempainen, Tossavainen, & Turunen, 2013). Empowerment was rated as the most important intervention in health promotion in a study on attitudes towards aspects of health promotion interventions, and the patients rated alliance and educational support significantly higher than the staff did (Svedberg, Hansson, & Svensson, 2009). It has been recommended that the purpose of nursing care be clarified because some nurses in mental health care seem to be unaware that the main goal of nursing is to strengthen the health of the patients (Jormfeldt, Svedberg, & Arvidsson, 2003). There is some knowledge about important barriers to and possibilities for more health promotion in health services. Johansson, Stenlund, Lundström and Weinehall (2010) found that men and physicians were less positive than women and other health professionals to implementing more health promotion, and people working in primary care were more positive than hospital workers. Heavy workload, lack of guidelines and unclear objectives were linked to low agreement with the relationship between health promotion and

disease prevention (Johansson et al., 2010). I would argue that the health promotion potential in nursing science is still untapped, and that research and development is needed for the future about application of health promotion at inpatients ward of mental healthcare hospitals.

8.6 Project management – essential to successful service user involvement

In paper 3 the process of service user involvement carried out in the first part of the study was explored. The features and structures of the collaboration, which the service users felt strengthened and encouraged them, were presented. The experiences of advisory team members and their ‘within’ position were emphasised. Here I want to focus on my point of view; the facilitation of the process through project management, from an external point of view. Service user involvement both demands and presents opportunities for new understandings of research designs and management (Rickinson, Sebba, & Edwards, 2011).

Working on paper 3, the advisory team and I made some drawings to help us describe the collaborations process. These illustrations evolved to form two figures presented in paper 3 and presented again in chapter 9 as Figure 9. It presents a structure for the level of service user involvement in the different stages of the research process in the first part of my study. We argued that this figure is of general interest and holds the potential to be a tool for those involved in the planning of research involving service users. The figure may be adapted to unique descriptions in other studies, particularly useful for project leaders. However, it is the features of our collaboration process, the working structure and atmosphere that encouraged the advisory team to become the researcher’s helping hand, illustrated in Figure 10, which is of relevance to project management that I would like to discuss here. To feel safe in a supportive setting was important to the members of the advisory team. They perceived the leadership of the team, the meeting structure and the role clarification as important in creation of such a setting. The focus on us being a team and on what is possible helped create an atmosphere where the team members due to their perceived appreciation of their own, and each other’s, worth as important and valuable contributors. We reached a stage where they perceived themselves as the researcher’s helping hand, due to the appreciation of the breadth of their experience, from all aspects of their lives, including experiences of both illness and health. Collaboration is dependent on each person being involved, but facilitating the processes leading up to that is the project manager's responsibility. I would argue that the project leader is the driving force in a collaboration process.

Processes of service user involvement as a part of the research design have important implications for the management of projects and the requested capabilities of the project leaders (Rickinson et al., 2011). Ensuring effective user involvement presents very real demands for the project leader; a range of issues such as time and resources, collaboration and engagement, which require new kinds of skills and capabilities (Rickinson et al., 2011). McLaughlin (2006) discusses the possibilities, benefits and costs of involving service users and claims that careful planning including resources, training, support, timescale and remuneration need to be addressed. Cautious planning by me before initiating the study and before every meeting and workshop was essential for the outcome of the tasks we accomplished. Service user involvement should not be entered into lightly. Several issues emerged during the study, and required time in order to be solved as part of the evolving collaboration process. The project leader needs to be prepared for the unexpected and be able to respond quickly and appropriately (McLaughlin, 2006). Challenges could come in the form of an acute inpatient hospitalisation for one of the team members, or a transport problem coming up 10 minutes before the meeting started. The working pace of service users might differ from that of the project leader. Supporting the service users' participation requires adaptation to their pace and acceptance of the consequences for the collaboration process. For instance my preparation for a discussion on ethics was postponed until the next meeting because another urgent issue came up. All the requirements, extra demands and resource constraints might result in studies taking up more resources and lasting longer making research with service user involvement more time consuming than planned. This situation could be explained by the young and evolving nature of service user involvement, which has been described as fragmented and uncoordinated. It should be more consistently embedded in research infrastructure (Minogue & Girdlestone, 2010).

At the heart of user involvement in research is knowledge exchange processes. Therefore, a key issue for the project leader is to support the flow and interplay of different kinds of knowledge and expertise within and beyond the team. According to Rickinson et al. (2011) researchers leading processes of service user involvement need to have not only project management skills, but also skills in group dynamics, communication and relationships; skills for weaving together different perspectives, meanings and priorities during the research process. The relational expertise in engaging service users is about intellectual leadership related to knowing 'who and when' more than 'what, how and why' (Rickinson et al., 2011). Researchers need to understand the issues from the service user

perspective and how to support their participation (Minogue & Girdlestone, 2010). The support of participation is easy to underestimate (McLaughlin, 2006). Good practice guidance for achieving an active involvement is to provide emotional practical and research support, and make every effort to accommodate the service users' needs (Wallcraft et al., 2009). An argument most researchers will agree with, but how do one start, proceed and how do you know when you have arrived at a productive collaboration process? The experience I gained from undertaking the present study leads me to argue for starting with thorough discussions with supervisors, colleagues and service users about the purpose of the service user involvement. The uniqueness of the purpose is a defining characteristics of service user involvement (Smith et al. 2008) , meaning the purpose gives guidance on who, when and how many. Purposive selection of the service users has been important to the collaboration process and the outcome of my study. For team building we used exercises to get to know one another beyond our labels "service user" and 'researcher', as suggested by Wallcraft et al. (2009). The process of writing a presentation of each team member and myself (see Attachments) was essential for several purposes. It was of significance for me to know who each member was, as Rickinson et al. (2011) request, and also for us to know one another beyond our labels as Wallcraft et al. (2009) suggest. This brings me to another approach relevant to management of service user involvement, the salutogenic approach to human relationships. The history of the person is essential in a salutogenic orientation (Vinje et al., 2016). Like Antonovsky's interest in the movement toward health (Antonovsky, 1979), I endeavoured to have an eye for strengths and resources, smaller or larger elements or actions with the potential to take us all some steps up the staircase of mental health (see Figure 8). Having a focus on what is possible, as shown in our guiding principles with a solution oriented focus presented in paper 3, reflected our conscious focus on a salutogenic approach. In our collaboration process I endeavoured to make the tasks we dealt with comprehensive, manageable and meaningful to invest energy and time into, in accordance with Antonovsky's three core components of SOC (Antonovsky, 1979, 1987).

As bids for funding are increasingly linked to requirement of service user involvement, the need for dedicated resources to support researchers in integrating service user involvement also increases (Minogue & Girdlestone, 2010). Rickinson et al. (2011) claim that tokenistic forms of service user involvement could be the result of limitations on resources such as time and money. This leads to a risk of including service users in limited and superficial ways, or designing studies where service user involvement is restricted to less

important parts of the research process (Rickinson et al., 2011). Service user involvement with the range and scope my study had is time-consuming, resource intensive and requires energy and enthusiasm throughout the process. However, I agree with McLaughlin (2006) when she argues that working with service users can be great fun, and I would add that it can also bring support and enthusiasm in the study. This is in addition to the enhanced research quality service user involvement brought to the study, as claimed in paper 4. Based on the findings in my study and my experiences as project leader I claim we need to give more attention to the project leader position. Experiences from both service users and researchers on successful management should be subject for evaluations and research. Findings from a review of research and current practice in service user involvement made by Smith et al. (2008) indicate that this new type of collaboration presents a need for education and training of researchers. Currently there seems to be little evidence on what kind of training best supports relationships with service users (Smith et al. 2008) . I suggest know-how must be shared and training for service users and researchers on all levels, junior as well as senior, is of significance.

Arriving at the situation we describe in our paper 4, where the service users enhanced the research quality of an IPA study, required time, resources, enthusiasm, and project management. There certainly is a variety of ways to release the potential in service user involvement, and there is a need for more research on the cost and benefits, as well as on different pathways to finding and utilising the power of multiple perspectives in research design development and enhancement of research quality. However, the process towards the situation described in paper 4, where the advisory team became the researcher's helping hand and helped 'expand the horizon of understanding' – in the words of Gadamer (1993/1960), requires leadership and project management.

8.7 Limitations

Included in this thesis are four papers mutually dependent of each other. In paper 1 and 2 findings from the IPA study involving services users were presented. The process and the outcome of this service user involvement were presented in paper 3 and 4. Without the service user involvement, the findings presented in paper 1 and 2 would have been different, and without the IPA study including the service user involvement, paper 3 and 4 would not have existed. However, the connections between these four papers and how they relate to each other have been challenging to make explicit. In that way it might be a limitation. I have tried to present the process behind the four papers in a linear manner to make it explicit, but for me

the process was experienced more like a spiral. My intention has been to present the process with the challenges and choices I made along the way, in the order they occurred. My advice for future studies would be to plan for the two parts or processes from the beginning and to include them in the research proposal.

Starting out my study, I was concerned with the IPA methodology and how I could design an IPA study involving service user involvement. Further, a case study design was used to study this applied service user involvement. Today I am open to the possibility of developing this design with experiences from the field of participatory action research (PAR) (Baum, MacDougall, & Smith, 2006; Whyte, 1991). The processes which evolved between the advisory team and myself have several similarities with the purpose of PAR. At the heart of PAR is a collective, self-reflective inquiry undertaken by individuals and researchers in order to understand and improve upon the practices in which they participate (Baum et al., 2006). The purpose of PAR is to enable action through a reflective cycle, in which the individuals involved collect and analyse data and then determine what actions should be followed (Baum et al., 2006). This applied to our process; the advisory team and I, collected and analysed data from our collaboration process in the IPA study. Thereafter, through analytical discussion, the findings presented in paper 3 and 4 evolved. I would argue that the explicit focus on actions was not present in our collaboration. However, I suggest taking advantage of the PAR approach in the future, in interventions aiming to implement knowledge acquired from this thesis and several other sources, and through this to improve mental healthcare services.

I, the researcher, including my values, beliefs, assumptions, training and clinical practices have coloured the research. Adopting a salutogenic framework to my study so explicitly and extensively has influenced what I saw and what I did not see. This might be seen as a strength or a limitation. I have tried to be explicit about my salutogenic orientation and how it has permeated the study and this thesis. I have deliberately searched for factors promoting mental health, rather than focussing on obstacles or adverse conditions. My salutogenic orientation has influenced my thinking, hopefully my living and being, and consequently moved other aspects into the background. Herrman et al., (2005, p. 12) claim “Mental health is everybody’s business”, and therefore the promotion of mental health and health is important to all human beings, and warrants studies from different positions, through different lenses and using different methods and perspectives. This thesis represents one contribution. For future research, I would suggest larger projects with several partners to

make triangulations in research methods, cultures and professional positions, and including perspectives of researchers, patients and relatives.

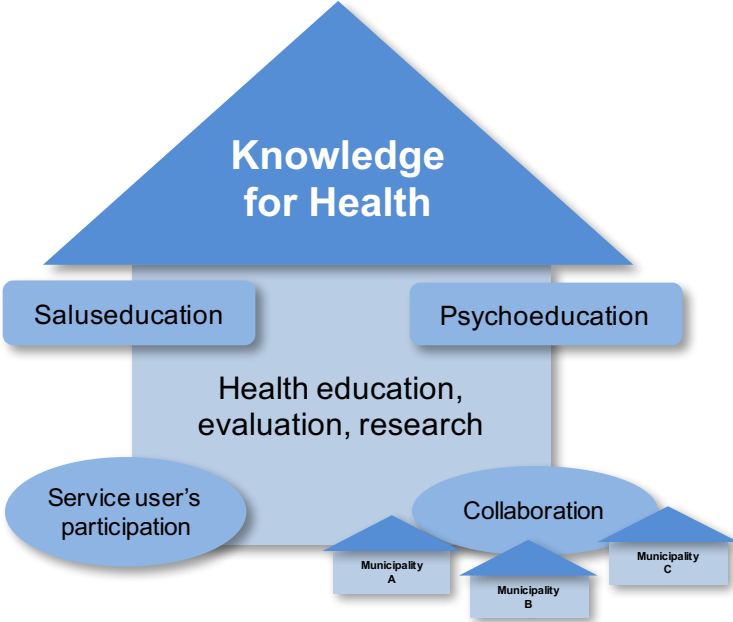
The knowledge base of healthcare services for persons with severe mental disorders has in recent years' undergone a rapid and positive development, which has influenced people's daily lives. Significant theories contributing to the growth of knowledge have not been discussed thoroughly in this thesis, and this could be seen as a limitation. Recovery is said to be the overarching aim of mental health care (Davidson et al., 2008). This is a promising and exciting field with many similarities to mental health promotion. My aim from the outset was to study the phenomenon of mental health on its own terms. At that time, I assessed the majority of recovery knowledge as being concerned with the journey away from disease. Today, recovery research is mainly focused on ways to promote living as well as possible in daily life with an illness. Consequently, for the future I see many possibilities to improve the life of people with mental disorders by complementing knowledge of recovery with knowledge of mental health promotion.

8.8 Implications for clinical practice

The overall purpose of my study 'Positive Mental Health – from what to how' was to contribute to the knowledge base of health promotion by exploring the experiences of persons with mental disorder. In paper 1 and 2 the 'what' part of the title in my study was addressed. The findings presented in paper 3 and 4 might have some answers to the 'how' part. Summing up my experiences from undertaking this thesis I see a potential for implementing some of the acquired knowledge into the clinical practice I am part of and where the study emanated from. Inspired by the 'how' part of the title of my study some implications for clinical practice might be suggested.

As part of the interviews, the participants were asked to share their dreams for the future mental health promotion hospital. Inspired by their stories I would like to share my ideas for further improvements of services in a mental healthcare hospital. I would suggest establishing a centre focusing on Knowledge for Health - a place for developing and sharing knowledge aiming to promote a life with more mental health and less mental illness for persons with severe mental disorders (see Figure 7). The target group is the hospital's service users, meaning both persons with severe mental disorders and their relatives. The main purpose of a Knowledge for Health centre is health education, planned activity designed to produce health or illness related learning (Green & Tones, 2010). The aim is to help the

service users lead a more productive and meaningful life within the community by offering evidence based theoretical and experiential knowledge of health and mental disorders. Activities at the Knowledge for Health centre are run by clients and staff on an egalitarian basis and in close partnership with local healthcare and social services in the municipalities within the hospital's catchment area. The Knowledge for Health centre should take advantages of the experience and evaluations from the Fountain house and Clubhouse Model (Lehtinen, 2008), a partnership movement addressing important health promotion initiatives for persons with severe mental disorders and addiction.



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Figure 7: The knowledge for health centre

9 Conclusion

This thesis shows that lived experiences by persons with severe mental disorders can be a rich and important source of information contributing to the health promotion knowledge base.

The study's title is 'Positive mental health – from what to how'. The question 'what is mental health?' was answered in paper 1 and illustrated in the Figure 8.

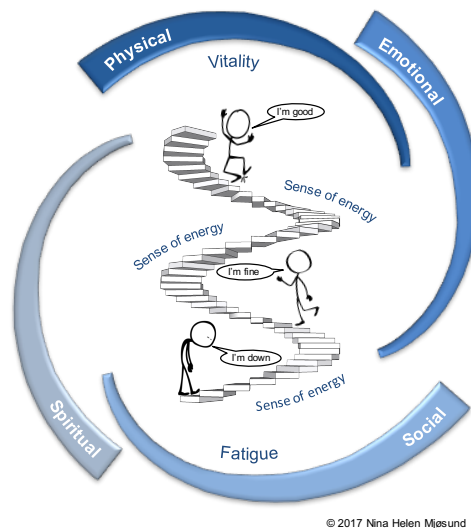


Figure 8: Perceived mental health

- Mental health is dynamic like a movement up or down a staircase and is an ever-present aspect of life.
- Mental health is nourished by experiences in emotional, social, spiritual and physical domains of life, accompanied by a sense of energy.
- Perceived mental health is expressed through body language and everyday spoken language.

As presented in paper 2, the mental health promotion experiences from the inpatient setting of a mental healthcare hospital could help answer the question of 'how' in the study's title.

- The learning processes that occurred in the hospital were health promoting.
- The former patient's appetite for both salutogenic and pathogenic knowledge was motivated by a craving for less illness and more health and wellbeing in future daily life.
- The former patients support the evolvement of educational activities to complement the curative activity of mental healthcare hospitals.

There seems to be promising prospects of service user involvement in research studies, evaluations, and in the reorientation of the healthcare services. In paper 3 we presented

features of the applied service user involvement in the present study. In Figure 9, from paper 3, the levels of involvement at the different stages of the research process are illustrated. The levels of involvement were dynamic and varied throughout the research process.

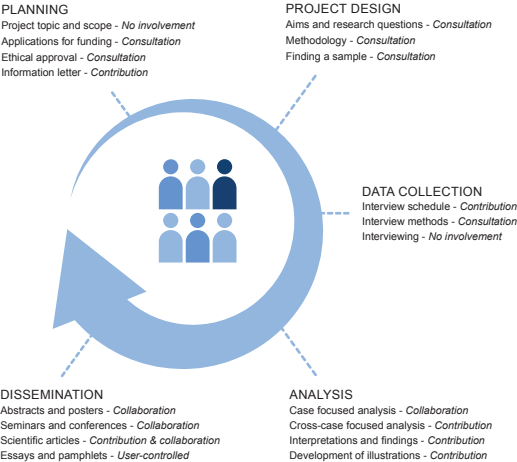


Figure 9: Levels of involvement in the stages of the research process

The advisory team identified six significant features that facilitated their contributions to the research process and helped them both to see themselves as valuable resources and to feel competent. The features are illustrated in Figure 10, from paper 3.



Figure 10: The collaboration process - working structure and atmosphere

- Clarification of roles among the partners.
- A predictable meeting structure.
- Clear leadership promoted a safe and supportive setting.
- Being a member of a team.
- The focus on possibilities to counterbalance a focus on obstacles.
- Being seen and treated as a whole person, with a life story which included life events and experiences of both health and mental illness.

The power of multiple perspectives came across in the collaboration processes between the advisory team and the researcher. In paper 4 we examined and described the joint process between the advisory team and the researcher that involved analysing the empirical data from interviews with the participants. As illustrated in Figure 11 from paper 4, the advisory team became ‘the researcher’s helping hand’.

- The variety of perspectives gave more insightful interpretations of nuances, complexity, richness or ambiguity in the interviewed participants’ accounts.
- The interpretative element of IPA was enhanced by the emergence of multiple perspectives in the analysis of the empirical data.
- Essential to increasing understanding of the participants’ experiences was the viewpoints of service users with similar experiences of struggling with mental disorders, at the same time and place as the participants.



Figure 11: The researcher's helping hand

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Attachments

Attachment A: The information letter to the advisory team

Attachment B: Presentation of the advisory team members and the research fellow

Attachment C: The information letter to the participants

Attachment D: The interview schedule

Forskningsprosjektet: God psykisk helse - fra hva til hvordan

Hva er opplevd god psykisk helse og hvordan kan den styrkes og beskyttes – pasienterfaringer fra dagligliv og innleggelse i psykisk helsevern

22.2.12.

Forespørsel om å delta i referansegruppe

Vi vil spørre deg om å delta i en referansegruppe i forskningsprosjektet: "God psykisk helse – fra hva til hvordan" ved Klinikk for psykisk helse og rus, Vestre Viken HF. Referansegruppen skal bidra i utviklingen av prosjektet gjennom hele forskningsprosessen. Prosjektet starter i januar 2012 og er beregnet avsluttet etter tre år. Gruppen vil bestå av tre personer med pasienterfaring, en pårørende og to helsepersonell, i tillegg til forskeren som er ph.d.-kandidat.

Prosjektets formål er og utforske god psykisk helse hos personer med psykisk lidelse. Psykiske helse er noe annet enn fravær av psykisk sykdom. Helse kan styrkes gjennom tiltak som fremmer velvære *samtidig* med at sykdom bekjempes. Sykehus har et sterkt fokus på sykdom, symptomer, diagnoser og behandlingstiltak. Kunnskapsgrunnlaget er hovedsaklig basert på patogeneseperspektivet (sykdommers opprinnelse). En komplementær kunnskapsutvikling basert på en salutogen (helsens opprinnelse) tilnærming gir fagfeltet flere verktøy. Formålet med studien er å utvikle kunnskap om god psykisk helse gjennom å undersøke helsebringende erfaringer. Vi vil undersøke hva som beskytter og fremmer helse i sykehusavdelinger i psykisk helsevern.

Personer som tidligere har vært innlagt vil intervjues for å få frem deres erfaringskunnskap. Følgende aspekter utforskes: A) hva er god psykisk helse B) hva oppleves som helsebringende erfaringer og hva svekker den psykiske helsen og C) erfaringer med helsefremming under sin innleggelse i sykehus og D) hva er deres mening om hvordan sykehusets tilbud bør utvikles for å fremme helse samtidig med at sykdom diagnostiseres og behandles.

Informantene i studien er personer som har vært innlagt i en døgnseksjon i Klinikk for psykisk helse og rus i Vestre Viken HF i løpet av de siste to år. Vi planlegger å snakke med ca 15 personer i forskningsintervju. Intervjuene vil vare ca 1 ½ time, ved behov kan det bli flere møter med samme informant. Vi ønsker å gjøre lydopptak av samtalen og informanten kan selv bestemme hvor intervjuet skal gjennomføres.

Medlemmer i referansegruppen er personer som vil bidra i utviklingen av forskningsprosjektet. Personer med en spesiell kompetanse ønskes. Vi ønsker å få medlemmer som har erfaring med spesialisthelsetjenestens psykiske helsevern fra forskjellige roller og posisjoner. Tre medlemmer vil ha tidligere erfaring fra pasientrollen, gjerne erfaring fra innleggelse, og en pårørende til en nærstående som har vært i behov av innleggelse i psykiske helsevern. To medlemmer i tillegg til forskeren, er helsepersonell med spesialistutdanning innen psykisk helsevern. Alle har interesse for helsefremming og ønsker å bruke sine erfaringer og kompetanse til å utvikle forskningsprosjektet.

Aktuelle oppgaver for referansegruppen er å delta i utformingen av informasjonsmateriell om studien, informert samtykke og intervjuguide. Gruppen vil være et forum for diskusjon og vil kunne gi innspill til valg og prioriteringer i utvikling av prosjektet gjennom hele forskningsprosessen. Ved

deltagelse vil du gi et verdifullt bidrag til et forskningsprosjekt som prøver å øke vår kunnskap om god psykisk helse og utvikle helsetjenestene til å fokusere mer på helsefremming. Dette er i tråd med lovverk, retningslinjer og politiske føringer som regulerer helsetjenestene.

Referansegruppen er åpen i den forstand at medlemmer kan velge å gå ut av gruppen før forskningsprosjektet er avsluttet. Medlemmer som ikke er ansatt i Vestre Viken vil motta reise- og møtegodtgjørelse etter etablerte takster for brukermedvirkning. Arbeidsformen til gruppen kan medlemmene i samarbeid med forskeren selv være med å utforme, det kan være seg på telefon, via e-post og ved deltakelse på møter. Møtehyppigheten vil kunne variere avhengig av arbeidsmengden, men minst et møte i semesteret vil planlegges. Møtene vil bli avholdt sentralt i Drammen eller der det passer best for medlemmene.

Taushetsplikt: Medlemmene i gruppa forplikter seg til et taushetsløfte når det gjelder informasjon som tilflyter medlemmene om de andre medlemmene i referansegruppa eller informasjon i tilknytning til forskningsprosjektets innsamlede datamateriale.

Prosjektleder: Psykiatrisk sykepleier Nina Helen Mjøsund, ph.d. kandidat ved Norges Teknologisk og Naturvitenskaplige Universitet og spesialkonsulent ved Forsknings- og utviklingsavdelingen i Klinikk for psykisk helse og rus, Vestre Viken HF, postboks 135, 3401 Lier. Jeg kan kontaktes på e-post nina.helen.mjosund@vestreviken.no eller direkte på mobil 97097708.

Veiledere: Professor Geir Arild Espnes, leder ved senter for Helsefremmende forskning, avdeling for sosialt arbeid og helsevitenskap ved NTNU, og førsteamanuensis Hege Forbeck Vinje, Institutt for helsefremmende arbeid, Fakultet for helsevitenskap, Høgskolen i Vestfold, og Politices Doktor, universitetslektor Monica Eriksson, Högskolan Väst, Institutionen för Omvårdnad, Hälsa och Kultur, Avdelningen för Hälsa och Kultur, SE-46186 Trollhättan, Sverige.

Finansiering: Vestre Viken HF finansierer forskningsprosjektet. Det vil også søkes andre kilder om finansiering.

Samtykke til deltakelse i referansegruppen i forskningsprosjektet:

God psykisk helse – fra hva til hvordan

Jeg er villig til å delta i referansegruppen i forskningsprosjektet

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om prosjektet

(Signert, rolle i studien, dato)

Each individual made the following presentations. They were written in Norwegian and then translated to English. The first versions were finalized March 2013. The attached versions were updated December 2016. All members of the advisory team explicitly approved the presentations.

Research fellow Nina Helen Mjøsund leads the advisory team and can be contacted at sbmjon@vestreviken.no or nina.helen.mjosund@gmail.com

Motivation for initiating the project and the advisory team: In the last years I have developed a strong interest in people's inner strength and resources. How growth, thriving and joy can be promoted by actively and consciously seeking out positive opportunities rather than solely focusing on limitations and problems fascinates me. The theoretical knowledge on health promotion and salutogenic processes made me believe that especially the mental healthcare sector can develop new tools based on this approach. Mapping out this field of knowledge showed that little exploration has been carried out on the meanings of the patients and their experiences of what promotes mental health and what positive mental health entails for them. Inspired by user involvement, I wanted to bring the patients' and relatives' perspectives actively into the study. Hence the advisory team was initiated, thereafter developed in cooperation with its members.



Experience with the health services: The majority of my experiences with the health services have been as an employee. I was trained as a nurse in the nineteen eighties when nursing science and approaches of care were still heavily influenced by the medical model. In the nineteen nineties I qualified as a psychiatric nurse and completed my master in nursing science (Cand.san./MNSc) in 2003. Taking my own training to become a nurse and later a psychiatric nurse into consideration, the majority of my training provided knowledge about the consequences of disease in daily life and I acquired skills caring for the sick. I am proud to be a nurse and the training in nursing science was influential for my working career. I recognize that my own assumptions changed over time and during my career, especially after I started working in a more multidisciplinary way. In the later years I have been educated in public health and health promotion; a turning point for me to embrace an expanded role as a 'mental health nurse'.

I have held various positions in the specialized healthcare services, all in hospitals. At first, I worked with children and their families. I developed a particular interest in children with chronic diseases such as diabetes and cystic fibrosis. Thereafter, I worked with young adults with severe mental disorders. In the later years, management and mental health research and development have been my field.

A couple of years ago my mother suffered a serious depression; at the same time my father was dying of cancer. In this period of about a year I experienced being the close relative of my severely ill parents. Encounters with the health services included contact with their GP, community healthcare and both mental health and somatic hospitals. This experience has been an important motivation for the project.

Thoughts on developing the health services: A lot of excellent treatment and care are provided in healthcare services and many receive help. But I do believe that the time spent in hospital can also be used to actively promote people's resources and their own strength in the recovery process, strengthen their ability to cope with new outbreaks and to improve health and quality of life. However, we have little knowledge about this kind of approach. It is therefore important to acquire more knowledge through research, so that health promoting initiatives can be evidence based. I also believe that the patients' own experiences can be utilized actively both in research and with regards to prioritizing in clinical practice.

Other roles and interests: I am 54 years old, married, the mother of two young adults and daughter of a mother who lives more than 700 km away. I enjoy skiing and staying fit. Spend as much time as I can in my Croatia – my holiday destination of choice.

Relative advisor **Lise Baklund** can be contacted at lise.baklund@vestreviken.no.

Motivation for participating in the project: In a few years working as a family therapist and philosopher I have come to recognize one important fact. The knowledge, about which factors contribute to health, and the dissemination of this knowledge, has greater impact when conveyed by someone who has personal experiences of struggling with illness. Stories from therapy told by families and individuals about resources and turning points in life have helped me when working with other patients and families. There is a lot of value to be found in the transfer of these stories.



Experience with health services: My experience with the health services has been gained as an employee, a patient and a relative within both psychiatric and somatic healthcare services. In my family mental health is something that goes up and down, sometimes quite far down. As a family therapist working in child and youth psychiatry, encounters with young people in mental crisis and their families have made me particularly aware of existential issues in therapy. In addition to several years of clinical experience, I have as an advisor in the R&D department been in charge of several development projects and participated in strategic work on department and division level.

Thoughts on developing the health services: My experience from the health services is that we focus too much on measures and methods, and not enough on the quality of the relationships and interactions between patients and healthcare providers. Health care professionals are often the ones who with simple resources can constitute a big difference for the patients, but do we leverage this resource to its fullest? We know that relationships to helpers are important and we should look at how these can improve further.

Professional background: I hold a master in philosophy, have worked in an addiction clinic with young adults, worked as a family therapist in an emergency department for youth, ran a private conversation centre and currently work as an advisor in the R&D department.

Other interests and roles: I am 45 years old, married, and the mother of two girls. I am involved in the activities that the girls enjoy: gymnastics, skiing, cats, arts and crafts. I enjoy cooking, chatting with friends, running in the forest, watching movies and reading. I had to leave the project in February 2014 due to heavy workload planning my PhD project.

Patient advisor **Mette Haaland-Øverby** can be contacted at mette.haaland.overby@gmail.com.

Motivation to participate in the project: This project affects me due to my experience from the healthcare services. Living with a mental illness has given not only personal experience but also professional interest in mental health. I recognize the salutogenic explanation of how coping and sense of coherence affect one's mental health. The project seeks to produce knowledge based on peoples experience with mental health, which I consider to be important in order to improve the services and increase relevance to patients



and relatives. My commitment to health concerns both work and studies, so I particularly find interest in the project's theoretical framework and methodology. My expectations include professional gains, new contacts and personal development through being able to contribute with my experience-based point of view. My reflections are built on experience both as a patient and as an employee. Participating in the advisory team allows me the opportunity to follow a research project I am interested in both on a personal and professional level, in addition to staying connected to a professional environment I have positive experiences from working with.

Experiences with the health services: I was an inpatient at the mental health hospital for 9 months and have received treatment as an outpatient for 5 years. I have participated in a psychoeducational multi-family group and been in contact with mental health care services as a preventive measure during pregnancy. Being treated in the mental healthcare services has allowed me to live a healthy life. Being admitted to hospital is an opportunity to find resources within a person which that person can make use of later on in the recovery process. The inpatient stay is only a small part of the recovery process measured in time, but I believe it is a crucial part of it. Overall, my experiences from the health services are positive.

Thoughts on developing the health services: My experience is that knowledge about what promotes good health in itself promotes good health. I believe that language is an important key to good communication, and wonder if the recovery process could start with healthcare professionals using language based more on patient descriptions than professional terminology when communicating with patients. Lived experiences of what is described in the textbooks can be used to express the same thing through a different language. Patients' experiences and descriptions can form the tools necessary to develop the health services. My wish is for the mental healthcare services to involve people with user experience at all levels of the service, and that collaborative research is prioritized and experiential knowledge recognized. Further, knowledge about mental health should be easily accessible to everyone and more people should have access to specialized healthcare and be given the opportunity to improve their health.

Professional background: I currently work as an experience consultant and co-researcher on projects run by the Norwegian National Advisory Unit on Learning and Mastery in Health (NK LMH). I studied social sciences at university and completed the training for employees with user experience as well as the course on cooperation based mental health research at

Buskerud University College. I have professional experience from the health services from working as a nursing assistant, an employee with user experience, a user representative, experience consultant and co-researcher. I receive 50 % disability benefits due to schizoaffective disorder.

Other interests and roles: I am 37 years old, married and have children born in 2012 and 2016. Having children was the greatest risk I could take in terms of relapsing into illness. It went well and I am enjoying parenthood. I have close relationships with my family and have some good long term friendships. I am philosophically and politically conscious, my finances are bad but my values are good. I give my health high priority, especially sources of positive mental health. My interest in and coping derived from nature and the outdoors has increased in line with my recovery process over the last few years, and this is something I will continue to nurture.

Patient advisor **Sven Liang Jensen** can be contacted at sven@liang.no.

Motivation to participate in the project: I wish to contribute towards demystifying and normalizing mental illness. More research, increased knowledge and understanding of mental health are important. Nobody can help being sick, but everybody can choose how they act and think if they get affected. The hope is that my experiences can contribute towards helping others and myself to develop coping strategies that can reduce the disadvantages associated with living with a mental illness. My experience is that different offers and measures from the ones I originally encountered in the healthcare sector have had the greatest positive impact on my recovery. I believe in people's ability to heal themselves under the right circumstances. Involving users is the key.



Experiences with the health services: I have struggled with repeated depressions for about 10 years. My first encounter with the health services was with my GP. I was diagnosed with moderate depression and put on sick leave. Through family I found a course on mastering depression, which was very useful for me. The depressions became both lengthy and repeated and I was referred to the specialized health services. I have received outpatient care and have been treated by four different doctors and one psychologist. Reading up on cognitive therapy, as well as trying out several forms of medication has been recommended to me. I was offered

a course on bipolar disorder that I greatly benefited from. The course gave me knowledge and factual information that has inspired me to develop coping strategies. Following this course I became a member in a self-help group for people with bipolar disorder. Here we experiences and develop coping strategies together. No matter how you feel or what you are experiencing the self-help group is there.

Thoughts on developing the health services: After long periods of assessments from 2004 a specific diagnosis was only made in the spring of 2009, which was later altered in the fall of 2011. The diagnosis itself does not concern me, however an ascertained diagnosis gives rights and opens up for offers that I would have liked to have accessed earlier, such as the bipolar course self-help group and cognitive therapy. What I am looking for are healthcare services that comprise more than anti-depressants and stabilizing medication. I feel a need for greater focus on preventive measures than the ones I have been offered. We need to focus less on treating individual symptoms, and rather look at the whole picture. Focus should be as much on exercise, nutrition, social offers and physical pain as it is on psychopharmacological drugs, in my experience. Treatment scenarios must include GP, the health services, the Norwegian Labour and Welfare Administration office, employers and family. When I am depressed I am not able to contribute actively to my own treatment, but I need help. Cooperation towards finding measures that are experienced as positive by the person who has fallen ill is important. An individual plan is a good tool. The person in question must be included in developing the treatment plan through user involvement. I wanted to participate in this research project to assist in unveiling knowledge about activities and measures that lead to improved mental health. It is necessary to develop knowledge about what is important for the person with a mental illness to thrive in addition to the knowledge we have about more traditional forms of treatment.

Professional background: I am a civil engineer from NTNU, and I have worked for large engineering companies. I have been chairman of the board, founder, and ran an online store.

Other interests and roles: I am 46 years old, married and the father of two teenage girls. My great passion is flying. I have flown model airplanes since I was 14, and I am now an ultra-light aviation instructor. I wish to contribute positively to society, work as a civil engineer and cultivate my interests in flying, diving and water sports. I need to be mindful of my own ups and downs and work actively with my coping strategies. Having a diagnosis does not make me a different person.

Patient research advisor **Solveig Helene Høymark Kjus** can be contacted at solvhele@online.no

Motivation for participating in the project: The project caught my attention because I have experiences from inpatient stays in the specialized health services. I have numerous experiences that have both strengthened and weakened my mental health. For me it means a lot to contribute towards an emphasis on what actually works. It also feels good that my experiences are seen as a valuable resource.



Experiences with the health services: I visit a community day centre and receive follow-up from the mental health services. I have also taken part in a treatment program with a multi-family group together with my parents. We continue to meet as a self-help group. The last few years I have spent a lot of time as an inpatient in at the hospital. Sometimes short acute stays, other times I have needed longer stays. What has been the most important for me are the good conversations where the person I am talking to is genuinely interested in understanding how I am doing in order to be able to help me. In addition, it has meant a lot to have meaningful activities such as creating something with my hands or experiencing nature during my hospital stays. This has provided some respite from all that is painful and difficult.

Thoughts on developing the health services: It scares me that the hospital has less and less focus on meaningful activities, now most of those kinds of activities have been discontinued. I believe there are others like myself who feel the need for a break from thoughts surrounding illness. Previously there were activity leaders in all departments. In my opinion one cannot expect people to recover faster when one has to constantly deal with the difficult matters.

Professional background: I have a PhD in physics and worked for a few years before becoming fully disabled. Despite not being able to work I stay in touch with the academic environment through participating in a research project at the University of Oslo.

Other interests and roles: I am 43 years old, previously married but now living alone in my house with a cat. I have a vegetable garden and lots of space for my hobbies. I spend a lot of time knitting, crocheting, doing decoupage, making candles, etc. In addition I enjoy being out in nature and these last years I have hiked across the mountains either with a tent or going from cabin to cabin a few days each summer. I believe it is important for me to stay in contact with friends and family and I prioritize this even though it is not always easy.

Relative advisor **Irene Norheim** can be contacted at sbnoir@vestreviken.no.

Motivation for participating in the project: In implementing and coordinating psychoeducational family work in the hospital, I have met many persons with severe mental illness and their families who have made a big impression on me. Many of them work hard to get better and to establish a life they are satisfied with, where interests and social networks are important elements. I am interested in how we as healthcare providers and ‘the system’ can support and strengthen this process and contribute by being cheerleaders. To achieve this we need more knowledge about health promoting factors and processes, therefore I believe this project is an important contribution! I also have family members who suffer from severe mental disorders. This has affected large parts of my life. I have seen first-hand how illness can be an obstacle to living and doing what one wants to do and be – experiences of loss, pain and sorrow I know my family members have felt. These are also experiences I have had from my relative’s point of view. I have a clear impression of what contributes to keeping hope alive; not giving up and pushing through, personal resources and abilities, will, the importance of having someone to love, having interests and engaging in meaningful activities, and good helpers.



Thoughts on developing the health services: My experiences as a relative and a professional have created a motivation in me to work on developing the services offered at the hospital. Both good and bad experiences throughout many years have shown me that there is a great potential for improvement, and often it is the small things that can determine whether the person and his/her network receive the help they need to be able to take steps themselves and experience that everyday life can be handled even through a difficult life situation.

Professional background: I trained as an occupational therapist and hold a master’s degree in clinical mental health. In addition I have been educated in the fields of health education, management and psychoeducational family groups. I have worked as an occupational therapist, a manager in the community health services, a project manager, and since 2005 I have been in charge of the coordination and implementation of psychoeducation family work in our Division of mental health and addiction.

Other roles and interests: I am 47 years old, married and the mother of two boys. My interests include physical activity, reading, spending time with family and friends. I also enjoy traveling and experiencing people, nature, and sightseeing!

Relative advisor **Inger- Lill Portaasen** can be contacted at ingerlill.portaasen@ebnett.no.

Motivation for participating in the project: As the parents of a daughter with schizoaffective disorder, we have had two very different encounters with the healthcare services in two different counties. In the first county we received little to no information, and the psychiatry was defined by concealment, denial, shame



and Freudian guilt distribution. We were put on the side, like the disempowered and uninformed spectators of a negative approach. When we moved to a different county, we met a different form of treatment and understanding of illness. The focus was on acknowledgment, knowledge, achievements and openness, and as parents we were seen as an important resource in our daughter's healing process. This quantum leap is my motivation for participating in the project. I have been given the opportunity to be a resource rather than a problem, and my wish is for other relatives to also have this experience.

Experience with mental healthcare services: My first meeting with psychiatry was a shock. To my horror I realized that I was being viewed as the cause of my daughter's problems; this shattered my fragile self and dismissed me to the sideline. I still refused to feel ashamed though, and broke the interdict on speaking to my daughter about her problems. I demanded and practiced openness, thus experiencing an interesting cultural collision.

In our current county the contact has been very positive. My daughter's experience is that of being believed and taken seriously; she received good help. As parents we were invited to participate in a psycho-educative multifamily group. There we experienced the positive effect of working methodically to master practical situations and feelings. I have an unwavering faith in the individual's inherent resilience, and have been allowed to contribute towards mobilizing my daughter's inner strength and resources. At home we work a lot on registering and celebrating achievements, and I feel like an important contributor. This has rebuilt my self-esteem, and for my daughter's sake I believe this is important. From time to time my daughter and I are asked to share our experiences from participating in a psychoeducational multifamily group. This is something we are very happy to do. We have also recorded this sharing of experiences as an educational DVD.

Thoughts on developing the mental healthcare services: I believe that it is important to activate and nourish each individual's resilience and enable health promoting experiences. This is something I would really like to be a part of working towards introducing or re-

introducing as a part of the methodological approach within psychiatry. Unfortunately, when it comes to budgeting, this type of activities often get dismissed as either dispensable or immaterial, despite providing an experience of mastery and the possibility to express inner pressure through another language. It gives me great concern that the treatment offered can vary so much depending on which part of the country you live in, or which therapist you happen to be allocated. I would like to see a national debate on what and how the mental healthcare services should be. Placing somatic and mental healthcare in the same location when new hospitals are being built is a sign of normalizing and acceptance of mental afflictions, but we are still far from what I wish for.

Professional background: I trained as a teacher, with master in folk art and Norwegian language and a specialist in school development and management. I have taught at all levels of school, as well as held positions in school management and as acting principal at a public skiing high school. I have also worked at an international school with English as the language of teaching and administration, and as a Norwegian teacher in adult education.

Other roles and interests: I am 63 years old, divorced, and the mother of three adult children plus grandmother of two. I have been politically active for 30 years, mostly in the domains of culture and health. I combine an interest in botany with photography and hiking in the mountains together with my poodle Silver. I am also a member of a history group that engages in Knights' sports.

Forespørsel om deltakelse i forskningsprosjektet:

God psykisk helse - fra hva til hvordan

Hva er opplevd god psykisk helse og hvordan kan den styrkes og beskyttes – pasienterfaringer fra dagligliv og innleggelse i psykisk helsevern

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie ved Vestre Viken HF. Hensikten med studien er å utvikle kunnskap om god psykisk helse hos personer som har en psykisk lidelse, og hvordan god psykisk helse kan fremmes i sykehus.

Psykisk helse er noe annet enn fravær av psykisk sykdom. Både opplevelsen av psykisk velvære og sykdomsbelastning kan virke inn på vår opplevelse av å ha en god eller dårlig helse. Vi er interessert i hva god psykisk helse er for deg i ditt liv. Vi jakter på de positive historiene og vil høre om dine helsebringende opplevelser og hva du mener svekker din helse. Vi vil snakke med deg om du opplevde noe som fremmet din psykiske helse mens du var innlagt. Vi er også interessert i din mening om hvordan sykehusets tilbud bør utvikles for å fremme helse samtidig med at sykdom diagnostiseres og behandles. Ved deltagelse vil du gi et verdifullt bidrag til en studie som prøver å øke kunnskapen om god psykisk helse og om hvordan vi kan utvikle helsetjenestene i en mer helsefremmende retning.

Hva innebærer studien

Jeg ønsker å snakke med deg om dine opplevelser og erfaringer i et forskningsintervju, der vil det fokuseres på tema som kan besvare forskningsspørsmålene. Hvis du samtykker i å delta, vil vi sammen avtale tid og sted for et intervju. Intervjuet varer ca 1 ½ time, pauser kan legges inn etter behov og vi kan møtes flere ganger. Du kan selv bestemme hvor intervjuet skal foregå, enten på et kontor ved forskningsavdelingen, hjemme hos deg eller et annet sted.

Mulige fordeler og ulemper

Deltagerne i forskningsstudien vil bli spurt om å reflektere og fortelle om sine helsebringende erfaringer og gode opplevelser. Det å beskrive og dele erfaringer kan gi mulighet til å få øye på og bli bevisst ressurser en selv har eller som finnes tilgjengelig. Et forskningsintervju er noe annet enn en terapisaftale, men noen ganger kan det å samtale gjøre at vanskelige og sårbare temaer blir berørt. Hvis dette skjer med deg og du ønsker hjelp til å håndtere dette, vil prosjektleder hjelpe deg med å få kontakt med behandler på sykehuset. Hvis behovet er av mer avgrenset karakter, kan prosjektleder, som er spesialsykepleier i psykisk helsearbeid, tilby seg å snakke med deg spesielt om dette.

Hvordan vi spør akkurat deg

Vi er interessert i kontakt med personer som har vært innlagt i en døgnsseksjon i Klinikk for psykisk helse og rus i Vestre Viken HF i minst to uker i løpet av de siste to årene. Prosjektleder har snakket om forskningsstudien med behandlere ved forskjellige seksjoner i klinikken. Behandlerne er deretter bedt om å spørre personer de har i behandling og som de tror kan delta og bidra i forskningsstudien. Derfor er du blitt spurt.

Hva skjer med informasjonen fra deg

Informasjonen du bidrar med i forskningsintervjuet skal brukes til å utvikle kunnskap om god psykisk helse slik det er beskrevet i hensikt med studien (se over). Vi som gjennomfører intervjuene eller behandler opplysninger om deg har taushetsplikt og informasjonene du gir behandles fortrolig. Direkte gjenkjennerende opplysninger som navn og fødselsnummer erstattes

med en kode. Navnelisten som knytter ditt navn til koden oppbevares nedlåst og kun godkjent personell knyttet til prosjektet har adgang til navnelisten. For at vi skal få med oss alt som blir sagt i intervjuet, ønsker vi å gjøre lydopptak av samtalene. Lydopptaket kan deretter bli skrevet om til tekst, alt skriftlig materiale fra samtaler vil bli aidentifisert. Dette betyr at navn, steder og annen informasjon som kan si hvem du er, blir endret slik at resultatene publiseres på en slik måte at din identitet ikke kommer frem. Lydbåndopptakene oppbevares i låst skap ved FoU-avdelingen og skriftlig materiale fra intervjuene lagres på en egen forskningsserver.

Funnene fra studien vil bli formidlet gjennom vitenskapelige artikler og foredrag. Funnene vil da alltid være aidentifisert slik at det ikke er mulig å finne frem til hvem som har bidratt i studien. Forskere vi samarbeider med er underlagt samme taushetsplikt som oss. Opptakene vil hele tiden være under vår kontroll. Vi regner med at prosjektet avsluttes innen 31.12.2016. Datamaterialet (lydopptak og navneliste) vil vi likevel oppbevare fram til 31.12.22 for at det skal kunne være tilgjengelig for vitenskapelig arbeid eller kvalitetskontroll. Om ønskelig kan deltagerne få tilgang på resultatene av forskningsprosjektet etter at det er avsluttet. Prosjektet er godkjent av Regional komité for medisinsk forskningsetikk.

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, uten at dette vil få noen konsekvenser for din behandling ved sykehuset. Alle opplysninger vi da har samlet inn fra deg vil bli slettet, såfremt funnene fra studien ikke er publisert. Dersom du har spørsmål til studien eller ønsker å trekke deg, kontakter du prosjektleder. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side.

Prosjektleder: Psykiatrisk sykepleier og cand. san. Nina Helen Mjøsund, ph.d. kandidat ved Norges teknisk-naturvitenskapelige universitet (NTNU) og spesialkonsulent ved Forsknings- og utviklingsavdelingen i Klinikk for psykisk helse og rus, Vestre Viken HF, postboks 135, 3401 Lier. Telefon: [970 97 708](tel:97097708), e-post: sbmjon@vestreviken.no.

Veiledere: Professor Geir Arild Espnes, leder ved Senter for helsefremmende forskning, Institutt for sosialt arbeid og helsevitenskap, NTNU. Førsteamanuensis Hege Forbeck Vinje, Institutt for helsefremmende arbeid, Fakultet for helsevitenskap, Høgskolen i Vestfold. Politices Doktor, universitetslektor Monica Eriksson, Högskolan Väst, Institutionen för Omvårdnad, Hälsa och Kultur, SE-46186 Trollhättan, Sverige.

Prosedyre for videre kontakt:

Hvis du vil høre mer eller er positiv til å delta i prosjektet kan du gi beskjed til din kontakt i sykehuset som gir beskjed til prosjektleder. Du vil da bli kontaktet av prosjektleder. Du kan også selv når som helst, kontakte prosjektleder for å melde deg som deltaker i forskningsprosjektet. Samtykkeerklæringen (se neste side) må underskrives før forskningsintervjuet starter.

Finansiering av prosjektet

Prosjektet er finansiert av Vestre Viken HF. Det finnes ingen interessekonflikter eller bindinger som påvirker prosjektleders uavhengighet.

Samtykke til deltakelse i studien:

God psykisk helse – fra hva til hvordan

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle, dato)

God psykisk helse – fra hva til hvordan

ID.NR. _____

Intervjudato: _____

Jeg vil starte med noen innledende spørsmål før vi går over til å snakke om dine erfaringer som vi er interessert i for å utvikle kunnskap om helse.

Bakgrunnsopplysninger

Alder:

Kjønn:

1. Høyeste fullførte utdanning:

Grunnskole:

Videregående:

Høyskole:

Universitet:

Annet:

2. Bosituasjon – bor sammen med:

Alene:

Samboer:

Ektefelle/Partner:

Enke/enkemann:

Besteforeldre:

Barn:

Kollektiv:

Slektninger:

Andre:

3. Arbeid eller utdanning i nåsituasjon:

Fulltidjobb:

Deltidjobb:

Hjemmeværende:

Fulltidsstudent:

Deltidsstudent:

Kombinerer jobb og studier:

Arbeidssøkende:

Annet:

4. Andre faste aktiviteter på dagtid:

Dagsenter:

Frivillig arbeid:

Hobbyaktiviteter:

Annet:

5. Deltar du jevnlig i noen fritidsaktiviteter?
fotoklubb

Kirke, idrettslag, kor, musikk, filmklubb,

Hva:

6. Andre ting:

7. Første gang du ble diagnostisert med en psykisk lidelse:

Årstall:

8. Hvilke tjenester har du benyttet eller hatt kontakt med?

DPS: Sykehus: Poliklinikk: Tjenester i kommunen: Hva da?

Poliklinikk: Privat institusjon: Private tilbud: Hva da?

Annet:

9. Hvilke behandlingstilbud benytter i dag?

Sykehus: Poliklinikk: Tjenester i kommunen: Hva da?

Annet:

10. Kjenner du hvilken diagnose du fikk ved siste innleggelse i sykehuset?

11. Har du deltatt i noen form for kurs eller seminarer der du har lært om sykdommen?

12. Hvor mange ganger har du vært døgninnlagt?

En gang: 2: 3-5: 5-10: >10:

13. Når var du døgninnlagt sist? Hvor:

DPS: Sykehus: Annet:

14. Bruker du medisiner til behandling av din psykiske lidelse: Hvilke type medisiner:

Antipsykotika: Antidepressiva Sovemedisiner: Beroligende:

Annet:

15. Andre opplysninger:

Temaguide med mulige underspørsmål for bruk i individuell dybdeintervju:

Hensikt: Å besvare forskningsspørsmålene

Hva er god psykisk helse?

Åpent spørsmål. Ingen spesiell kontekst. I livet ditt. Inkluderer drømmer, tanker, forestillinger. Nåtid, fortid og fremtid (barn, i ungdommen, tidligere faser av livet, før og etter sykdomsdebut eller andre viktige livshendelser)

Hverdagsliv

Kan du fortelle meg hva det betyr å ha det bra for deg i ditt liv?

Utdypende: Hva betyr det å ha god psykisk helse? Hva kjennetegner den? Hvordan merker du det? Hvordan oppleves det? Hvis du fritt kunne drømme hvordan en er drømmedag for deg? Hva må være tilstede for at det kan beskrives som god psykisk helse? Kan jeg se det på deg tror du? Fortell om opplevelser som har gitt deg en følelse av god styrke? Er det å ha god psykisk helse bra i seg selv eller er det bra for noe annet også? For hva da? Er det bra for andre at du har det bra? Hvordan da?

Kan du fortelle om hvordan det å greie ting du synes er utfordrende påvirker din psykiske helse?

Utdypende: Å gjennomføre (greie, mestre) daglige gjøremål hvordan påvirker det den gode psykiske helsen? Hvilken betydning har det at du greier å håndtere oppgavene i livet ditt?

Er det forhold rundt deg du vil trekke frem som påvirker din psykiske helse?

Utdypende: familie, venner, bolig, tilgang til butikker, naturen, kommunikasjonsmuligheter, aktiviteter, jobb, fritid, kjæledyr, andre personer, helsetjenester, organiserte aktiviteter.

Følelser

Hvilke følelser kan du knytte til opplevelsene av god psykisk helse?

Utdypende: Hvordan oppleves det, hva skjedde (skjer), hva kjente du i kroppen, halsen, brystet? Hørsel, syn, lukt, kroppslige uttrykk, inntrykk? Indre ideer? Kan du fortelle om noen opplevelser der du har følt deg sterk og hatt flyt, er glad eller lykkelig? Beskriv noe som kan gi deg en følelse av glede? Hva med lykke? En tilfredshet?

Begreper og beskrivelser

Hvis du skulle beskrive god psykisk helse med andre ord, hvordan vil du da beskrive det?

Utdypende: Hva sier du når du snakker om det å være i den positive enden av god psykisk helse? Hvilke begreper bruker du? Hva er det motsatte av god psykisk helse? Bruker du forskjellige ord i forskjellige situasjoner når du snakket om disse opplevelsene? Hvordan da?

Alder og livshendelser

Hvordan opplever du å bli eldre eller mer voksen i forhold til opplevelsen av god psykisk helse?

Utdypende: Er noe endret? Hvordan?

Kan du gi eksempel på noe du har opplevd som inneholder det du betegner som god psykisk helse?

Utdypende: Hvordan var det? Hva gjorde du? Hvordan kjentes det inni deg? Hva følte du? Andre sanseintrykk, lukt, lyd, smak? Kan du beskrive en opplevelse som får deg til å investere energi for å oppnå den igjen?

Andre mennesker – sosiale relasjoner

Kan du fortelle meg om hva felleskap og samvær med andre betyr for deg?

Utdypende: På hvilken måte? Kan du beskrive mer om hva som får deg til å fungere bra? Hvordan påvirker andre deg? Betyr det noe spesielt for deg? Hvordan da? Hvordan synes du ditt lokalsamfunn utvikler seg, blir det bedre for deg? Hvordan?

Bevegelse i helsetilstand - helsebringende eller helseforringende erfaringer

Åpent spørsmål, ikke knyttet til en kontekst. Skille på opplevelser og erfaringer i oppvekst og voksenliv, før, etter sykdomsdebut

Kan du oppleve at psykisk helse er noe som endres eller bevegtes? Hvordan oppleves det?

Utdypende: Hva opplever du hvis du får mer god psykisk helse? Hvordan merker du det? Hva kjenner du? Hvordan oppleves dette etter at du ble syk? Hva er eventuelt endret etter sykdomsutbrudd?

Er det noe med deg, i deg, eller i ditt liv som påvirker en bevegelse eller en stillstand i din helse?

Utdypende: Har du opplevd at noe er bra for helsen din, men du greier ikke å gjøre mer av det eller ta imot det?

Helsebringende opplevelser

Kan du fortelle meg om erfaringer i livet ditt som du mener styrket din gode psykiske helse?

Utdypende: Kan du fortelle meg om en opplevelse som fikk deg til å føle deg bedre? Skjedde det raskt eller over tid? Hvis du tenker på opplevelser som har vært bra for deg etter at du ble syk, hva vil du da trekke frem?

Helseforringende opplevelser

Kan du fortelle om noe du har opplevd som har forringet din psykiske helse.

Utdypende: Har du noen eksempler fra livet ditt der noe har brutt ned din psykiske helse. Kan du fortelle om en opplevelse som ikke var bra for deg, en hensenedsettende erfaring? Er det noe du kan gjøre noe med?

Helsefremmende erfaringer fra innleggelse i sykehus

Spørsmålene er knyttet til en kontekst; innleggelse og i tid til etter sykdomsdebut. Forankre beskrivelsene i tid, gjør det lettere å erindre opplevelser.

Hva var viktigst for din psykiske helse da du var innlagt i Klinikk for psykisk helse og rus?

Utdypende: Da du var innlagt opplevde du noe som fremmet din gode psykiske helse? Tenk tilbake, da du var på det dårligste, hadde du noen helsebringende opplevelser da? Var det annerledes når du var bedre? Hvordan?

Opplever du at det er andre forhold som påvirker din gode psykiske helse når du er innlagt sammenlignet med før og etter innleggelse, altså hjemme?

Utdypende: Hvordan da? Hva er annerledes?

Hvordan påvirker svingninger i sykdomsbelastningen din opplevelse av psykisk helse?

Utdypende: Hvordan? Kan du fortelle om noe du opplevde på sykehuset som beskriver dette?

Er det å ha det bra noe annet for deg nå, enn før du fikk den psykiske lidelsen?

Utdypende: Hvordan? Kan du fortelle om noe du opplevde annerledes?

Forslag til endring av helsetjenestene - hvordan få mer helsefremming i sykehus

Fremtid, hva kan endres for fremtiden. Drømmer.

Hvis du kunne bestemme hvordan skulle sykehusene endre seg for å bli mer helsefremmende?

Utdypende: Hva burde være annerledes? Hva bør vi gjøre mer av? Hva bør utvikles videre? Hva skal til for å få til en positiv endring? Hva kjennetegner et helsefremmende sykehus i psykisk helsevern mener du?

Mjøsund, N. H., Eriksson, M., Norheim, I., Keyes, C. L. M., Espnes, G. A. & Vinje, H. F. (2015) Mental Health as perceived by Persons with Mental Disorders – an Interpretative Phenomenological Study. *International Journal of Mental Health Promotion*, 17(4), 215-233. Doi: <http://dx.doi.org/10.1080/14623730.2015.1039329>.

Paper 1

Is not included due to copyright

Mjøsund, N. H., Eriksson, M., Espnes, G. A. and Vinje, H. F. (2016) Reorienting Norwegian healthcare services: listening to patients' craving for learning. *In review*.

Paper 2

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Paper 3

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Paper 4

RESEARCH METHODOLOGY: EMPIRICAL RESEARCH –
METHODOLOGYService user involvement enhanced the research quality in a study
using interpretative phenomenological analysis – the power of
multiple perspectives

Nina Helen Mjøsund, Monica Eriksson, Geir Arild Espnes, Mette Haaland-Øverby, Sven Liang Jensen, Irene Norheim, Solveig Helene Høymork Kjus, Inger-Lill Portaasen & Hege Forbech Vinje

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Abstract

Aim. The aim of this study was to examine how service user involvement can contribute to the development of interpretative phenomenological analysis methodology and enhance research quality.

Background. Interpretative phenomenological analysis is a qualitative methodology used in nursing research internationally to understand human experiences that are essential to the participants. Service user involvement is requested in nursing research.

Design. We share experiences from 4 years of collaboration (2012–2015) on a mental health promotion project, which involved an advisory team.

Methods. Five research advisors either with a diagnosis or related to a person with severe mental illness constituted the team. They collaborated with the research fellow throughout the entire research process and have co-authored this article. We examined the joint process of analysing the empirical data from interviews. Our analytical discussions were audiotaped, transcribed and subsequently interpreted following the guidelines for good qualitative analysis in interpretative phenomenological analysis studies.

Results. The advisory team became ‘the researcher’s helping hand’. Multiple perspectives influenced the qualitative analysis, which gave more insightful interpretations of nuances, complexity, richness or ambiguity in the interviewed participants’ accounts. The outcome of the service user involvement was increased breadth and depth in findings.

Conclusion. Service user involvement improved the research quality in a nursing research project on mental health promotion. The interpretative element of interpretative phenomenological analysis was enhanced by the emergence of multiple perspectives in the qualitative analysis of the empirical data. We argue

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Introduction

Interpretative Phenomenological Analysis (IPA) (Smith *et al.* 2009) is found to be a valuable qualitative methodology in nursing research in general (Snelgrove 2014, Strickland *et al.* 2015) and in mental health nursing research in particular (McCann *et al.* 2012, Albert & Simpson 2015). IPA is recommended in nursing and related disciplines as a valuable way to investigate and understand health, health care and illness from the service user perspective (Biggerstaff & Thompson 2008, Mapplebeck *et al.* 2013, Powell *et al.* 2014, Smith & Rhodes 2014). When using IPA, the researcher explores how participants make sense of their personal and social world (Smith 2015). IPA acknowledges the researcher's centrality to analysis and his/her ability to reflect on and analyse the accounts that the interviews provide (Brocki & Wearden 2006). Any help the researcher receives with the reflection and analysis process can add further depth to the findings (Wagstaff & Williams 2014).

Around the world today, involvement of service users in health research in general is on the rise (Nilsen *et al.* 2006, Boote *et al.* 2015, Forbat & Hubbard 2015), also in mental health research (Minogue *et al.* 2009, Staley 2009, Wallcraft *et al.* 2009) service user involvement is prevalent. Several research funding agencies now require applicants to

that service user involvement and interpretative phenomenological analysis methodology can mutually reinforce each other and strengthen qualitative methodology.

Keywords: advisory team, health research, interpretative phenomenological analysis, mental health promotion, multiple perspectives, nursing research, qualitative analysis, qualitative methodology, research quality, service user involvement

Why is this research or review needed?

- Improving nursing research methodology is an ongoing process.
- Service user involvement is requested, however evidence for its quality enhancing potential needs to be examined.
- Interpretative phenomenological analysis is commonly applied in nursing research. The methodology holds features that may benefit from service user involvement, in turn increasing the research quality.

What are the key findings?

- Involving an advisory team in the stage of analysis in a mental health project gave more insightful interpretations of nuances, complexity, richness or ambiguity in the interviewed participants' accounts.
- The power of multiple perspectives came across in the interpretation of interview texts by adding breadth and depth to the findings.
- Service user involvement and interpretative phenomenological analysis methodology can mutually reinforce each other. This methodology has the potential to make service user involvement meaningful, creative and manageable. The methodology can benefit from service user involvement in terms of validation of findings.

How should the findings be used to influence policy/practice/research/education?

- Researchers using qualitative methodology should adapt service user involvement in health and nursing research projects.
- Nurses in clinical practice and service users should be aware of the synergy and power of multiple perspectives brought into decision-making in nursing and healthcare research and development.

always consider involving service users in studies (Ives *et al.* 2013). Increasing focus is placed on evaluating the impact of service user involvement on health research and the potential benefits to research quality (Gillard *et al.* 2010,

Barber *et al.* 2011, Brett *et al.* 2014, Forbat & Hubbard 2015). However, a wide literature search identified few articles reporting on service user involvement in IPA studies. These articles included one user-led study (Pitt *et al.* 2007), another involving a mental health service consumer who transcribed the interviews (Knight *et al.* 2003) and one describing analytical dialogues with two academics that were service users (Wagstaff & Williams 2014). In addition, one paper reported on a participatory action research study using IPA as part of the analysis, where a mental health nurse manager worked alongside six people whose identity moved beyond ‘mental healthcare service users’ to embracing that of co-researchers (Hutchinson *et al.* 2012).

This article is based on our experiences conducting an IPA project which involved service users throughout the entire research process. The project ‘Positive mental health – from what to how’ explores how mental health is perceived by persons with severe mental illness (Mjøsund *et al.* 2015). The methodological framework was based on IPA. Influenced by the increasing demand for service user involvement in research and the flexibility of IPA (Smith *et al.* 2009), collaboration was established between the research fellow and five service users, whom are also co-authors of this article. Our 4 years of collaboration (2012–2015) have provided the experiences evaluated in this article. We report on how the multiple perspectives in our collaboration process contributed to deepening interpretations and enhancing research quality. Hence, we argue for a development of the IPA methodology through the involvement of service users in the research process.

Background

Interpretative phenomenological analysis

IPA draws on phenomenology and hermeneutic philosophy and is guided by an idiographic commitment towards particular instances of lived experiences (Smith *et al.* 2009). Examples include personal experiences of hope in the first episode of psychosis (Perry *et al.* 2007), early intervention in psychosis service (Harris *et al.* 2012), stigma in schizophrenia (Knight *et al.* 2003) and mental health crisis (Albert & Simpson 2015). The analytic process involves a double hermeneutic: the researcher makes sense of accounts of lived experiences told by participants, who in turn make sense of what is happening to them (Smith 2011). The philosopher Gadamer emphasizes the effect of history and tradition in the interpretative process, where meaning emerges from interaction between the text and the interpreter, in a fusion of horizons (Gadamer 1993/1960). Consequently, the analysts bring prior experiences, assumptions

and preconceptions to the encounter and the process of making sense emerges in the light of former experiences (Smith *et al.* 2009). The idiographic focus guides us to get close to the participants’ personal world, to explore the ‘insider’s perspective’ of the phenomena being studied. Experiential knowledge and perspectives with less distance between experience and interpretations can contribute to more reliable and accurate findings (Beresford 2005). The analytic process of IPA is characterized by flexibility, rather than a prescription of a single method for working with qualitative research data (Smith *et al.* 2009). There have been discussions about relevant criteria in evaluating the quality of IPA (Brocki & Wearden 2006, Smith 2011). Smith *et al.* (2009) argued for Yardley’s (2000) general criteria for good qualitative research: sensitivity to context, commitment and rigour, transparency and coherence and impact and importance. Smith (2011) found it necessary to further specify these criteria and thus developed a set of guidelines to assess articles reporting IPA studies. He used these guidelines to rate over 50 articles as unacceptable, acceptable or good (Smith 2011). An acceptable article has a coherent, plausible and interesting analysis; an unacceptable article has an analysis not of sufficient interest and is poorly evidenced. Smith (2011) further emphasizes that a good article meets the criteria of an acceptable article and additionally offers an in-depth analysis, where the interpretations are strong and successfully illustrate the complexity, ambiguity, richness and nuance in participants’ accounts.

Service user involvement

Service user involvement is desired and justified by ethical and theoretical (Ives *et al.* 2013), as well as political and methodological reasons (Bryant *et al.* 2012). Despite this trend of service user involvement, participation in the stage of analysis of qualitative research data are limited. A few notable exceptions exist. Gillard *et al.* (2012) describe a process of qualitative data analysis in a mental health research project with service user and carer involvement, leading to complex findings that would otherwise have been missed. Sweeney *et al.* (2013) demonstrate the value of multiple coding in enabling service users’ voices to be heard in qualitative data analysis. Flicker and Nixon (2015) describe their experiences with analysis of qualitative data in health promotion research designed to involve patients and community members. Also, in the tradition of participatory research involvement of service users in the analysis process is often neglected (Nind 2011). However, Jackson (2008) describes the participatory qualitative analysis process with marginalized women in three projects. Stevenson (2014) illustrates the process of data analysis together with

people with an intellectual disability. Cotterell (2008) discusses the analysis involving working together with service users suffering from life limiting conditions. Experiences of participatory processes, practices and pitfalls are described in a study involving socially excluded teenagers participating in data interpretation and analysis (Byrne *et al.* 2009). Experiences from setting up and working together with a service user research group are reported (Fothergill *et al.* 2012). However, in our literature search we were unable to identify articles discussing involvement of an advisory team of service users in the analysis and its outcome on research quality. Albeit, the literature on qualitative methodology has given some attention to the inclusion of teams of researchers (Pope *et al.* 2000, Pope & Mays 2006) and teams of researchers with different backgrounds (Bradley *et al.* 2007), as well as triangulation through multiple analysts (Patton 1999). Despite this trend of involvement in the stages of the research process, there are few examinations of adverse impact of service user involvement. Apart from Forbat and Hubbard (2015) who claim that caregivers trained to interview may lead to contrary rather than collaborative accounts.

Service user involvement in research can be characterized on a continuum from low to high (Hickey & Kipping 1998). The research process includes several stages and the level of involvement can alter between: (a) consultation; (b) contribution; (c) collaboration; (d) control and finally no involvement (Sweeney & Morgan 2009).

The study

Aim

The aim of this study was to examine how service user involvement may contribute to the development of IPA methodology and in turn enhance the research quality.

Design

A case study design was used to investigate the contemporary process of collaboration in depth. Case study design is an empirical inquiry which study phenomenon in its real-world context, when the boundaries between the phenomenon and context may not be clearly evident (Yin 2014). The inspiration and the point of departure for our examination in this article is the project 'Positive mental health – from what to how'. The purpose of this project was to explore, from a health promotion perspective, how mental health is perceived by adults affected by severe mental disorders along with inpatient experiences (Mjøsund

et al. 2015). Service users were involved in all stages of the research process. The method for service user involvement has materialized throughout the collaboration with five research advisors in an advisory team. The involvement of the team members in the analysis stage of the main project can be characterized as collaboration according to Sweeney and Morgan's (2009) levels of involvement. The collaboration level of involvement is when service users are in active partnership with researcher(s) in the research process. The power to make decisions is shared between the service users and the researcher (Sweeney & Morgan 2009). The collaboration between the research fellow and the advisory team is the contemporary phenomenon we investigate by a case study design (Yin 2014). The collaboration took place in 33 structured meetings of 2-3 hours in length over 4 years, each divided into two parts. The first part contained orientations and operational matters, while the second part was organized as a workshop. The workshop agenda focused on discussing research ethics, the theoretical framework, qualitative methodology, interpretations of research data and other relevant topics in the research process.

Participants

In the main project, 12 participants were purposively selected (Patton 2002), persons with experiences which could illuminate the research questions. These former inpatients interviewed are referred to as 'participants' (not to be confused with the 'research advisors').

The advisory team

Six potential members recognized from a large network of former participants in psychoeducation courses for patients with severe mental illness and their families were contacted and given an information letter developed by the research fellow. The letter described the topic of the main project, the purposes of service user involvement, allowance, tentative length of collaboration and meeting frequency, possible working methods and desired contributions and expected subjects for workshops. Meeting and travel expenses were covered in accordance to governmental guidelines. Six members were considered to be a suitable size to form a well-functioning team over time. The inclusion criteria were either living with a severe mental illness (psychotic or bipolar disorder) (three persons) or being a family member of someone living with a severe mental illness (three persons) and the ability to share experiences in a team. 'Patient advisor' (PA) or 'relative advisor' (RA) is used to denote team members either diagnosed with a mental illness, or having a family member with mental illness. The advisory team thus

holds experiences of similar life, health and illness events; in the same time period; from the same setting (a local hospital Trust); and from daily living in the same culture (Norway) as the project's participants. The advisory team has designed the following description of their relevant experiences in their own voice:

Patient Advisors: We have former, recent, present and ongoing extensive experiences from acute healthcare, long-time inpatient stays, coercive treatment and outpatient treatments in our local Hospital Trust. We are diagnosed with severe mental disorders. We possess experiences of being in recovery as well as being recovered, focusing on how to stay well and prevent relapse of the disorder. The perspectives of living alone or with a partner, or being divorced with a small as well as a large family are represented.

Relative Advisors: We possess experiences of being a parent, child or sibling to family members with severe mental disorders. We have years of experience with healthcare services aiming to get customized treatments and care for our family members. From very positive experiences, to some less positive ones, to negative experiences with the health services – the full range is represented in the team.

Patient Advisors and Relative Advisors: Some of us are engaged in service user organizations and in education and teaching by sharing our user experiential knowledge in groups and seminars. We vary in age from the thirties to the sixties. All of us are educated at university or university college level and some have academic training at master or PhD level. Members are, at the moment, either in full or part time jobs or education and some have income from the Labor and Welfare Service.

During the process of collaboration it turned out that the advisory team members possessed several competences, qualifications and skills which were not initially required. For example, one of the advisors is educated as a language teacher. This came in handy in the production of posters and presentations. One relative advisor decided to leave the team after two years because of a heavy educational workload. She has neither contributed to the analytical discussions described here, nor to the writing of this article.

The 'research fellow' (RF) is used to denote the first author, a mental health nurse with extensive experience from clinical practice and management positions in a mental health hospital. The project was supervised by a professor in health promotion research and two associate professors in health promotion, of whom two are trained nurses and one is a trained social worker. The supervisors did not take part in the meetings between the advisory team and the research fellow.

Ethical considerations

The main project was conducted in accordance with The Health Research Act (2008) and approved by the Norwegian Committees for Medical and Health Research (2012/566 B). Before the advisory team met and started working together, each team member signed an agreement aiming to secure the confidentiality of the participants in the main project. The first workshop was devoted to a comprehensive discussion of several ethical aspects. Practical dilemmas, such as how one might understand and apply confidentiality in different everyday situations (related both to the participants in the main project and to each other as research advisors) were addressed. The advisory team did not know the participants' identity and all identifiers (as age, names of; places; sections in the hospital; cities and villages; schools; profession) were removed from presented excerpts.

Each member was requested to make a presentation of her/himself which the research fellow was permitted to use in different situations when talking or writing about the team. The process of creating such a presentation formed a practical ethical clarification and trained the members to be consciously introspective and reflective about their own situation. Hence, an ongoing sensitivity and active focus on ethical dilemmas continued throughout the research process.

Data collection

The data used to interpret and discuss the outcome of the service user involvement was gathered from our analytical discussions in the main project. The research fellow conducted in-depth interviews guided by a semi-structured schedule; the interview dialogues were audiotaped; transcribed verbatim and made anonymous. In line with the IPA methodology an ideographic case focused analysis was carried out before the next interview was conducted (Smith *et al.* 2009). Hence, data collection and data analysis are simultaneously ongoing processes in IPA studies. The stages of the analytical process are illustrated in Figure 1.

Preliminary interpretations based on analytical discussion in the advisory team and with supervisors on transcripts from the three first interviews identified preliminary themes. This process was aided by the computer software NVivo 10 (QSR International 2012). Paragraphs in the transcripts regarding the preliminary theme: 'emotions related to mental health' were identified. The advisory team collaborated with the research fellow to analyse this preliminary theme more in depth. Parts of transcribed interviews with

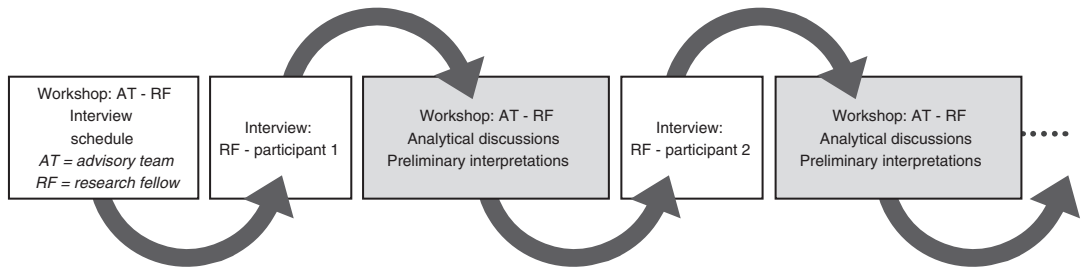


Figure 1 Collaboration in workshops between the advisory team and the research fellow.

emotional related issues were distributed to each advisory team member. To increase transparency (Houghton *et al.* 2013), a part of the interview dialogue between one participant and the research fellow which formed the base for the advisory team’s analytical discussion is presented in Table 1.

The advisory team revised the excerpts with the instruction to read and make notes alongside the paragraphs that had content they felt familiar with or where it concurred with experiences in their own lives. Paragraphs they became curious about or did not understand were also important to highlight. The research fellow listened to the specific audiotape from the interview with the participant and read the transcripts several times during the same period of time.

Data analysis

After these preparations, the team members and the research fellow discussed their notes and preliminary interpretations in workshops. These workshop sessions were audiotaped, transcribed and interpreted by one patient advisor and the research fellow influenced by Smith’s (2011) discussions on the characteristics of a good interpretative phenomenological analysis. In addition, the interpretations were discussed with the rest of the advisory team and the supervisors.

Rigour

To ensure robustness (Tobin & Begley 2004) of our inquiries and justify the best research practice or the pursuit of methodological rigour (Maggs-Rapport 2001), several decisions made throughout the research process need to be outlined (Houghton *et al.* 2013). The process of each team member creating a personal presentation formed, in addition to the ethical clarification, a team-building process where the advisors and the research fellow got to know each other. These reflexive accounts highlight how the team

members’ history and personal interests clarified the multiple perspectives applied in the data analysis, a procedure suggested to secure the credibility of studies (Houghton *et al.* 2013). From this process, a role clarification also emerged. The team members and the research fellow were perceived as equals, but with different roles and responsibilities in the collaboration. In the initial workshops, the advisory team received training in issues relevant for the research process. We focused on discussing research ethics, theoretical framework, qualitative methodology, aim of IPA methodology and interpretations of research data. Discussions about our own feelings and pre-understanding related to the phenomenon we investigated were conducted to enhance an active reflexivity on the roles as interpreters. The prolonged collaboration (4 years) between the team and the research fellow enhanced the possibility to gain a comprehensive understanding of the phenomena we investigated. Prolonged engagement is a mean to enhance the credibility (Houghton *et al.* 2013). The team collaborated with the research fellow in the creation of figures. Doing this together provided increased external validity (Yin 2014) of illustrations, making them more comprehensive and meaningful to a broader audience. During oral and poster presentations, we found that the advisory team had a certain way of reaching the audience, which strengthened the presentations. The advisory team members are co-authors of this article, which includes contributions to the study design and substantial collaboration in analysis and interpretations of the transcripts, as well as validating the article by revising the content critically. The collaboration on writing this article concurs with the recognized method of ensuring credibility of findings in case study research (Houghton *et al.* 2013).

According to Smith *et al.* (2009), rigour refers to the thoroughness of a study, in terms of the completeness of the analysis undertaken. That is close to the aim of this article, to discuss how involving service users in the analysis may contribute to a more thorough and complete analysis.

Table 1 Excerpt from the transcript of the interview between a participant and the research fellow.

Excerpt from transcript of an interview between a participant and the research fellow.

P = participant, RF = research fellow.

P That's how my sister's dog behaves. He is absolutely hysterical when I visit (laughs). Is it possible to be so happy to see someone (laughs)? It's all so very funny. However, I really benefit from the open air, if I manage to get out the door. It's not so important where I go when I get out the door.

RF Several people are talking about a threshold...

P Yes, it's there, you know.

RF You said nearly the same thing about your experiences in the hospital as well, with regards to getting both pushed and dragged?

P Yes, to get you started...

RF ...and then you get a rather good feeling afterwards once you have reached your goals. Keeping in mind this threshold ... there was one participant who told me that when she was discharged and returned home, a nurse visited her every day at ten o'clock so they could go hiking together.

P Hah! That's fantastic!

RF And so they hiked together for a few weeks until she finally managed to do it herself.

P Yes, really?

RF That was the assistance she needed at the start ... to get it to become a habit, a structure in her life then, and it had been very important for her to manage this activity.

P Yes, it was a sort of jumper cable (laughs).

RF Yes! Excellent! I like that kind of expression.

P (Laughs) It's a bit like putting jumper cables on the engine ... Yes, just to get started again, a little bit of help with the simplest little things can make you manage the threshold completely on your own finally, huh ... That is so important as well. I think there are many who do not understand the whole thing, the reasons why it can be so difficult to go over the threshold ... And then it's very fulfilling when you then come to the kind of place where they understand why you do not pass the threshold... It is important.

RF Yes, they must have the knowledge and be able to understand the challenges.

P Yes, they understand why we somehow can't manage to get it done.

Findings

Excerpts from our analytical discussions in a workshop are presented in Table 2. In this workshop, we discussed the transcript from the fifth interview conducted (see excerpts in Table 1). Hence, we brought preliminary assumptions from analytical discussions on former transcripts into the interpretation of this participant's account. In Table 2, our

dialogue is outlined in the left column; on the right side, we share our understanding of what each paragraph of the conversation adds to the analysis. We interpreted these paragraphs to confirm or correct the preliminary interpretations or to add more nuances, complexity, richness or ambiguity to the interpretations of participant's account.

As illustrated in Table 2, the advisory team played a central role in several levels of interpretations. The iterative element of the analysis in IPA research is seen in the dialogues between something we had discussed and made sense of and the new transcript of the interview with the next participant. The understanding became a pre-understanding in the face of something new; either a new interview text or an added account from one of the advisors. The involvement of service users in analytical discussions gave more complexity; it compared, contrasted and modified the interpretations as part of the sense making process and confirmed interpretations. Together, we possessed a potential for an expanded understanding. In Figure 2, we illustrate a metaphor; 'the researcher's helping hand' developed by the advisory team to illustrate how they perceive their position in the analysis stage. The advisory team expanded the horizon of understanding. The team perceived an increase in time and commitment to the project. This is illustrated by the gradual widening of the arrow.

Discussion

Our process demonstrates that service user involvement may be a means to enhance the rigour or trustworthiness of analysis in IPA studies. The purpose is to be sufficiently interpretative, to move beyond a simple description to an interpretation of what it means (Smith *et al.* 2009). Aiming to make sense of the participants' experiences in the main project, we wanted to strengthen the interpretation capacity by applying perspectives from service users with similar experiences as the participants. This concurs with Hutchinson *et al.* (2012), which recognized the relevance of service users' (co-researchers) direct experience of the service, treatment and diagnosis under discussion, to add insight and depth to the process of analysing in their study. The IPA methodology helps us make sense of the participants' understandings of their lived experiences through a comprehensive interpretation process, including the perspectives of the advisory team. According to Smith (2011), 'experience cannot be plucked straightforwardly from the heads of the participants, it requires a process of engagement and interpretation on the part of the researcher and this ties IPA to a hermeneutic perspective' (Smith 2011, p. 10). In our project, the help is organized systematically through service

Table 2 Interpretation of a conversation between the advisory team and the research fellow.

Excerpts from a conversation that took place at a workshop on preliminary interpretations of the interview with participant 'Paul'. Topic of discussion: feelings that can be involved in the experience of mental health.

RF = research fellow, PA = patient advisor, RA = relative advisor.

	Excerpts from the conversation:	Comments:
RF	In order to complete the tasks Paul set out to do; it sounds like he needs energy? Several participants likened illness to a shaky start engine unwilling to start. Is this referring to something similar? Some participants talk about others acting as a start engine for them. Is the start engine a good metaphor? Does motivation also get paralyzed when the start engine is paralyzed?	The research fellow adds related concepts from former participant interviews to the discussion.
PA3	When I am ill it feels like the motivation is chemically and physically gone. The human aspects or thoughts and emotions linked to motivation no longer exist and are not possible to access.	A patient advisor contributes with her experiences, which adds richness
RF	Is it possible to imagine how we can get the engine started? The motivation to do something about the engine that is not starting... is that also lacking? Is that determined by willpower?	The research fellow wonders and ponders over one preliminary interpretation.
PA3	Others can try to be a source of motivation, or they can remember for me what I have done before and what can get the engine started again. Others can see from an outside perspective how my health resources are doing.	A patient advisor confirms and draws a link to a more theoretical concept.
RF	Others can help with strengthening these health resources. With regards to this, Antonovsky also said that the health resources can be out there without us being able to access and use them.	The research fellow adds a nuanced theoretical understanding.
PA1	It is not that simple...	Patient advisor adds doubts.
RA2	When the start engine doesn't work, someone else can be of assistance by supporting and maintaining routines. That is possibly what one can do when someone is in that phase, stay by their side and be present until it starts working.	A relative advisor adds the important factor of significant others in the process of recovery.
RA1	My daughter now has this certainty that things will look up again. But is it the first, second or third time she is ill that she gets this certainty about things looking up again? Belief in the future also comes from experience. Things go uphill and downhill.	A relative advisor adds complexity.
RF	What is it about when one has been ill for many years? Is it a belief in the future or is it experience? And when does this certainty come?	The research fellow asks the team for their experiences, aiming to deepen the understanding.
PA1	I don't feel certain about things looking up again even though I have experienced it many times.	A patient advisor confirms and adds ambiguity.
PA3	Me neither. The participant invested in himself and in feeling good. That's the same for me in order to regulate myself. He has strength and willpower to act.	A patient advisor confirms and nuances the understanding.
RA1	You can't be invested when you are knocked out and down. It is a battle to get there.	A relative advisor confirms.
RF	...and it isn't driven by willpower, it might also be dependent on an illness too...	The research fellow ponders over an understanding
RA2	...timing maybe? Could it be about thinking in a different way?	A relative advisor confirms and adds complexity.
PA3	Maybe it's also about reconciliation and acceptance? The status of our health affects whether we are able to be invested in everyday life.	Patient advisor sees connections to other types of feelings.
PA3	Yes, when we are mentally ill the engine that is required to both improve our health and fight illness stops.	Patient advisor draws on lived experiences to form a more theoretical understanding.
RF	One participant said: It's not just the engine that stops, the battery is flat too.	The research fellow confirms with an example from another participant.
RA2	We experience a lot of similar things when it comes to our health, but the levels or processes that people with mental illnesses go through might be fundamentally different from those who don't have a mental illness. And what lies behind this difference?	Relative advisor ponders over something she doesn't understand related to her relative's lived experiences.
PA3	My functioning level when I have a bad day is lower than for a healthy person having a bad day. The scope is different.	Patient advisor confirms.
RA1	Having a bad day is more of a hindrance to living a full life for someone with a mental illness than it is for me.	Relative advisor also confirms.

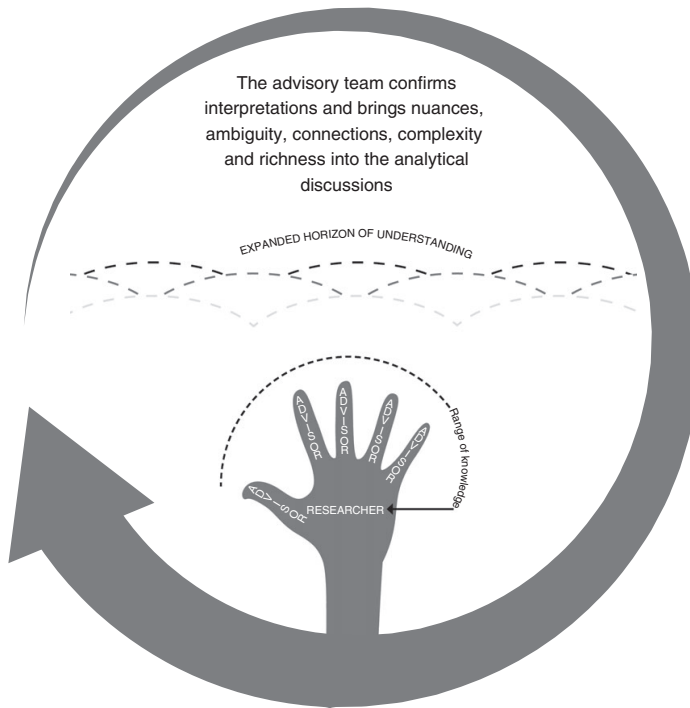


Figure 2 The impact from service user involvement – increased breadth and depth of findings.

user involvement. Thus, we claim that the advisory team contributes to what Snelgrove (2014) outlines as the aim of IPA researchers: to offer believable and confident representation of the participants’ experiences supported by meaningful data and well qualified themes. The advisory team possesses comprehensive insight into the phenomenon we sought to understand; the members added understanding from their own life, thereby deepening the understanding of meanings and enriching the interpretations. This added understanding promoted the requested move from the descriptive to the interpretative (Brocki & Wearden 2006). Service user involvement can thus be a means to increasing the rigour of IPA studies. Smith *et al.* (2009) refer to rigour as the thoroughness of a study. The analysis needs to be conducted systematically and thoroughly, with sufficient idiographic engagement. Bringing the perspective of service users into the analysis, we will argue, increases the completeness of the analysis undertaken. This is in line with benefits identified in a health promotion study applying participatory analysis with diverse stakeholders (Flicker & Nixon 2015).

Wagstaff and Williams (2014) describe how two academic service user reviewers assist the researcher in thinking about the participants’ experiences from an as informed

position as possible and sharing reflections on themes and issues in their IPA study. They argue for a better analysis, which includes a level of interpretation from the researcher that is partly informed by the input from the service user reviewers. Our experiences coincide with their acknowledgement of the service user reviewers’ ability to broaden the researcher’s thinking and to provide much needed perspectives.

As illustrated in Table 2, the research fellow shares her preliminary understanding with an explicit aim to gain input from the team. The multiple perspectives present in our team concur with recommendations by Bradley *et al.* (2007) to involving a team of researchers with different backgrounds to improve the breadth and depth of analysis and findings. The inclusion of teams in the analytical discussions is in accordance with methods to enhance the credibility in research (Yardley 2000, 2015, Powell *et al.* 2014) and it is based on the assumption that more than one analyst can improve the consistency or reliability of analyses (Pope *et al.* 2000, Pope & Mays 2006). Triangulation through multiple analysts to reduce potential bias that comes from a single researcher is also recommended (Patton 1999).

The understanding of the participants' meaning making and preliminary interpretations can be confirmed or nuanced through recognition in some of the advisors' lived experiences. When the patient advisor says: 'It is not that simple...' (Table 2) something happens in the team. We need to stop for a moment and go deeper into the issue being discussed. These situations may foster tensions in the team (Gillard *et al.* 2012). We solved the tension by viewing disagreement simply as a different perspective. This attitude promoted a climate where interpretation with an alternative content is not understood as a contradiction, but more as a new direction for understanding which can be followed or not. IPA is a research approach which accepts multiple versions of the reality dependent on interpretations (Snelgrove 2014). There are no definite versions or absolute certainties about a valid truth, rather, the ideal is to have good enough interpretations (Smith 2004). As also observed by Gillard *et al.* (2012), the range of perspectives in our team enabled us to elicit various possible interpretations and thereby to move beyond a simplistic analysis. In our efforts to describe the process of added interpretations, we ended up with metaphors like; 'layers of layers like in an onion' or 'building a wall brick by brick'. 'The researcher's helping hand' developed from a process where the team members came to acknowledge their own perspectives and experiences as significant. The perceived power of metaphors in our meaning making process is in accordance with the discussion of metaphors as tools for communicating and sharing experiences in studies with an IPA methodology (Shinebourne & Smith 2010). Gillard *et al.* (2012) reflect on the extent to which involvement of health service users in their research team coproduced knowledge through the qualitative analysis process. They recognize that a layer of interpretation begins from the interpreters' individual perspective (Gillard *et al.* 2012). This is what we tried to accomplish by giving the individual advisory team member time to work with each interview transcript before sharing understandings in workshops.

Involving the advisory team can also be understood as a move towards an improvement of the intersubjectivity of the interpretations (Smith 2011). Essential to IPA is the ontological assumption that a human being's position in the world is always perspectival, always temporal and always in relation to something. Knowledge is gained from the embodied nature of our own individual situated perspective of our relationship with the world; the experience is contextual (Smith *et al.* 2009). There is a chain of connections between embodied experience, talking about the experience and a participant's making sense of and emotional reaction to, the experience, Smith elaborates (2011). We would thus

argue that this is why IPA methodology is suited to make use of the power of multiple perspectives in the interpretation of research data.

Smith (2011) advocates validity checks by independent researchers with some interest and knowledge in the topic at hand, also known as peer validation (Kvale & Brinkmann 2009) or peer debriefing (Houghton *et al.* 2013). We have explored how research advisors with similar experiences of illness to those of the interviewed participants offer insights into how a given person (the participant) in a given context (daily life and inpatient stay in hospital) make sense of (perceives) a given phenomenon (mental health). In our project, the researchers and the advisory team's interpretations are not discussed with the interviewed participants, also known as member validation (Kvale & Brinkmann 2009) or member checking (Morse *et al.* 2002, Houghton *et al.* 2013). Both peer and member validation is advocated to support the credibility of the findings. However, it is debated and suggested to be used with caution (Houghton *et al.* 2013). Member checks may actually invalidate the interpretative work of the researcher and maintain a level of analysis inappropriately close to the data and the descriptive level (Morse *et al.* 2002). For us, it was also a question of resources and time, as well as the creation of more data brought into the analysis. Member validation may be an exercise which can produce a mountain of data, according to Smith (1994). However, researchers conducting co-operative inquiry take advantages of the reflexivity by including participants as fully self-reflexive co-researchers into studies. Engaging participants as co-analysts provides more than confirmation of interpretations, or member validation, it capitalizes on digging more deeply into the interpretative resources and the additional reflection of the participants (Smith 1994). We want to underline the significance of the purposive recruitment of each team member from the same context and with similar experiences as the participants of the actual IPA study. This is a feature of service user involvement, which ensures it can be applied in diverse cultures, settings and studies internationally.

The different team members identified, recognized and made sense of more implicit parts of the participants' accounts based on their recognition of what they themselves had experienced. They brought meaning to the surface by articulating some of the tactile and implicit features of the accounts of the participants. When reading Table 2 carefully, we can see that the research fellow often brings the dialogue back to theoretical frameworks, while the advisors have their attention closer to the participant's cognitive and affective reactions to their experiences. This concurs with findings in Gillard *et al.*'s (2010) investigation of the

impact of ‘service user researchers’ conducting qualitative analysis. The perspectives of the research fellow and the five advisors complement each other and together they, in the words of Gadamer, expand the horizon of understanding (Gadamer 1993/1960). We experienced that the synergy and power of several persons’ life stories helped us to explore in more detail the content and complexity of the meanings the lived experiences held for the interviewed participants, which in turn enhanced the quality in IPA. The community of our team enabled us to see further and wider than the researchers had the capacity to do on their own.

We wish to underline the benefits of bringing service users into the writing process as co-authors. The analysis developed further during the writing phase. According to Smith (2015), the division between analysis and writing up is, to a certain extent, a false one. Writing continues to give voice to the range of perspectives in the team (Gillard *et al.* 2012). We experienced the emergence of a new layer of interpretation while writing this article; the analysis is not complete until the last word is written down. Again, the perspectives from the advisors helped to bring forward what the research fellow initially had not seen. Beresford (2005) suggests the co-authorships from those who have similar experiences to draw on their first-hand knowledge. The input from the advisory team members by co-authorship in this article is of great value, credibility and legitimacy, in line with what Beresford (2005) requests.

Limitations

While presenting the multiple perspectives as a useful approach to analysis, the possibility of being too informed and becoming too dependent on our preconceptions and suppositions to catch sight of nuances and meanings in the participants’ accounts is recognized. We prevented this by the iterative element of IPA as described by Smith *et al.* (2009). For each interview, the research fellow moved mentally and practically back and forth through the data, adding perspectives from the team and going back to audiotapes and transcripts.

The focus of this article is on exploring our (the research fellow and the advisory team’s) own experiences. Other aspects might have come in the foreground if our collaboration had been evaluated by somebody else and according to other or added variables, prospective instead of retrospective.

Granting useful experiences on a novel application of service user involvement in the IPA methodology, the positive capacity of the advisors and the power of multiple perspectives may be due to artifacts of the research fellow and the

team members, rather than be a reflection of the method. Every project and every team involving humans has its own life and will develop along its own trajectory. The unique members of the team turned out to be resourceful for the project. Although, it can be argued that this team is a special case, we believe there are potentials in all teams. However, there are few detailed accounts of the process of service user involvement, as well as the benefits, challenges and learning during the process of involvement (Barber *et al.* 2011, Sims *et al.* 2013). The working structure and the atmosphere in the process of collaboration need to be examined in future research. We need to know more about the conditions which promote the service users to use their knowledge actively in the different stages of the research process.

Bringing service users into the analytical discussions compared with involving a team of researchers to safeguard multiple perspectives may have some disadvantages. Service users may need education in research specific issues such as ethics and methodology. This is time consuming. Involving service users in analysis of transcripts from former patients with similar experiences may give rise to affective issues and support for all involved into the research process, not only the participants, needs to be considered (Lalor *et al.* 2006). We recognize the potential risk of discussing our own feelings rather than interpreting the data in the analytical discussions. However, we were actively reflexive about our own feelings, as well as our pre-understandings. Extensive service user involvement is time consuming; it requires increased funding in terms of resources, training, support and remuneration (McLaughlin 2006) and can be experienced as an additional burden in an already heavy workload for the researcher (Pollard & Evans 2013). Our comprehensive collaboration, both in length (4 years) and on several activities throughout the entire research process, can be difficult for other projects to replicate. Nevertheless, we hope that our experiences can inspire other researchers and service users involved in health research to make use of at least some aspects of our research design. Supplementary research is needed to further develop the IPA methodology and to learn more about promoting conditions for service user involvement.

Conclusion

This novel involvement of mental health service users improved the quality in a nursing research project on mental health promotion, applying IPA. The perspectives of the researchers together with those of the advisory team expanded the horizon of understanding in the research

project. The interpretative element of IPA was strengthened by the emergence of multiple perspectives in the analysis of the empirical data. The collaboration gave interpretations with deeper insight into the complexity, nuances, ambiguity and richness of the participants' accounts and thereby increased the depth and breadth of the analysis, as well as validated the findings. The flexibility of the IPA methodology makes it particularly suited to benefit from service user involvement. This article, co-authored by researchers and service users, may inspire other researchers to use and customize several aspects of our experiences to involve users' knowledge into all stages of their research. Our hope is that our findings will contribute to advancing the qualitative research methodology.

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Author contributions

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (<http://www.icmje.org/recommendations/>):

- substantial contributions to conception and design, acquisition of data or analysis and interpretation of data;

- drafting the article or revising it critically for important intellectual content.

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