SOCIAL DIGNITY IN COMMUNITY-BASED MENTAL HEALTH SERVICES

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Stockholm 2013
ABSTRACT

Background: An essential element of community-based mental health services is the relationship between service users and mental health workers. This thesis explores how service users’ personhood and intrinsic human value are recognised or at risk in those relationships. There is focus on “Recovery” and “Ethics of caring”, and the concept “Social dignity” is used as a perspective.

Purpose: The overall purpose was to explore mental health service users’ experience-based knowledge about being recognised, and to describe and suggest how this knowledge was and could be foundation for mental health workers’ knowledge and clinical work. In Paper I, the aim was to explore how service users describe and make sense of their encounters with other people. Paper II described service users’ understanding of being in relationships with professionals and how these relationships limited or enhanced recovery. Paper III aimed to reveal and express knowledge about meanings of recognition of clients’ personhood and intrinsic value as human beings, based on mental health workers’ lived experiences of long-term relationships with clients. And Paper IV explored examples of mental health workers’ processes of development and learning.

Method: Project A: “Dignity in everyday life” and project B: “Focus on experience-based knowledge” are based on phenomenological hermeneutical lifeworld research. In project A, 11 service users were interviewed about their experiences of being recognised and how they would like to be recognised, and “Interpretative Phenomenological Analysis” with focus on analysis of singular cases guided the analysis. In project B, 8 experienced mental health workers participated in multi stage focus groups (four sessions) to develop knowledge about what is involved in recognising service users in community-based mental health services. “Interpretative analysis of lifeworld” and “Phenomenological hermeneutical method for researching lived experience” guided the analysis.

Findings: Recognition depended on experiences of being valued and significant, and that the service user’s participation in the relationship was acknowledged by the mental health worker. The service users lived in a “struggle to be me” and a “struggle to be recognised”, and experiences of being in relationships in which they were recognised were a great relief (Paper I). The struggle to be recognised was a dilemma between on the one hand being open and risking to lose the right to be a narrator in his or her life; and on the other to protect own identity and risk being isolated and alone. Opportunities to be open and trusting in relationships with mental health workers were found to be related to factors which contribute to recovery (Paper II). Mental health workers’ modes of “being”, give opportunities for service users to be open and trusting. Being in relationship with the aim to promote dignity led to enhanced self-respect for service users as well as mental health
workers (Paper III). Openness and indecisiveness were important factors for developing practical wisdom, and processes of development and change were nurtured by re-evaluation of experiences, thus contributing to develop and maintain dignity promoting practices (paper IV).

**Conclusion:** Integrating service user’s experience-based knowledge as a foundation for mental health workers’ knowledge and clinical work depends on health workers being open to and impressed by the service user in each present moment; allowing service users to be narrators in own life; and awareness that services users’ perspectives and experiences represent a unique insight that needs to be valued. The main aim for dignity promoting practices is not primarily to induce development or change in the service user, rather to recognise and value him or her in his or her present state. By being in relationship with the service user, the mental health worker can acknowledge the service user as an active agent and demonstrate to him or her that his or her life is significant. Openness and trust can be nurtured by acknowledging the service user’s personal struggle; by understanding withdrawal and speaking to internal voices (as well as other “symptoms”) as human experiences rather than merely signs of illness; and by recognising the person’s intrinsic human value. Bearing this in mind, mental health workers need to engage in ongoing development processes towards openness, as it is in the present moment in each encounter that the services may succeed or fail.
LIST OF PUBLICATIONS


III. Ådnøy Eriksen, K., Arman, M., Davidson, L., Sundfør, B. & Karlsson, B. (accepted) “We are all fellow human beings”: Mental health workers’ perspectives of being in relationships with clients in community based mental health services. *Issues of Mental Health Nursing*. In press

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1 INTRODUCTION

Mental health workers in community-based mental health services report that they work actively to understand and provide services based on service user’s perspectives. They talk about “tuning in” to the service user, and about “being present”, “seeing and listening”, and “acknowledging” each person as an individual. In spite of this, service users still experience loneliness, to be overlooked, not being listened to, and not being understood.

“Ben” and “Ann” participated in the current study, and their reflections about their relationships with mental health workers can illustrate some challenges in the service user - mental health worker relationship. The main theme in Ben’s narrative was trying to make other people understand who he is and how he makes sense of his life. At the time of the interviews he spends most of his time alone in his room as he has concluded that the mental health workers are not able to understand, and that trying to speak openly about his thoughts and experiences will cause trouble. He reflects: “It is not that I want to keep secrets, it’s just that people are not really interested”.

Ann speaks very positively of the people she relates to in the mental health services. She trusts that they have her best interest at heart, and that they are ready to help when she needs it. At the same time she is aware of limitations to what extent the mental health workers understand the significance of what she is sharing. Knowing this, she considers carefully what it is appropriate to say, and to whom. She reflects: “My life is difficult as I carry all of this alone”. When asked why she volunteered for the research project she says: “Maybe someone can learn from my experiences - that other people will not have to live like that”.

Ann and Ben both long to be included and belong in fellowship with other people. And in this thesis their loneliness and trouble to present themselves in fellowship are understood as an ethical challenge to mental health workers, as well as to our society. Service users’ narratives about “being recognised” and “not being recognised” is a starting point to develop knowledge about of what facilitates experiences of being worthy of respect; being allowed to share one’s own life with others; and experience the ability to contribute in fellowship with others.
2 BACKGROUND

The context of the study is community-based mental health services, and the focus is on relationships between service users and mental health workers in those services. Relationships and interactions between persons are understood as opportunities for promotion of dignity, and it is taken for granted that service users and mental health workers are equals and should be treated with decency and respect. Experience-based knowledge about being recognised is explored in order to become aware of how the relationships between mental health workers and service users facilitate or are obstacles to service users’ recovery processes.

The research builds on lifeworld philosophy (see Figure 1), and ontological, epistemological and methodological stances are in line with this theoretical approach. Various perspectives have guided the research. The concept “Social dignity” is used as a moral stance as well as a help to discover what may be at stake in the mental health worker – service user relationships. “Ethics of care” is introduced, as being in relationships with service users is understood as responding to the service user: promoting and maintaining his or her identity as a valued person and acknowledging his or her right to meaning in his or her lifeworld. And thirdly “Being in Recovery”, as the starting point of firsthand perspectives. The methodological choices support the intention to let firsthand perspectives inform knowledge about mental health workers’ responses. Aspects from action research are combined with phenomenological hermeneutic tradition to incorporate experience-based knowledge in the contributions to the academic field.

In the following text the context and motivation for the study is described with a focus on what community mental health services are meant to do, how dignity-promoting relationships are part of those services, and why it may make sense to focus on social dignity in community-based mental health services. After this, central concepts in the study are motivated and explained: “Social dignity”; “Ethics in care”; “Recovery”; and “Lifeworld”. Some contemporary research concerning dignity and mental health will also be presented.
Figure 1 *Theoretical inspirations*
CONTEXT AND MOTIVATION

Community-based mental health services

Norwegian municipal mental health services are “community-based” in the sense that people using the services live in their own homes, belong in their neighbourhood and local community, and in the sense that the services provide services based on opportunities in and the “culture” of that local community. The Department of Health and Caring states that persons seeking help due to mental health problems should primarily receive services in the local community (“nærmiljøet”). The services’ main concern should be coping strategies and service user’s perspective, and the aim to strengthen service users’ independence, autonomy, and ability to cope. This is done by organising housing with sufficient assistance, providing necessary and personalised health and social services, by giving opportunities to take part in meaningful activities or work, and opportunities to participate in social settings to avoid social isolation (Sosial- og helsedirektoratet, 2005).

Human relationships are emphasised as an important element in the services. The services should ensure continuity for the service user through stable relationships and encounters with fewest possible persons, as well as ensure that service users are treated with respect, that he or she experiences be included in decisions, and that he or she trusts the person providing the services (Sosial- og helsedirektoratet, 2005). Thus municipal mental health workers strive to build long term relationships with the service users, and most service users will have one or two health workers as his or her personal coordinator.

During the years 1998-2008, the municipal services were developed through the reform “Escalation plan for mental health” (Norge Sosial- og helsedepartementet, 1997). The reform involved strengthening the competence and range of services within the mental health field, both by employing more persons with better competence, and by moving focus from primarily illness and illness management to issues like social inclusion, employment, housing, and economy. While the specialised mental health services still focus on diagnosis, persons working in the community-based mental health services claim that their focus is persons’ everyday lives such as help with practical issues (washing up or paying the bills), and flexibility in appointments (low threshold for contact, help at once, or within a few days) (Almvik, Borge, & Berntsen, 2006).

The reform was also an ideological project; it invited a renewed and extended understanding of human beings, mental health, and knowledge about these issues (Andersen & Karlsson, 2011). It was a shift from exclusion to integration, from focus on suffering and illness to focus on the person with mental illness and his or her life situation (Ekeland, 2013). Evaluations of the reform showed that the capacity of the mental health services had increased according to the intentions, but that the work to change values and attitudes in the services and in society had only partly succeeded (Forskningsrådet, 2009). Based on the
evaluations of the reform the Department of Health and Caring concluded that further work was needed to strengthen user involvement in the services, and to integrate service users’ experiences as a natural part of the services provided (Sosial- og helsedirektoratet, 2003). This thesis focuses on challenges to values and attitudes, and contributes to integration of service users’ experiences as a natural part of the knowledge in the services.

**Challenging attitudes and cultures**

“*Us*” and “*them*”

Mental health workers are challenged to move their focus from a person’s diagnosis and treatment for that diagnosis to focus on service user’s perspectives and to how they relate to persons with mental health problems. This challenge is not specific for the Norwegian context; several studies from other countries describe how mental health service users experience humiliation and lack of understanding in mental health services. These studies indicate that there are two related issues to be aware of. The first is that defining and categorising a person’s mental health problems from an outside perspective (rather than based on the person’s own understanding and perspectives) increase the risk of dignity violation in health care (Jacobson, 2009b). Professionals have power to label or define the experiences of the service user, and the experiencing subject loses opportunity to present his or her experiences. The second issue to be aware of is diversity in focus and priorities between health worker and service user. One study describes that health workers focused primarily on illness and symptoms, while the service users were concerned with issues linked to “being”, “belonging” and “becoming” (Gunnmo & Fatouros Bergman, 2011). Professionals’ inclination to focus on illness and symptoms thus can become an obstacle to integrating service users’ perspectives.

Society as well as persons working in the mental health services may think of mental health problems as something happening to someone else. Mental health issues are kept at a distance by defining such problems as something “apart from”, or “different from”, and to avoid becoming involved (Almvik et al., 2006). We may have pity on “those” who have mental health problems, but “those” are still not recognised as someone like “us”. Lemvik suggests that the health services place the problem with the clients, and thus avoids making the uncomfortable effort of acknowledging that the problem may be in the services (Lemvik, 2006). Persons living with mental illnesses experience this gap between “us” and “them” as an estrangement (Myung-Yee & Woochan, 2009). Odd Volden (Andersen & Karlsson, 2011) gives examples that illustrate how the distance is maintained in the way mental health issues and mental illness are presented in society. People make distinctions between “ordinary” hospitals as opposed to “psychiatric” hospitals, and speak about “psychiatric patients” as opposed to “ordinary persons”. For example, a newspaper reported to the public that an office served “ordinary persons with normal problems”; it is not a “psychiatric service” (Andersen & Karlsson, 2011, p 40).
This inclination to keep a distance and avoid becoming involved needs to be confronted with a counteractive force as it is deeply rooted in the way we speak about mental health services and persons with mental health problems. For persons to experience recognition and inclusion the “us” and “them” should become “we”. Mental “un-health” is an experience anyone may have, and there should not be distinctions between “Us” who have been defined as sensible and not insane, and “Those” who have lost their senses and are insane (Andersen & Karlsson, 2011).

Relationships contribute to recovery from mental illness and respect for service users’ dignity can be a help to strengthen the service user and decrease the power of the professional. To give priority to forming relationships in which service users’ dignity is protected and promoted may thus contribute to improve mental health services. Topor (2001) found that various treatment interventions were not essential in recovering from severe mental illness, but that entering into and maintaining relationships with other people is crucial (Topor, 2001). And Kogstad (2009) points out that there are reasons to reduce professional authority, and suggests that user-based approaches with a focus on respecting clients’ dignity may be a way of doing this (Kogstad, 2009).

“We”

In this thesis the concept dignity is introduced to strengthen this sense of a “we”. Dignity is a help to see that persons with mental health problems are essentially human beings like other human beings, and mental health problems are a part of human life. Dignity is also introduced to avoid some of the distinctions between the health worker and the service user, as a help to become aware of humiliating practices, and to explore the dialectic relationship between service users’ experiences and health workers’ responses. The mental health worker - service user relationship is made up of one person seeking care and another person being the carer. Even so, focus on each of these persons as fellow human beings may be a help to get away from the notion of the professional as the authority who owns the power to define, and also a way of valuing the service user as an active and contributing person. It is taken for granted that we are all vulnerable and depend on others in our everyday lives, and all persons contribute to their own and other person’s lives (lifeworld) in some way.

Another attempt to strengthen the sense of “we” is to strengthen the value of experience-based knowledge and claim that this knowledge is an essential part of professional knowledge. Valuing experience-based knowledge by doing research together with service users can be useful to ask research questions with relevance to service users and patients, and also a way of challenging existing knowledge about what mental health problems are. Co-research can move the power to define what questions are worth asking, and which knowledge is needed, as well as develop insight and knowledge that would otherwise be hidden (Borg & Kristiansen, 2009).
A co-researcher with firsthand experiences as a mental health service user was invited to take part in the research project. As there is a quest to make service users’ experiences a natural part of the services it makes sense to involve service users in developing the services as well as in the processes of developing the knowledge needed in the services. People who have experienced or have struggled with mental problems have unique personal experiences, and they know the services from experience. This perspective and knowledge may contribute to unique insight and extended understanding of mental health (Borg & Kristiansen, 2009). User involvement in research is based on the idea that human beings are experts on their everyday life, and that this is an essential source of knowledge for research on human beings and understanding society (Borg & Kristiansen, 2009).

PERSPECTIVES AND POSITION IN ACADEMIC FIELD

Social dignity

The understanding that all human beings are significant, that we have special value, or even possess something holy is deeply rooted in our culture and tradition. The Universal Declaration of Human Rights, Article 1 reads: “All men are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood” (United Nations, 1948). Thus, most countries in the world have agreed that dignity defines human beings, and that “recognition of the inherent dignity” of the person is a foundational human right.

Persons are worthy of respect as he or she is a bearer of something that should not be destroyed, something “holy” or something that has special value. This core of humanness or “dignity” is linked to human value, to the office of being human, and holiness (Edlund, 2002). Eriksson (2013) claims that “… human dignity is her [the human being’s] freedom, and at the same time she is tied to the responsibility of being human, and by the responsibility given in the human office” (p 70; Author’s translation). This illustrates that dignity is linked to what it means to be a human being, and also to living one’s life as a human being. Experiencing dignity, or to experience being valued, is linked to the courage and power to live (Edlund, 2002). Nordenfelt (2004) agrees that the concept dignity always involves dimensions of value, and explains dignity as being worthy of respect of others and oneself. He describes various types of dignity: “Dignity of merit”; “Dignity of moral stature”; “Dignity as a virtue”; and “Dignity of identity”. The “Dignity of identity” is of most interest in this thesis; it is the dignity we attach to ourselves as individuals, and the respect for our own identity. Nordenfelt (2004) goes on to say that this does not depend on merits but is attached to the integrity of the person. Humiliation by others, an accident, trauma, or illness might change the person’s self-respect and thereby the dignity of identity (Nordenfelt, 2004).

Jacobson (2007) introduces “Social dignity”, understood as a consequence of human dignity. Human dignity implies that all human beings are equal and should be treated with decency and respect, and this is experienced and bestowed in interaction with other people.
The way a person sees him or herself depends to a certain extent on how he or she is perceived by others, as this reflection is part of living in the world as interconnected to others. Based on this, all human interactions are opportunities to promote dignity, or to violate it (Jacobson, 2009b).

In this thesis “social dignity” was used as a motivation and a perspective. Motivation in the sense that dignity is understood as a moral value; it is taken for granted that dignity-promoting relationships are worth striving for. And perspective as it was a help to see what may be at risk in relationships, keeping in mind that all persons are essentially valued persons and included in a shared humanness. During the research process, and especially when informing participants about the study “social dignity” was rephrased to: “experiences of being seen, heard and met” and “to be valued and acknowledged” (interviews with service users, project A); and to: “acknowledge person’s perspective”, “to value the person”, “to understand”, “to be concerned and involved”, and “to recognise” (focus groups with mental health workers, project B).

Ethics of care
Ethics of care builds on the ontological stance that human beings are intersubjective. The focus in caring is on being rather than doing, and the idea is that being in an interpersonal relationship evokes or calls for a moral response. Persons are motivated and morally addressed by the vulnerability of other persons (Nortvedt, Hem, & Skirbekk, 2011). The ability to empathise with and identify with (and perhaps even love) others provides motivation to respond to the other, and this ability to love seems to be linked to a deeper awareness of our universal connection to each other, which seems to inspire altruistic acts (Mastain, 2006).

Martinsen (2006) refers to intersubjectivity as sharing a fundamental likeness; the person recognises or sees him or herself in other persons. And based on this we may grant each other access to participate in each other’s lives (Martinsen, 2006). This participation should not reduce the person to an object, and not rob the other person of his or her understanding of him or herself. To be a caring professional is daring to be a human being, with the foundational perceiving awareness and approach that life is worth caring for and protecting, and in this “being a human being”, the other person is allowed to emerge (Martinsen, 2006).

With this explanation of caring relationships it becomes possible to shift the focus from what mental health work is or should be, to how mental health services may be a response to service users’ firsthand experiences. It is not a question about knowing from outside what is good for the other person, or providing services based on methods and definitions. It is about being privileged and trusted to participate in the service users’ lives and thus respond based on service users’ “challenges” to mental health workers and the mental health services.
An implicit part of this is to make space for the other person, to respond to his or her contribution rather than based on an agenda decided before the person made an impact. There is need to create a space, or life opportunity, in which the person has freedom to be an embodied subject. This space or moment in time that allows the other to emerge has been described in different ways in the literature. Stern’s theory about “the present moment” (Stern, 2004) explains how the person’s opportunity to be known and to share what it feels like to be him or her is linked to the core of the person’s humanness. Anderson (2005) writes about “Not-Knowing” indicating not a lack of knowledge but the need to be open to the other, as we do not know his or her world (Anderson, 2005). In nursing literature expressions like “attentiveness in care” (Klaver & Baart, 2011) illustrate the need to dwell in the moment and take in the impression from the other and basing our response or being on that. And Milton (2008) writes that “true presence” involves attentiveness to the moment-to-moment changes in meaning as the nurse bears witness to the person without judging or labelling. And she goes on to say that the attentiveness is an anticipation of what is yet to be, and linked to an intentional reflective love reflecting the belief that each person is to be respected with a venerable regard (Milton, 2008).

This way of thinking can indicate how mental health workers are challenged to leave the theories about mental illness and plans for treatment in the back of their minds in encounters with service users. There is a call for openness or indecisiveness, an awareness of not being an expert, and a readiness to learn from the service user. This attitude involves a risk for the health worker: in order to give room for the situation in that moment and maintain a patient’s dignity, integrity, and self-respect the health worker must dare to be in unpredictable situations, and be prepared to think and act flexibly (Borg, Karlsson, & Kim, 2010).

**Recovery**

“...recovery refers primarily to a person diagnosed with a serious mental illness reclaiming his or her right to a safe, dignified, and personally meaningful and gratifying life in the community while continuing to have a mental illness”. (Davidson & Roe, 2007, p 464)

This thesis focuses on “personal recovery” or “being in recovery”, rather than symptom remission and restoration of functioning associated with the term “clinical recovery” (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). Being “in recovery” indicates that mental illness is just a part of the person, and the person in recovery has overcome the effects of being a mental patient and regained some degree of control over his or her own life. (Davidson & Roe, 2007). To overcome the effects of being a mental patient happens in a social world. Even if the recovery journey is personal, it unfolds within a social and interpersonal context (Topor et al., 2011).
The recovery thinking is a reminder that all persons are subjects and agents, and this agency may be acknowledged and supported by the mental health worker, or ignored. Recovery is sometimes described as a journey in which the person is “in the driver’s seat” (Tondora, Miller, Guy, & Lanteri, 2009). The person in recovery is the driver, and the mental health worker may join the person in his or her journey by listening to the driver, maybe talk about the journey, be in dialogue about what they see, suggest which route to take, and even sometimes take over the driving at the driver’s request. But decisions about aims for the journey, the pace, the direction and the means of travelling should always be decided by the main driver.

Topor et al. (2011) found that friendships and being part of a family are important for recovery, and that persons in recovery emphasise relationships with particular helpers as positive in their recovery rather than specific methods for treatment. The essence seems to be to interact with persons who regard him or her as unique and multi-faceted rather than relate only to him or her as a person with psychiatric problems (Topor, Borg, Di Girolamo, & Davidson, 2011). Karlsson and Borg (2013) agree that family and friends are important, and also mention social factors like housing, employment, education, and money as crucial elements in supporting (or limiting) a person’s opportunity to recover. A person’s social relationships can nourish growth, development, and hope, by believing in people and providing opportunities for cooperation (Karlsson & Borg, 2013).

Recovery also moves the attention away from “health” and “illness”, to focus on everyday life and being a person with civil rights. Borg and Davidson (2008) found that living with mental illness poses practical problems and affects everyday life in a number of ways, and point out that normal environments and activities seem to be the most common and most effective arenas for recovery. “Citizenship” understood as being a member in society and taking up rights and responsibilities in the local community have also been found to actively support recovery processes (Rowe & Pelletier, 2012).

THEORETICAL FOUNDATION: LIFEWORLD

Ontology: Intentionality and inter-subjectivity

The research process is based on phenomenological hermeneutic lifeworld approach, understanding persons as embedded and immersed in a world of objects and relationships, language and culture, projects and concerns (Smith, Flowers, & Larkin, 2009). Bengtson (2006) writes that the lifeworld is the reality the person takes for granted. We are in the lifeworld with other people, and the way we associate with objects and people is inherited or given from person to person. Human experiences in the complexity of the lifeworld are before (or more foundational) than all intellectual activities. We are always part of the world, and being in the world is a condition for our experiences and our understanding of ourselves and of each other (Bengtsson, 2006). Based on this one may say that human
beings are part of an already pre-existing world and at the same time shape the world by being part of it.

This way of thinking has consequences for how our understanding of what humanness entails or what a human being is. Two foundational defining elements of human beings are described here as they have relevance in becoming aware of how humanness (or characteristics of human life) may be at stake in relationships between service users and mental health workers. The first concept is intersubjectivity, which according to Stern (2004) is a condition for humanness, as we possess a primitive and pre-reflective mental experience of the other as an embodied being like ourselves. “This involves the mutual interpenetration of minds that permits us to say, ‘I know that you know that I know’... a reading of the contents of the other’s mind” (Stern, 2004, p 75). The second concept, intentionality, takes into account that even if human beings are intersubjective, they are also fundamentally different from each other. Each person has his or her unique position in the world, and significance and meaning is based on his or her position, history, or personal experiences of relatedness to things, persons and him or herself. This unique position is what Husserl called intentionality: “the relationship between the process occurring in [the person’s] consciousness and the object of attention” (Smith et al., 2009, p 13). Merlau-Ponty developed this thinking further focusing on the lived experience of the subject as a body; it is our bodies which shape the fundamental character of our knowing about the world (Smith et al., 2009).

What implications do these concepts give to what it means to recognise a person as a human being? Intersubjectivity makes us able to understand and be empathic with the other person. At the same time we can never share the other’s experience as the intentionality, or the embodied experience of that person depends on his or her position and the significance of the present situation in the person’s lifeworld. Assuming intersubjectivity implies assuming that persons wish to connect to others, and want to share his or her experiences and the way he or she understands these experiences, with other persons. To relate to others and be able to be known and to share what it feels like to be them is a primary motivational drive (Stern, 2004). Social inclusion is fundamental to experience and understanding: it is in recognising and in being recognised by the other that persons develop a sense of self and identity as human beings included in relationships with other people (Schibbye, 2009).

Persons can be understood based on the motivation for social inclusion as well as motivation to seek meaning (Binder & Vollestad, 2006). Recognising persons as intentional means recognising that the person makes sense and knows about his or her world based on what he or she actually experiences. Other people defining logical truths cannot compete with the person’s personal body-subject reality. Smith et al. write that the intentional quality and meaning of the “mineness” and “aboutness” of an experience always is personal to the body-subject (Smith et al., 2009). And recognition depends on understanding that this
experienced life of the body in the world “comes before” (Bengtsson, 2006) or is more significant than the abstract or logical ones (Smith et al., 2009).

**Epistemology; experience-based knowledge and phronesis**

Building on phenomenological and hermeneutic philosophy also influences the view of what knowledge is. As mentioned above, the tendency to define and explain mental health service users’ problems and illnesses from an outside perspective may lead to humiliation. To take service users’ perspectives as foundation for the services, the experiences of the service users need to be valued and given room. The knowledge needed to promote dignity in mental health services can never be learnt in a book or by practicing some kind of method. The theory may be a help to understand, but the experiences of respecting and being worthy of respect depends on how the theory is interpreted in the encounter with the other person. The knowledge needed to know how to be or act in the actual situation depends on practical wisdom (phronesis) developed in complex practical situations (Eikeland, 2008; Gates & Higgs, 2013). Thus service users’ experience-based knowledge and mental health workers’ experience-based knowledge are essential elements in deciding what knowledge is needed to promote dignity, to promote recovery and to provide “good” mental health services.

Or, according to Karlsson (2003), knowledge is understood in relation to social processes and contexts, rather than theories expressed as logic rules. Knowledge involves a complexity: emotions, the intersubjective, and elements that have not been named; it is developed as we live in our lifeworld and as we explore and experience life and our relationships to other people (Karlsson, 2003).

**CONTEMPORARY SEARCH**

The fields of research related to the main ideas in this thesis are wide, and focus on a variety of issues such as caring relationships, recovery, dignity, experience-based knowledge, knowledge development and so on. Table 1 gives an overview of related concepts used in the research literature, and list some studies concerned with those concepts. The list is far from complete as other issues and many other relevant studies could have been included.

A more detailed presentation of some other studies is presented (in the text following table 1). These are sorted in three headings: “Dignity and mental health” that include only recent studies; “Dignity in health care” that illustrate the relevance of the concept dignity in health care; and “Recovery-oriented practice” that include some studies that add to the knowledge about how relationships and social aspects influence recovery.
Table 1. List of relevant research

<table>
<thead>
<tr>
<th>The relationship as contributing to health (&quot;Therapeutic relationships&quot;)</th>
<th>(Berggren &amp; Gunnarsson, 2010; Browne &amp; Courtney, 2007; Halldorsdottir, 2008; Moyle, 2003; Peplau, 1996; Perraud et al., 2006; Quinn, Smith, Ritenbaugh, Swanson, &amp; Watson, 2003; Rogers, 1951; Topor et al., 2006)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recovery-oriented practice</td>
<td>(Anthony, 1993; Borg, Karlsson, Tondora, &amp; Davidson, 2009; Borg &amp; Topor, 2003; Davidson, Tondora, Lawless, O’Connell, &amp; Rowe, 2009; Deegan, 1988; Deegan &amp; Drake, 2006; Drake &amp; Deegan, 2008; Rowe &amp; Pelletier, 2012; Stanhope &amp; Solomon, 2008)</td>
</tr>
<tr>
<td>Professional development and re-evaluation of practical experiences</td>
<td>(Billett, 2008; Boud, Walker, &amp; Keogh, 1985; Fish, 1998; Gates &amp; Higgs, 2013; Higgs, Richardson, &amp; Dahlgren, 2004; Lützén, Dahlqvist, Eriksson, &amp; Norberg, 2006; Magnusson, Lützén, &amp; Severinsson, 2002; D. Schon, 2001)</td>
</tr>
<tr>
<td>Studies based on service user involvement in research</td>
<td>(Bjørgen, Dagfinn, Johansen, Karl Johan, 2002; Borg &amp; Kristiansen, 2009; Caron-Flinterman, Broerse, &amp; Bunders, 2005; Kotecha, 2007; Nasjonalt kunnskapssenter for helsetjenesten - Seksjon for kvalitetsutvikling - GRUK, ; Nytingnes &amp; Skjerve, 2006; Rose, 2008; Rose, Fleischmann, &amp; Wykes, 2004; Trivedi &amp; Wykes, 2002)</td>
</tr>
</tbody>
</table>

**Dignity and mental health**

Gustafsson et al. (2013) explored nurses’ experiences of violation of patient dignity in clinical caring situations in involuntary psychiatric care, and found that violation of dignity was linked to not taking the patient seriously, ignoring patients, exposing patients, physical violation of patients, asymmetrical relationships, betraying patients, and predefining patients. They conclude that the need to keep patients in involuntary care makes it hard to avoid humiliation and recommend that nurses should reflect on ethical issues and be conscious of their actions, rather than blindly following ward routines (Gustafsson, Wigerblad, & Lindwall, 2013).

Lindwall et al. (2012) write that dignity may emerge when the will and courage to be there for someone else permeates the caring act. Preserved dignity is associated with courage to be present and dignity violation by acts of creating powerlessness. To offend a patient’s dignity is associated with being in an inner value conflict, as the caregiver has acted against
his or her own will (or not acted according to his or her own values) (Lindwall, Boussaid, Kulzer, & Wigerblad, 2012).

Granlien and Granerud (2011) have studied aims and values in a user led mental health centre and found that the aims and values in the centre nurtured trust, belonging, and feeling safe. The most important value was respect, which was linked to values like openness, equality/reciprocity (“likeverd”) and being fellow human beings (“medmenneskelighet”). The experience of being trusted and responsible (trust); to be needed and significant (belonging), and the experience of things being ok (feeling safe) give persons experiences of self-respect in meeting society, and may give strength to handle life in spite of difficulties in life (Granerud & Granlien, 2010).

Skorpen et al. (2013) found that patients in psychiatric hospital wards linked dignity to dignity-promoting experiences described as “being met as equal human beings” and “experience of dignity in spite of suffering”. Dignity-inhibiting experiences were linked to “suffering due to inferior feelings” and “suffering and fighting for one’s own dignity”. These viewpoints show the vulnerable position of patients and also illustrate how each person working in the ward can make a difference to patients’ experiences of dignity (Skorpen, Thorsen, Forsberg, & Rehnsfeldt, 2013).

Chadwick (2012) found that involving service users in educational programs enhanced patient centred care. She suggests that workshops for healthcare practitioners in which service users tell their own stories may reaffirm practitioners’ knowledge, skills and values and thus lead to improved service users’ experiences of the care (Chadwick, 2012).

**Dignity in health care**

Todres, Galvin, and Holloway (2009) have developed a value framework for qualitative research, and suggest that being aware of the essential constituents of what it means to be human may be a help to judge the humanisation of care. They bring attention to eight overlapping dimensions: Insiderness as opposed to objectification; Agency as opposed to passivity; Uniqueness as opposed to homogenisation; Togetherness as opposed to isolation; Sense-making as opposed to loss of meaning; Personal journey as opposed to loss of personal journey; Sense of place as opposed to dislocation; and Embodiment as opposed to reductionist view of the body (Todres, Galvin, & Holloway, 2009).

Edlund et al. (2013) present a concept determination of human dignity to gain a deeper understanding of the concept and to increase nursing science knowledge of the concept. They found that the core of absolute dignity involved: the holiness of human beings; their absolute human worth; and the freedom granted to human beings which implies responsibility and a duty to serve one’s fellow-human beings. Relative dignity is related to the shape of human dignity as it emerges in daily human life through specific values formed in the prevailing culture. The person may experience relative dignity when he or she is in a context in which his or her own values are in accordance with the values in the context.
There may be a need to adjust values when being faced with changes in life (Edlund, Lindwall, von Post, & Lindström, 2013).

Pettersen and Hem (2011) suggest that the concept “Mature care” (rather than “Altruistic care”) may be a help to emphasise the interaction and reciprocity in a caring relationship, and thus a help to avoid viewing caring as a one-sided activity. To be a mature agent means to be able to shift between different perspectives, finding solutions, and having contextual sensitivity (Pettersen & Hem, 2011). The mature agent is able to balance the concerns of the self with those of others and act from the principle of not causing harm (Nordhaug & Nortvedt, 2011). The concept is further developed by Ekeberg (2011) who suggests that the mature agent acts with the virtue of integrity. She understands the virtue of integrity as a personal and social virtue, a virtue that makes the person able to guard his or her own boundaries, but at the same time able to perceive others’ needs and let their experiences and opinions matter. Acting with integrity discloses an ability to manifest oneself as a subject by standing for something before others – and thereby upholding clear boundaries – while still providing space for taking an epistemic interest in others’ views (Ekeberg, 2011). Striving for integrity as a personal as well as social virtue may be a help to find the balance between being invaded by another person’s feelings, opinions and standards (the embodied experience), but nevertheless be affected by the other person (be emphatic and respond to the other person).

In addition to the notion “social dignity” (referred to on p14-15) Jacobson and Jacobson and colleagues (Jacobson, 2007; Jacobson, Oliver, & Koch, 2009; Jacobson, 2009b) have explored dignity from various perspectives. They found that indifference, detachment, invasion of the other, objectification, limited freedom, definition and discrimination were some of the factors that lead to violation of dignity in health care situations. Asymmetrical relationships, rigid routines, and focus on reaching quantitative goals are circumstances that increase the risk of dignity violation (Jacobson, 2009a). Dignity promotion became more likely when one actor in an encounter is in a position of confidence, position of compassion, and in position of solidarity, and she also found that dignity promotion is a distinct activity, or a kind of work (Jacobson, 2009b).

Halldorsdottir’s (2008) theory about the nurse-patient relationship from the patient’s perspective describes the relationship between nurse and patient as a dynamic lived reality characterised by a sense of spiritual connection, which is experienced as a bond of energy. This bond of energy, or connection, may be life-giving and greatly empowering for the patient. This kind of relationship may develop when the nurse is perceived by the patient as genuinely caring, competent and having professional wisdom. She introduces the metaphors “the bridge” symbolising openness in communication and the connectedness experienced by the patient in a life-giving nurse-patient relationship, and “the wall” symbolising negative or no communication, detachment and lack of nurse-patient relationship (Halldorsdottir, 2008).
Recovery-oriented practice

Leamy et al. (2011) developed a conceptual framework for personal recovery in mental health. The framework is relevant, even if it does not emphasize the relational or social perspectives, as part of this framework was used in Paper II (to discuss how relationships may facilitate or limit opportunities for recovery). The framework involves characteristics of the recovery journey (13 characteristics) and the following characteristics: “recovery is aided by supporting and healing environment”, and “recovery can occur without professional intervention” are the ones that include the social or relational aspect, and the characteristics: “recovery is a journey”, “recovery as a struggle”, “recovery is an active process”, and “individual and unique process” may be social as they depend on the possibilities the person is given in the community. The framework also describes recovery stages: Precontemplation, Contemplation, Preparation, Action, and Maintenance and Growth (Leamy et al., 2011). The third element in the conceptual framework is the recovery processes: Connectedness, Hope, Identity, Meaning, and Empowerment (CHIME), which proved useful in defining issues central to recovery (Paper II).

Topor et al. (2006) focused on the social nature of recovery, and found that sense of belonging and participation in community life were key elements of experiencing healing and recovery in psychosis. Relationships with others facilitate recovery in three ways: someone “being there” over time without expecting changes or improvements in the person’s condition; someone “doing more” by making extra efforts which makes the person feel cared for in a genuinely human way; and someone “doing something different” by putting the needs of the person above those of the system or outside of the expected roles and rules. To be in a community may also facilitate recovery as it gives opportunities for the person to develop various roles, like being with supportive others and doing things that make the person feel meaningful, which may lead to a redefinition of self. Material resources like employment, housing and money, as well as a sense of belonging that may afford the person a sense of commonality with other people’s experiences were also found to be important (Topor et al., 2006).

Similarly, Schön et al. (2009) found that social relationships were a key experience in recovery, and their respondents attached central importance to the relationships in their lives. Through relationships the person may redefine themselves as a person (rather than a patient) with problems as well as abilities. The person in recovery seeks out socially rewarding environments as a way of managing, and reducing symptoms (Schon, Denhov, & Topor, 2009). From the service user’s perspective, the quality of the relationship to the professional is a major factor in determining whether the care is helpful. Important components of helping relationships were found to be non-stigmatising attitude, as well as the professional showing an active interest such as being willing to do something beyond established routines (Denhov & Topor, 2012).
3 AIM

The overall purpose of this research was to explore mental health service-users’ experience-based knowledge about being recognised, and to describe and suggest how this knowledge was and could be foundation for mental health workers’ knowledge and clinical work.

The aims and questions of each paper are

Paper I: To explore how mental health service users describe and make sense of their encounters with other people.  
-How may this perspective be a message to professionals (mental health workers) about ethical priorities when relating to service-users?

Paper II: To describe service users’ understanding of being in relationships with professionals. -How may these relationships limit or enhance recovery?

Paper III: To reveal and express knowledge about meanings of recognition of clients’ personhood and intrinsic value as human beings, based on mental health workers’ lived experiences of long-term relationships with clients.  
-How do mental health workers understand their “being in relationship” as an opportunity to accept and acknowledge the client? -How do they adapt and respond to clients’ “being in relationship”?

Paper IV: To explore examples of mental health workers’ processes of development and learning as they appear in focus groups intended to develop practical wisdom.  
-How might these processes of development and learning contribute to develop practical wisdom in the individual as well as in the practice culture?
4 MATERIAL AND METHODS

OVERVIEW OF STUDIES

Table 2. Overview of studies

<table>
<thead>
<tr>
<th>Projects</th>
<th>Participants</th>
<th>Data material</th>
<th>Analysis</th>
<th>Papers</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Dignity in everyday life. Planned, organised and analysed together with co-researcher with experience as mental health service user.</td>
<td>Eleven persons depending on community-based mental health services at least three times a week.</td>
<td>19 in-depth interviews lasting 30-90 minutes, audio-taped and transcribed verbatim, and summaries from joint process with co-researcher.</td>
<td>Interpretative Phenomenological Analysis (IPA). Focus: Values and priorities in encounters with professionals</td>
<td>I Recognition as a valued human being: Perspectives of mental health service users.</td>
</tr>
<tr>
<td>B Focus on experience based knowledge. Planned and organized with co-researcher, based on findings from “Dignity in everyday life” (Project A).</td>
<td>Eight experienced community mental health workers.</td>
<td>Four focus-groups lasting 90 minutes, audiotaped and transcribed verbatim, and summary from each group.</td>
<td>Interpretative analysis of lifeworld. Focus: Meanings of recognition.</td>
<td>II Challenges in relating to mental health professionals: Perspectives of persons with severe mental illness.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>IV Strengthening practical wisdom - elements in mental health workers’ processes of development and learning.</td>
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</table>

RESEARCHING LIVED EXPERIENCE

Three slightly different “life-world” methodological approaches guided the research. The common factor in the approaches is the focus on phenomenological and hermeneutic philosophy, and thus the aim to explore, describe, or understand the world as it appears to someone.

Phenomenology is a philosophical approach to the study of experiences, and the everyday human world is seen as the foundation for science. Edmund Husserl developed phenomenology as a reaction to the scientific ideal of studying the world as something unrelated to the subject (Welton, 2003), and warned that if science was to focus only on
facts, the world would be dehumanised. Even objective facts in scientific studies are part of and have significance in the human world (Dahlberg, Nyström, & Dahlberg, 2008). The phenomena are that which shows itself for a subject, or appears to someone (Dahlberg et al., 2008), and the researcher seeks the essence of the phenomena, the foundational that is before science and reflection (Bengtsson, 2006). Phenomenology is a philosophic theory with different emphases and focuses (Smith et al., 2009), and many philosophers have developed Husserl’s philosophy further, with slightly different emphasis. Relevant for this study is Merlau-Ponty who sees intersubjectivity as intercorporeality, which means that we reach others through our bodily position in the world (Smith et al., 2009).

Hermeneutics is the philosophy of understanding through interpretation, and was originally an attempt to develop surer foundations for interpretation of biblical texts (Smith et al., 2009). Focus may be on methods and purposes of interpretation: to uncover the intentions or original meaning, and see the connection between text and context (Smith et al., 2009). The hermeneutic approach involves engaging in the hermeneutical circle (or spiral), seeing details in light of the whole and the whole in light of the details, and thus engaging in a process in which new insights can appear. The methodology makes it possible to seek the intention and rationality behind actions, attitudes and values (Hummelvoll, 2003). Lifeworld research is useful in health sciences as it allows us to focus not only on “what” something is or “what” persons are, but also including “that” something is and “that” persons are (Bengtsson, 2006).

Phenomenology and hermeneutics are different traditions, and there are variations within both traditions, and because of this it may be hard to be “true” to any one of the phenomenological or hermeneutic thinkers when exploring persons’ experiences. Phenomenology is concerned with describing what appears to someone, and that the essence of this appearance of the phenomenon is more foundational than our theories about it. Hermeneutics is used to interpret what appears, and in particular interpret texts and meaning. In spite of the differences several methodological approaches combine the two. Ekeland (2013) writes that even if the theories are complex and sometimes diverse, the bottom line is that the phenomena that appear, even if confused, need to be understood as human phenomena.

**COOPERATIVE RESEARCH**

The motivation to do cooperative research (with persons contributing based on their experience-based knowledge) is an awareness that academics are not always in a position to figure out what the relevant research questions are, and also that development of new knowledge will benefit from experience-based knowledge. Knowledge is understood as integrated in persons, and the persons involved in a research process contribute by being and participating, as well as by how he or she expresses his or her knowledge based on
personal experience, theoretical insights, as well as experiences with being in the clinical field.

Hummelvoll (2003) writes that involving service users and health workers in research may contribute to mend the gap between theory and practice, as it is a way of ensuring that the research is relevant, and can assist in overcoming the difference in value between academic knowledge and practical knowledge. The questions asked are important from the participant’s point of view, not only the researcher’s. The knowledge will be close to the experienced reality, rather than describe an external reality (Hummelvoll, 2003).

Borg and Kristiansen define cooperative research with service users (“medforskning”) as “research activity in which persons with firsthand experience with mental health problems take part in the various stages of the research process together with academic researchers” (Borg & Kristiansen, 2009, p 29; authors’ translation). A crucial point is how much influence is given to the service users in those processes. The motivation for involving service users should be to add to the quality and relevance of the research rather than being politically correct (Davidson, 2009).

In the current research projects, cooperative research was used to challenge and become aware of pre-understandings, as a help to extend perspectives, and to strengthen the relevance of the research. In project A, and partly in project B, a co-researcher with firsthand experience as a mental health service user cooperated with the main researcher. The co-researcher (Bengt Sundfør) had taken part in various organisations as an experience-based knowledge consultant, and also attended a course about user involvement in research at the time of the study (Sundfør, 2011). In project B mental health workers were involved as co-researchers. The design was multi-stage focus groups (Hummelvoll, 2008; Borg, Karlsson, Kim, 2010) based on participatory philosophy. The intention was to work together with the mental health workers in order to build new knowledge and see other perspectives and answers to the research question. To avoid confusion, the title “co-researcher” is (in this thesis) used only about the person with firsthand experience, while the co-researchers (the mental health workers) in project B are called “participants”.

**STUDY SETTINGS AND PARTICIPANTS**

**Project settings**

Project A, “Dignity in everyday life”, was set in a rural municipality with about 10 500 inhabitants. The community-based mental health services provided sheltered housing, a day-centre with various activities and opportunities for social contact, various organised social activities like parties, bingo, walks, and hikes, and also cooperated with various sheltered working arrangements. All users of the mental health services were appointed one or two personal contacts, who would coordinate the services for that person, and also aim to form personal relationships with the service user. The services were personalised depending on
the service user’s needs, but might typically include help with household activities, support with economic matters, counselling, support in contact with social services and other official services, and assistance with medication and health related issues as required. The relationship with the health workers varied from conversations about everyday issues, someone to talk to about their health, someone who would recognize signs of deterioration, going for walks, and advocacy and support in encounters with other professionals like the general practitioner, employment office and so on.

Project B, “Focus on experience based knowledge”, recruited mental health workers from four different municipalities. Two of these were municipalities including city-communities with between 35 and 40 000 inhabitants, and the other two were rural municipalities with less than 10 000 inhabitants. The common ground for all the five municipalities (Project A and B) were that the mental health services aimed to fulfil the goals described in national guidelines for community-based mental health services with user involvement and long-term stable relationship as a basis for the provided services.

Recruitment and participants

In project A, 11 participants were recruited from among users of community-based mental health services in the municipality. Persons older than 18 and using mental health services at least three times a week could be included. The participants were 7 females and 4 men, 4 were between 20 and 30 years old, and 7 between 40 and 60 years old. 4 had no formal employment, 6 worked part time in sheltered employment, and 1 worked fulltime in sheltered employment.

Information meetings were held for the service users and mental health workers in the day-centre and in the common room in the sheltered housing. Information was also given on posters and in staff meetings. Written information was available with information about the project, and this was distributed to service users via the mental health workers. Persons interested in taking part met the researcher and co-researcher in a meeting in which further information was given, the informed consent signed, and appointment for interview settled. All information was given both orally and in writing, and the participants were given telephone numbers of both the co-researcher and researcher. The participant decided the time and venue for the interview, and a meeting room in the local municipal library was suggested as a suitable venue for the interviews.

In project B, 8 mental health workers with at least three years of higher education and at least two years experience working in mental health services were recruited through the leader of the municipal mental health services. The participants represented four different municipalities, were women, and registered nurses. Seven had from three to six years of higher education, and one had more than six years. One had worked in mental health services less than three years, two had four to ten years experience, and five had more than ten years experience. The participants worked in day-centres; as consultants, meeting
service users in formal discussions in an office, or “in the field” giving individual support to service users in their everyday life.

INTERVIEWS AND DATA GATHERING

Project A: Dignity in everyday life

Development of the fundamental ideas for the study, as well as development of the interview questions, all information meetings, setting up appointments with the participants, and the actual research interviews were done in co-operation between researcher and co-researcher. Nineteen interviews were held; 17 of those by the researcher and co-researcher together. One participant chose to only speak to the researcher; the co-researcher did the second interview for another participant alone.

A pilot interview was done to test the question guide, and to reflect further on how the researcher and co-researcher could complement each other in the interview setting. Each participant was invited to attend two interviews with slightly different agendas. Eight participants agreed to come for the second interview, and the interval between interview one and two for each participant was from three to seven weeks. The interviews were held in the period December 2009 to June 2010, and lasted between 40-90 minutes. All interviews were audiotaped and transcribed verbatim.

The first interview one was done according to an interview guide with three themes: “People I like being with”, “People I do not like being with”, and “Helpers and the helpers’ priorities and values”. In the second interview the participant was asked to tell a story about feeling valued and important, and further questions were asked to understand and get more details concerning issues from the first interview.

Notes from discussions between the researcher and co-researcher after the interviews and in the process of analysis were also included in the data. Towards the end of the analysis, a group of consultants with firsthand experience were asked to reflect on the preliminary results, and notes from this meeting were included as the basis for further analysis.

Project B: Focus on experience-based knowledge

The multistage focus groups were held as four sessions with three-week intervals in the period April 2011 to June 2011. The same participants were present in all four sessions, except for one participant who did not attend session 1 and the co-researcher who did not attend sessions 3 and 4. Before the first group session, the participants were asked to read and sign the formal letter of informed consent, and also answered a short questionnaire about their thoughts about “promotion of dignity”. The group discussions were audiotaped and transcribed verbatim.

A programme was made for each session: the first session was based on results from project A, and the following sessions on results from Project A as well as on ongoing processes in the
multistage focus group. The participants were asked to discuss and reflect based on a theme or case that was presented. The participants contributed based on their previous experiences as well as by “trying out” ideas from the groups in their clinical work and reflecting further on their new experiences in following group sessions.

A summary from the previous session was sent to the participants before each session, and these summaries (as well as a summary made after the last session) were also included in the data material. Towards the end of the process of analysis (a year later, June 2012), a fifth group session was held to discuss preliminary results. This was not audiotaped, but a summary from this group was the basis for the further analysis process.

DATA ANALYSIS

Interpretative phenomenological analysis (Paper I and II)

In Papers I and II, Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009; Smith, 2011) was used to guide the analysis. IPA is concerned with detailed examination of human lived experience and aims to express the experience on its own terms rather than on predefined categories. IPA is phenomenological and connected to core ideas of philosophers like Husserl, Heidegger, Gadamer, Merlau-Ponty, and Sartre and influenced by the hermeneutic version of phenomenology. Heidegger and Gadamer are referred to as forging a hermeneutic phenomenology. In addition to phenomenological and hermeneutic philosophy, this method is also concerned with ideography, or the particular. There is commitment to the particular in the sense of detail, which leads to a thorough and systematic approach. There is focus on understanding how the particular experiences have been understood from the perspective of particular people, in particular contexts. The process of analysis thus emphasises examining single cases before making more general claims (Smith et al., 2009). It involves engagement and interpretation: an intensive qualitative analysis of detailed personal accounts derived from participants (Smith, 2011).

In step one, “Reading and re-reading”, and step two, “Initial noting”, co-researcher and researcher worked to get to know the material, with special attention to understanding the story of each individual. The researcher transcribed the text, and researcher and co-researcher read and listened to the text several times to validate the transcription, and at the same time get to know the material. Notes were made in the margins of the transcribed text by the researcher and co-researcher separately. Then going through the material together, the notes were used to contemplate the significance of what each participant said, and how this participant had presented his or her life-story to us. The cooperative work also involved contemplating the differences in how each of us understood what the participants expressed; differences in how each of us had responded to the participants in the interview setting; and discussions about how we could have been more open in the interview process. Notes were made based on this cooperative work.
Step three, “Developing emerging themes”, was done based on summaries of the main story representing each participant. In step four, “Searching for connections across emerging themes”, the themes from step three were modified through marking text in the material, and developed further to find themes that could be said to represent the material as a whole. This was a long process of trial and error, which ended up with a narrative based on the total material. Based on this the themes presented in Paper I emerged.

The analysis leading to Paper II was done by the main researcher alone, even if it was based on unanswered questions from the first collaborative analysis. The steps of analysis repeated the pattern from the first analysis, only that the detailed analysis was done for four cases, and patterns were sought based on these cases, and then developed further when going back to the total material.

**Interpretative analysis of lifeworld (Paper III)**

In Paper III, the analysis was supported by reflective lifeworld research, or the scientific interpretational attitude as developed by Dahlberg et al. (2008). Gadamer’s philosophy of science and relevant principles for developing hermeneutical methodological ideas are the basis for this methodological approach. Dahlberg et al. (2008) emphasise the phenomenological base of the understanding of hermeneutics. They emphasise scientific openness, but suggest that order and a systematic approach is not opposed to being open in the research process, and thus describe a way of analysing data material (Dahlberg et al., 2008). The analysis involves engaging in open processes of dialogues with the text, searching for underlying meanings, and going from tentative interpretations at the lower level of the hermeneutic spiral, towards a new whole at the higher levels of the hermeneutical spiral (Dahlberg et al., 2008).

As this was a multi stage focus group study, the “analysis” or work to answer the research questions started in the discussions in the group sessions, carried on in the summaries made based on the groups sessions, and was developed further in the discussion in the next sessions. The participants were engaged in the hermeneutic circle of moving from the whole (the aim of the study and the summaries from the group sessions) to the parts (the presented cases and the discussions about particulars). At the same time the participants (as well as the researchers) strived for openness to other group members’ as well as service users’ perspectives and being open to reconsider one’s pre-understandings.

When this joint process was over, the researcher (the co-researcher was not involved in the further analysis) went from being part of the dialogue in the groups, to trying to be outside the group and in dialogue with the data material. This was a systematic engagement with the data, and involved reading everything again to reach an understanding of the whole. This preliminary understanding guided the structural analysis: organising the material in themes and sub-themes that represented the meanings in the material. After this, the search for underlying meanings began. This included trying out tentative interpretations that would
explain the entire data set. In Paper III, the themes from the structural analysis were presented in a table, the interpreted meanings were presented in “Findings”, and the first sentence in “Main interpretation and discussion” sums up the total analysis.

Phenomenological hermeneutical method for researching lived experience (Paper IV)

In Paper IV, Lindseth and Norberg’s (2004) phenomenological hermeneutical method for researching lived experience guided the analysis. This method for analysis is inspired by the theory of interpretation presented by Ricoeur. A central element is Husserl’s phenomenological attitude in which the phenomenon is allowed to appear to the mind in its meaning structure, and its essential meaning or “essence” may appear. They also refer to Heidegger, Gadamer and Ricoeur in understanding that these essential meanings are something with which humans are familiar with in the practices of life. The methodology is not pure phenomenology in which essences are seen intuitively, but also not pure hermeneutics as the interpretation transcends that of the text and reveals essential traits of our lifeworld (Lindseth & Norberg, 2004).

Lindseth and Norberg (2004) focus on the meaning of each statement in the text. In the analysis for Paper IV the focus was on how each statement contributed to processes of development which is slightly different. Even so, the dialectic movement between open understanding and structured methodological explanation, as well as the steps of analysis were according to Lindseth and Norberg’s (2004) suggestions. The analysis was not a linear process from step to step, but rather a process of the understanding of the total material (step one naive understanding) informing and guiding the structured analysis (step two structural analysis) and vice versa.

The aim of the paper was to describe processes of development, rather than an end product or an image of how something is. Boud and colleagues’ (Boud et al., 1985) theory about “re-evaluation of experience” was useful as it provided a map to organise sub-themes and themes, and the model was slightly modified to allow the material to define the themes rather than letting the model define the material.

ETHICAL CONSIDERATIONS

For project A, the Regional Committee for Medical Research (Eastern Norway Ref 2009/1316) gave approval of the research after making sure that the information letter was in line with their standards, and also pointing out that a small sample study made it crucial to be aware of the risks of revealing the identity of the participants.
Extra effort was made to make sure that only the participants and the researchers knew who participated in the study. Because of the risk of the interviews causing unsettling thoughts, the participants could contact the researcher or co-researcher after the interviews if necessary. They were also informed orally and in writing that they could withdraw from the study and/or withdraw any part of what they had said at any time. The researchers were aware that asking persons about their relationships to other people may be very sensitive as it might “force” the person to reflect on issues that he or she would like to avoid talking about. The second interview was primarily to strengthen the quality of the research but a positive side effect was that it made it possible to get feedback about what impact the study had on the participants.

Project B was reported to the Norwegian Social Science Data Services (NSD number 26685) and procedures for information about the research and informed consent was followed. As the project involved presenting cases from project A, the Regional Committee for Medical Research confirmed in a letter (dated 09.03.11) that this could be done within the scope of the original permission.

The risk of revealing the identities of the participants in project A was a reason for not including the municipality from project A in the recruitment of participants for project B. In this way none of the participants in project B had any way of knowing or guessing the identity of the participants in project A. And this allowed us to be more specific and include details about the significance of particular events in the presented cases.
5 FINDINGS

RECOGNITION AS A VALUED HUMAN BEING (I)

In the paper “Recognition as a valued human being”, reciprocity was found to be essential in relationships between service users and health workers. The service users’ experiences of being valued and significant depended on his or her participation in the relationship being acknowledged. And in order to recognise the service user, professionals needed to give something; show humanness, or be personally involved.

The participants were asked about how they were and would like to be “seen and heard” by professionals. The answers were not instructions or directions to health workers, rather a presentation of who the participant was, what was important to him or her, and how he or she made sense of his or her life situation. And as these answers were responses to how the person would like to be seen and heard, it gives emphasis to recognition of the person as he or she presents him or herself and of how he or she makes sense of his or her life experiences.

The theme “It’s a struggle to be me” illustrated experiences of not being able to live the life that the person would like to live: of not being like other people, and of not living up to one’s own and other peoples’ expectations. The theme “It’s a struggle to be recognised” illustrated not being able to trust other people and needing to conceal what other people did not comprehend or recognise. These were issues that the participants “struggled with”, or were concerned with, were directed against, and actively engaged in. The last theme “I have been recognised” illustrated how being able to trust health workers (or other people) was an immense relief.

CHALLENGES IN RELATING TO MENTAL HEALTH PROFESSIONALS (II)

The findings in the paper “Challenges in relating to mental health workers” illustrated how the levels of openness and trust in relationships between service users and mental health workers might influence service users’ recovery. Levels of connectedness in relationships with professionals were “being detached”, “being cautious”, and “being open and trusting”. Detachment (or limited connectedness) was shown to limit recovery-related factors like Connectedness, Hope, Identity, Meaning, and Empowerment. And being in open and trusting relationships could enhance the same factors and thus facilitate recovery.

In relationships in which the participants experienced “being detached”, the professional was experienced as indifferent, hostile, or unwilling to understand the person and his or her experiences. This led to experiences of being disempowered, of having lost hope, of isolation, and of being incomprehensible to other people.
In “being cautious”-relationships there was conditional connection to the professional. The professional were experienced as recognising based on the professionals’ agenda; based on some predetermined image of who the service user was; of recognising on the condition of the person changing; or as recognising without taking what is recognised into consideration in the relationship. This led to experiences of having to consider what to share, with whom to share it, and also as to how something could be shared without risking too much. The person was left with the choice between speaking openly and risk losing the right to define meaning in his or her life, and the choice to avoid sharing and thus lose the opportunity to be included in human fellowship.

The person needed to make sense of what he or she experienced; his or her directedness to the world and his or her understanding of those experiences. Not relating to professionals can be understood as a way of keeping oneself sane, and of being true to own body-subject in the world. Not connecting to other people is thus necessary to protect own identity and own meaning. Based on this, limited connectedness was threats to main characteristics of human beings, as intentionality was in conflict with intersubjectivity.

In a trusting relationship there was a relief as there was no need to assess or evaluate, and the person could share his or her opinions, values, priorities and goals without risking that the professional did not respect it. This also gave opportunity to reconsider one’s own opinions and understanding of one’s own life, as the person was free to listen to the professional’s opinions and values.

“WE ARE ALL FELLOW HUMAN BEINGS” (III)

Based on the findings from Paper I it was assumed that recognition of service user’s personhood and intrinsic value as human beings depends on him or her being acknowledged as an active and participating agent, and on the health worker being personally involved and engaged in the relationship with the service user. The findings (Paper III) focus on modes of “being” that may improve recognition, or ways of being that are associated with dignity promotion, such as enhancing identity and acknowledging service users’ personal understanding/meaning. The themes were: “Being humble and in awe”, “Being willing to risk own understanding”, “Being in process”, “Being courageous”, “Being a positive counterforce”, and “Being aware of limitations to recognition”. The mental health workers were conscious that their way of “being” or their attitude and state of mind while trying to recognise, might either facilitate or reduce service users’ opportunities to present him or herself in the relationship.

The paper draws attention to the service user and the mental health workers as participating and shaping the relationship, and how both service user and mental health worker’s contribution is significant and makes a difference. This means valuing the contribution of each person’s “being” rather than what each person is conscious of contributing or achieving.
These modes of being, or the work to recognise service users’ personhood and intrinsic human value found to induce self-respect in (the service user and) the health worker. Human vulnerability (in the service users as well as in mental health worker) had positive impact in the sense that the health workers experienced becoming wiser and developed when being exposed to it. The encounters with services users led to further development as a human being and professional, and a prerequisite to this was openness and willingness to change. The mental health workers’ statements about being happy in their work were associated to experiences of excitement and feeling privileged about being persons who made a difference in the lives of other persons, and of being persons contributing to something worthwhile.

**STRENGTHENING PRACTICAL WISDOM (IV)**

Paper IV explored mental health workers’ processes of development and learning. The attitude of openness and willingness to risk one’s own understanding (as described in Paper III), seemed to nurture these processes of development and learning in the focus groups. The mental health workers listened to each other, reflected, and worked to see their own opinions in new perspectives.

In the processes of speaking with each other about their practices, the health workers expressed what they knew, found words for knowledge that had been tacit, and became aware of their own attitudes and experiences. They learnt from each other, and got a chance to re-evaluate their own practices in the light of the other person’s opinions, experiences and attitudes. They gained new insight and were able to contribute to development in themselves and each other.

The findings confirmed that openness and indecisiveness are important factors for developing knowledge for the individual health worker as well as for developing caring cultures in which service users can experience to be recognised. Engaging in discussions about practice and re-evaluating practice experiences may thus be a way to strengthen dignity-promoting practice cultures and of ensuring that individual health workers develop attitudes in line with such practices. Dignity promotion was found to be hard work, and continued attention and re-evaluation of experiences could contribute to maintain and promote “good” practices. The findings in paper IV represent one answer to how service user’s experience-based knowledge can be a foundation for mental health workers’ knowledge and clinical work. And also a suggestion as to how health workers may become better at “being” in ways that opens life opportunities for the service users.

**SUMMING UP THE FINDINGS**

The social dignity perspective was a help to see what may be at stake in relationships between mental health workers and persons living with severe mental health problems. A
The central issue in the service users’ experiences were experiences of not being like anybody else, which was associated with various levels of isolation or apartness from other people. As social dignity and caring ethics focuses on the relational perspective, this lack of connectedness to other people could not be seen as being caused by something in the person, but rather as a consequence of that person’s lacking opportunities to pursue his or her foundational motivational drive to connect to other people.

The findings also suggested some explanations of how the opportunities to experience connectedness to other persons were limited: the person’s narrative was not received by others (it was not understood, it was avoided, it was overheard, or it was redefined); the person was not recognised as an active agent (what he or she says did not make a difference, the relationship was defined before the person entered it); and the person was not recognised as valued in his or her present state (he or she was expected to adapt to standards, and development and change was the aim of the relationship).

Promoting and maintaining dignity entailed more than respecting from a distance; it was not only showing respect for and letting the person be who he or she is. It was not primarily about asking: “What can I do for you?” and responding to needs. The mental health worker was engaged in pro-active involvement representing an active counterforce against negative images the service users had about him or herself. Promoting dignity was active work, it involved engagement and involvement that developed and strengthened human potential in both the mental health worker and service user. Thus engaging in dignity-promoting relationships had the potency of changing the way both service users and mental health workers thought about themselves.
6 DISCUSSION

This thesis suggests that a person’s opportunity to enter into the unique and personal recovery-journey depend on being recognised as a valued and contributing human being by one or more “other” people. In this sense a beneficial starting point for recovery-oriented practices are “being in relationship” with the person seeking care, and attention to how these relationships contribute to recognition of the service user as a human being (an active agent motivated by foundational human drives towards meaning and connectedness). “Being in relationship” is an opportunity to fulfil one’s human potential, in the sense that one can experience to be valued and respected, experience to be significant and make a difference, and thus have a reason to live.

Maintaining and promoting dignity is a moral obligation, emerging from being in the relationship with the other, and responding to this obligation is linked to fulfilling one’s human potential; to confirm oneself and the other person’s identity and intentionality, and thereby be able to live according to the foundational human drive towards connectedness and intersubjectivity. This demands courage and openness, which is nurtured in relationships with service users as well as in reflection on one’s own and other health workers’ experiences.

The further discussion attempts to take a further turn in the hermeneutical circle, and ask what new perspectives and insights can develop based on broader understanding from the total research process. Based on the awareness of that service users’ narratives are not always received, that service users are not recognised as active agents, and that service users are not valued in his or her present state in relationships with mental health workers: How can mental health workers’ recognition in relationships with service users contribute to avoid or diminish such experiences? And how can mental health workers enhance service users’ opportunities to participate in open and trusting relationships? Three different focuses in the process of recognition are assumed to contribute to these questions:

- Recognition of the person as an active and struggling agent
- Recognition of the person as a narrator in his or her life
- Recognition of the person’s intrinsic human value

The following discussion explores the significance of each of these assumptions as to how they contribute to recognition of mental health service users as valued and contributing human beings.

RECOGNISING THE STRUGGLING PERSON

To recognise the service user as an active and struggling agent is one way of acknowledging the person as contact and meaning seeking. The struggle (as described in findings from
Paper I, see p 34) is understood as that aspect of the person’s (the acting agent’s) life which currently occupies his or her attention, to which importance is assigned, and upon which his or her energies are spent. Sharing the struggle with health workers (or other people) can give the person experiences of not being alone, and of respect and acceptance as his or her concerns are acknowledged as important by someone else (he or she is significant). It can strengthen the service user’s sense of belonging (Topor et al., 2006), or contribute to the spiritual connection or “bridge” (Halldorsdottir, 2008) between the health worker and the service user.

It might be argued that focus on the struggle is a focus on negative aspects rather than positive. On the other hand, focussing solely on the coping person or the person’s strengths bears with it a risk of discounting the fact that the person is in fact struggling. There is a fine balance between communicating pity: “I feel sorry for you” and demonstrating recognition and compassion: “I see that you struggle, and I care that you struggle”. Thus recognition of service users’ struggle puts the health worker in a position of compassion and solidarity, which Jacobson (2009b) suggested is likely to promote dignity.

To focus on the struggling subject is a means to acknowledge that the person’s life is difficult: the health worker does not back away from the person’s vulnerability, shame or suffering, and this can become a demonstration to the service user that the health worker is ready to be involved and prepared to endure. This opens opportunities to share without having to consider what is appropriate or expected. Halldorsdottir (2008) found that patients said it was important to be able to share both positive and negative feelings with the nurse, as this made the person feel like a normal human being. The patient experienced that someone worked with him or her rather than on him or her, and experienced that “I am not alone in this” (Halldorsdottir, 2008).

The mental health worker becomes a witness to the struggling subject, and faces and accepts the service user as he or she is in the present moment. Milton (2007) writes about bearing witness to persons as being connected to being attentive or true presence: Bearing witness is an interpersonal art reflecting (or demonstrating to the person) that he or she is respected with a venerable regard; and acknowledgement of that the person knows his or her way and live according to his or her priorities. Thus attentiveness means being present without judging or labelling (Milton, 2008).

To be accepted (and not judged or labelled) by other people, open opportunities to accept oneself, and this may open new ways of understanding one’s own life situation. Binder and Vøllestad (2010) found that being fully present in the emotions and thoughts that evolve can be a help to the person to accept what is there in that present moment. Even if the emotions are unwanted, they can be accepted as a part of being a human being. When the carer (mental health worker) visualises and cultivates conditions such as acceptance, goodwill and love, the person may learn to have compassion for him or herself (Binder & Vøllestad, 2010).
In summary, recognition of the struggling subject can assist in creating shared understanding and experience of connectedness. The service user is free to include the mental health worker in a “we” who work towards a common goal. To be part of this “we” the mental health worker needs to tune into the service user’s agenda, concern, language, and priorities. This willingness to let the service user make an impression in the relationship demonstrates that the health worker cares, and that person is significant. Thus, focus on the person’s struggle may be a path to allowing the person life opportunities, and a prerequisite for acknowledging him or her as an intentional and intersubjective human being.

RECOGNISING THE EXPERIENCING PERSON

If there is agreement that all persons have the right to be respected as equal in dignity and right, the ethics or “demand” to treat other people with respect comes first. Mental health services are obliged to recognise the person and his or her narrative in the present moment and let this be significant before defining and interpreting the person and his or experiences based on theory. The experiences of the body in the world “come before” and is more significant than the abstract and logical understanding (Bengtson, 2006; Smith et al., 2009, see p 18 in this thesis). Taking the experiencing body into consideration demands seeing “symptoms” as part of that person’s experiences, and the significance of the “symptoms” or how he or she incorporates the experiences in his or her understanding of him or herself need to be the foundation for understanding.

To recognise and understand withdrawal and speaking to internal voices (as well as other “symptoms”) as merely signs of illness is contrary to recognition of the person as he or she is in his or her present state. It is a threat to the person’s personhood and intrinsic human value as the person is not recognised as an experiencing subject but is understood based external definitions of his or her experiences. His or her experiences are insignificant in the sense that other people are moved by the defined symptoms rather than by the experiencing body-subject.

Naming human experiences as symptoms may increase the distance between “us” and “them” (see background p 12). Topor et al. (2006) write that there is a need to offer people commonality with other people’s experiences, and focussing on the experiencing subject rather than symptoms may be one way of achieving this. The findings (Paper I), as well as other studies (Johnson, 2012; Myung-Yee & Woocan, 2009; Shattell et al., 2007) reveal that persons living with mental illnesses experience a sadness or loss as they cannot include themselves in what is expressed as “ordinary” people. This experience may be strengthened rather than diminished when the person’s experiences are labelled as symptoms of being “abnormal”. Symptoms are something other “normal” persons can’t be expected to recognise as it is linked to having an illness rather than to living an “ordinary” life.
If symptoms are signs of illness, they are something to eradicate (rather than a phenomenon to make sense of). The person, however, may experience that the phenomena that are referred to as symptoms are an integral part of how he or she understands him or herself in the world. He or she is not just a passive bearer of an illness with symptoms, but an experiencing person who needs to incorporate his or her experiences in a meaningful and comprehensible manner. Health workers aiming to remove the symptoms fail to take the significance of the “symptoms” in the person’s life into consideration. Ekeberg (2011) writes that a person needs to guard his or her boundaries, when other people threaten the person’s ability to manifest him or herself before others. Thus, the discrepancy between understanding symptoms as something to abolish rather than something to make sense of, makes it impossible to be open and trusting. The person’s opportunity to act according to his or her primary motivational drive “to be known and to share what it feels to be them” (Stern, 2004) is removed. “Taking away” symptoms is a threat to how the experiencing subject comes to terms with his or her experiences and how he or she perceives him or herself in the world.

Limited opportunity to speak openly has several negative consequences. The first is that it is hard work to consider what to share. Hem et al. (2008) write that being distrustful poses a significant strain and that mutual trust is a prerequisite for ensuring that the therapeutic program will help the patient (Hem, Heggen, & Ruyter, 2008). The second consequence is that the person’s opportunity to collaborate with health workers is limited, and opportunities to diminish negative influences of internal voices or other “symptoms” can be lost. The third consequence is that lack of connectedness to other people may lead to increased attention to internal voices. Not being able to speak openly may thus amplify the role of “psychotic” internal voices. And a consequence of the latter one: when the person is alone with his or her voices and the content of the conversation with internal voices are not shared with others, the internal “discussions” become increasingly significant. In this case the outside world has no way of influencing the internal world of the person. Openness in relationships may provide the person with opportunities to allow mental health workers to contradict or influence the impact of negative voices. Remaining alone means not developing various social roles associated with redefinition of self (Topor et al., 2006).

Recognition of the experiencing subject requires expecting the service user to make sense and to expect that he or she is acting based on basic human motivations. Failure to present a narrative that makes sense to other people, problems with knowing how to ask for help, or “withdrawal” from relationships with mental health workers cannot be “blamed” on the patient or the nature of the illness, but rather on the opportunities or limitations the person is presented with in relationships with mental health workers as well as other people.
RECOGNISING INTRINSIC HUMAN VALUE

The third assumption implies that mental health workers recognition depend on being “in awe” of the intrinsic human value of the service user. The two other assumptions focused on recognition of the service user as an active and experiencing subject. This third assumption focus on recognition as something that does not depend on the service user as an active and experiencing subject, but on the person as a human being with intrinsic value. There is an element of recognitions regardless of, or in spite of the person’s motivations, values and aims. In this way of thinking, dignity or being worthy of respect is linked to the absolute human worth rather than to the person’s responsibility or duty to serve one’s fellow-human beings (Edlund et al., 2013). The emphasis is that human beings deserve respect even when one is not contributing by doing one’ duty or fulfilling one’s responsibility linked to the human office.

In this thesis it is argued that a person’s opportunity for self-respect and of experiencing to be worthy of respect depends on being respected by others. And dignity is understood as a norm or value to work towards (rather than a quality someone possesses) (Coventry, 2006). And as a consequence it can be argued that every human being contributes to the fellowship by just being (rather than by fulfilling responsibilities or duties), and that he or she “deserves” respect based on this being. Martinsen (2003) writes that human relations can be used to see and defend the unqualified human values and thus expand the other’s life-space. To be in awe of these unqualified human values is associated with gratification of life and receiving the other person (rather than conquering him or her), which is opposed to the world of productivity and results (Martinsen, 2003).

Thus the only agenda decided before the service user makes an impact in the relationship (see p 15) is to recognise intrinsic human value. To be in relationships with service users mean to respond to his or her perspectives and needs, but also to respond to him or her as a person with intrinsic human value. Service users report that they sometimes don’t know how to ask for help, and that they struggle to present a comprehensive narrative that other people can relate to. The aim in those situations can be to recognise the service user’s humanness rather than to comprehend or decide what the service user wants. Mental health workers can aim to facilitate service users’ experiences of being included in human fellowship, give the person opportunities to see that he or she is like other people, and to experience that even confusion, vulnerability, and incomprehensibility is part of human life.

Recognition and dignity promotion is thus to respond to the service user’s experience-based knowledge (integrate service users’ experiences as a natural part of the services provided (Sosial- og helsedirektoratet, 2003) but at the same time respond to the person’s intrinsic human value. Regardless of the service user’s experiences, the health worker recognises that the person is valued and deserves respect. The health worker is not just responding to what the service user wants or acknowledging his or her conscious wishes, but also responds based on the notion that all human beings are worthy of respect.
SUGGESTIONS FOR CLINICAL FIELD

The purpose of the research was “to explore mental health service users’ experience-based knowledge about being recognised, and to describe and suggest how this knowledge was and could be a foundation for mental health workers’ knowledge and clinical work”. A simplified answer to that purpose is that recognition depends on experiences of being like other persons and at the same time having opportunity to be a narrator in one’s own life (to present him or herself based on his or her embodied experiences). And the answer to how this knowledge can be a foundation for mental health services is that the services should facilitate service users’ opportunities to being in open and trusting relationships with mental health workers as well as other people.

Health workers develop ability to be open to and impressed by the service user in each present moment in encounters with service users and in re-evaluation of own practice. To make service users’ experience-based knowledge for mental health workers’ knowledge and practice thus depends on appreciating the service user’s experiences as important knowledge, and also appreciate that practical wisdom is essential in order to recognise service user’s experiences and perspectives.

Each new encounter is an opportunity to open or close life possibilities for the other person and every encounter is potentially a dignity-promoting encounter. Bearing this in mind, mental health services can never be good enough as it is in the present moment in each encounter that the services may succeed or fail. The usefulness of theory such as the findings in this thesis or can be proved in practical clinical situations. The following points are suggestions that can help health workers to develop further in their relationships with service users rather than norms or rules to be applied, as the question of the suggestions really contributing to recognition of service users’ personhood and intrinsic human value can only be answered in the encounter with the service user.

- Recognising the struggling subject and focus on what the individual’s struggle is about can relieve the struggle and at the same time be a way to recognise the person as a valued human being.
- Recognition depends on letting the service user be his or her own narrator, and this include the significance his or her experiences have in his or her life.
- Service users’ actions and participation in relationships with other people can be understood based on his or her foundational human motivations: to connect to others (intersubjectivity), and to protect his or her understanding of who he or she is (intentionality).
- Focus can be on the person’s opportunities to participate in open end trusting relationships (rather than on how the mental health worker can form such relationship with the service user) and how the services can contribute to this. Facilitation of such
opportunities can mean to prioritise supporting family and friends of the service user (being loved, belonging), facilitating arenas for peer support (recognise oneself in other people), or encouraging participation in ordinary social settings in the community (belong, be like other people and be significant).

- Each mental health worker, as well as the cultures in the mental health services, can engage in ongoing processes of re-evaluation based on responses from and relationships with mental health service users. Dignity promotion practices depend on ongoing processes of developing ability and willingness to endure indecisiveness and emotional strain.
7 METHODOLOGICAL CONSIDERATIONS

There was attention to issues that contribute to make the research trustworthy, relevant and valid throughout the research process. Describing the research processes contributes transparency, and this thesis is meant to show that there has been awareness about trying to operate within the boundaries of the ontological and epistemological assumptions, as well as of being systematic, structured, and work according to methodological guidelines.

An essential issue in lifeworld research is the phenomenological attitude which is striving for openness and not making definite what is indefinite (Dahlberg et al., 2008). The aim in the research is to see something more than our everyday approach to the world, the studied phenomenon should be allowed to show itself in its own pace and its own way, without us imposing ourselves or forcing the phenomenon into linguistic categories (Dahlberg et al., 2008). In order to see something more or something new we need to challenge pre-understanding, engage in self-reflection processes, and be aware of how we are part of and influence the world we aim to explore.

Three methodological issues are discussed in detail. The first point illustrates how the three methodologies are similar and within the ontological and epistemological framework, and also how they differ and thus contributed to the research process. The second point focus on knowledge development in relational processes, and illustrates how collaborative research supported the phenomenological attitude of openness. The third point explains knowledge development based on the engagement with the concept dignity.

COMPARING METHODS OF ANALYSIS

Three phenomenological hermeneutic methodological approaches were used in Papers I-IV. All three have a strong focus on an ontological base for how they suggest that data material can be analysed, and the theoretical foundation and approach for the three methodologies are similar. The similarities can be illustrated by the way the authors describe the methodologies. Smith et al. (2009) write that the base is the hermeneutic version of phenomenology, and Dahlberg et al. (2008) emphasis “a phenomenological base for the understanding of hermeneutic”, (p 276). Smith et al. (2009) also refer to Dahlberg (2008) for an “accessible and more detailed overviews... of the theoretical terrain” (p 39) which indicates that there is a common basis for the two approaches. Lindseth and Norberg (2004) similarly call the method phenomenological hermeneutical, and write that it needs to be hermeneutical as it is text that is interpreted in the analysis. But then goes on to write: “it is not the texts that are the subject matter to be investigated, but [rather] the ethics expressed in them.” (Lindseth & Norberg, 2004, p 146). Thus the phenomenological element is strong in all three methodological approaches.
Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009; Smith, 2011) was chosen in Project A as IPA involves detailed analysis of particular cases of actual life (Smith et al., 2009). This was a help to get to know the totality or the overall story of each person in order to understand how his or her dignity was violated, and how he or she understood his or her position in relationships to other people. The method is concerned with how the participants manifest the same themes in particular and different ways and this comes from detailed personal accounts from each participant (Smith, 2011).

As project B was a focus group study, focus on the particular case was no longer relevant. Dahlberg et al. (2008) was chosen in the analysis for Paper III as the theoretical foundation was similar to IPA, even if the suggested steps of analysis differ. An added advantage became apparent in the course of the analysis: Dahlberg et al. (2008) describe one methodological foundation, and then suggest two variations of analysis. The analysis for Paper III started out with “The descriptive analysis”, but changed to “The interpretative analysis” along the way. Dahlberg et al. (2008) write that their book is meant to provide methodological guidelines and open principles for research, and this made it possible to be flexible in the engagement with and analysis of the data material. The strong focus on phenomenological attitude was also useful, and became a reminder about engaging in an open attitude involving aspects like intersubjective openness; openness to meaning and essence; and openness and awareness of one’s own pre-understanding (Dahlberg et al., 2008).

Lindseth and Norberg’s method (2004) was used in Paper IV. This was chosen as the method suggests dividing the text into meaning units as part of the structural analysis (step two in the analysis), and this was useful in discovering how the elements in the discussion contributed to processes of learning. Lindseth and Norberg’s (2004) description of the openness required to understand, also added a new dimension to the open attitude described by Dahlberg et al. (2008). Lindseth and Norberg (2004) describe a dialectic movement between a non-methodical and methodical pole, and write that it is necessary to be open to understand (the non-methodical pole): “we allow the text to speak to us. We become touched and moved by it” (Lindseth & Norberg, 2004, p 149). Thus they suggest that openness also includes being engaged and involved in the sense caring about or not being indifferent to, which means that the suggested phenomenological hermeneutic approach, or how the researcher should be reflect and think, has strong parallels to the open attitude (being involved and engaged) the mental health workers are challenged to apply in encounters with service users.

To some extent the choice of methodological approaches were pragmatic rather than idealistic. It was about having useful guidelines as a support in doing the analysis rather than agreeing with or understanding all the specific details the authors describe. This approach seems to be in line with what the authors suggest, or at least in line with how they use the philosophy they build on. Smith et al (2009) point out that philosophers may formalise and give rigorous descriptions of elements in human experience, while the aim of the researcher
is to understand the lived experience and not the philosophical account of lived experience (Smith et al., 2009). So they claim that philosophy may be a help to see and become aware of the lifeworld, but that the quest for further insight and knowledge is more important than being true to the philosophy. And one might argue that this can be said about methodology as well, it is more important to present the findings than to be ‘true’ to some method. Dahlberg et al (2008) follow a similar thinking when they argue that philosophy can only be useful if it is “transformed and somewhat reformulated for the particular context it is meant to serve” (Dahlberg et al., 2008, p 86).

KNOWLEDGE THROUGH COLLABORATIVE RESEARCH

The knowledge in this research has been developed through relational processes between researchers, co-authors and participants and these processes are complex and very hard to describe truthfully. The results take shape while living one’s life and being engaged with and by the research material: speaking to people, reading, becoming aware of something. It is important to give credit to other people, at the same time it would not be good to claim that the research is collaborative if the co-researcher and others were not given power and real influence in the research process. The following text thus gives an account of the cooperation with other people as an effort to be open about the extent of “powersharing”.

The co-researcher, Bengt Sundfør, was employed in a 20% position for 18 months to take part in the project, and made a substantial contribution during that time. His personal qualities as an administrator, his ability to reflect and be critical, and his knowledge based on firsthand experiences were important in all stages of project A. Two advantages of the collaboration between researcher and co-researcher will be mentioned.

Thinking, analysing and reflecting with another person was a help to apply an open attitude. The researcher’s pre-understanding came from working in psychiatric hospitals and from teaching nursing students, and this frame of understanding was challenged in dialogues with the co-researcher throughout the research process. The different perspectives on issues like what can be expected from mental health workers, and what it entails to live with severe mental illness made it easier to discover one’s own prejudices.

The second advantage was the co-researcher’s participation in the interviews. Kvale and Brinkman (2009) write that interview knowledge is constructed in the interaction of interviewer and interviewee. Who the interviewer is, and who or what he or she represents, makes a difference to what is meaningful to share in the interview situation. Several participants in project A referred to the co-researcher as “one of us”, and stated that this made them trust that what they said would be understood. It was also obvious in the process of interviewing that the researcher and the co-researcher responded to different aspects in what the participants were expressing. Discussing this in the process of analysis made it clear that each researcher picked up on elements that he or she recognised from earlier experiences. Thus, the co-researcher contributed to openness in the interview
situation and focused on aspects that would not have been investigated if the researcher had done the interviews alone.

The limitations to “power sharing” and “real influence” from the co-researcher were that the highest priority in the research process was to finish the PhD rather than to adapt to the cooperative research process. Limited funding was also an issue, and the influence from experience-based firsthand knowledge would probably have been stronger if more than one co-researcher had joined the project.

Another attempt to let experience-based knowledge influence the research was to present preliminary findings for a group of people with firsthand experiences. This was a help to prioritise the findings and check the relevance of the results. Members in the group could relate to the ideas of what the “struggle” was about as well as the significance of the struggle. This gave confidence to emphasise the “struggling subject” even if this was in conflict with the researcher’s “professional thinking”, which suggests focusing on strengths, coping strategies, and “health” rather than issues associated with suffering and illness.

The multi-stage focus groups were also cooperative research. The extra group session in the analysis for Paper III changed the focus in the findings to include emphasis on long term relationships and the discussion guided the further analysis. Issues concerning the analysis for Paper II were also discussed in the focus groups, which meant that the participants to some extent became “co-researchers” in both project A and B.

Even if the researcher had the final word in the processes the presentation in this thesis and in the papers are products of learning and development in relational processes with other people.

THEORETICAL PERSPECTIVES

The thesis is also product of development and learning from engaging in “relational” processes with concepts and theoretical works. The theoretical framework presented represents main inspirations in the work, looking back at the process. The lifeworld approach was there from the start, at the same time the emphasis on human beings as intentional and intersubjective was presented as a result of the findings in Papers I and II. The emphasis on experience-based knowledge developed from an emphasis on service users’ perspectives, as well as a growing realisation that the mental health workers’ experiences were an important part of what they needed to know to do a good job. The relational and social aspects of the recovery-concept were also “discovered” along the way, and thus made the concept “recovery” more relevant to the main perspective “social dignity”.

A challenge in the research process has been coming to terms with the diversity in the concept “dignity”. It was hard to define and describe what the studied “phenomenon” was, as dignity is not something that appears to someone (or if it is, it is hard to define as such). Dignity gives association to a variety of issues in people’s minds and is also used to focus on
very different things. Various studies on mental health service users’ experiences mention dignity as related to housing and valued work, being treated with respect, being listened to, and being like other people (Granerud & Severinsson, 2003; Stabell & Nåden, Dagfinn, 2006; Tidefors & Olin, 2011). And dignity is associated with various attributes like respect, autonomy, empowerment, communication (Griffin-Hesling, 2005), and depends on “conditions around” or “the human culture” (Coventry, 2006). In other words the concept is wide and has relevance to many aspects of human life.

There is also confusion as dignity has a dual nature: it might be hard to distinguish between dignity as a quality someone possesses and dignity as a norm or value to work towards (Coventry, 2006). Nordenfelt’s “types of dignity” are based on facts, or on how dignity is experienced and bestowed in society (Nordenfelt 2004), while Wainwright and Gallagher (2008) point out that dignity, or the understanding of human being as equal and bearers of intrinsic value, is not a fact, but a moral value (Wainwright & Gallagher, 2008).

In this thesis dignity was used as a moral value rather than a description of how society is. It has been a help to keep the focus on the “core of our humanness” (Jacobson et al., 2009). It was also a help to keep the thought that the person’s self-respect and identity was influenced and formed in relationships with other people, as well as by his or her position in the world.

During the research process other concepts like “integrity”, “citizenship”, “relational perspective”, “mature care”, “reciprocity”, “recovery”, “ethics of care”, “self-respect”, “identity”, “being a narrator”, “be worthy of respect”, and “recognise intrinsic human value and personhood” were a help to be specific about the studied phenomenon. And that illustrates an advantage of having “dignity” as perspective. As the concept was wide it gave opportunity to be open to what emerged in the research process. Concepts that would frame the research and be relevant to explore the findings could be decided based on the research process and the analysis. Another advantage was that the concept is common in everyday language and easy to communicate to participants in the study, and this also became a help to motivate that the research was worthwhile.

The concept “integrity” (a personal and social virtue) as described by Ekeberg (2011) is probably closest to the foundational idea for the project. And using this concept would probably have made it easier to be precise. At the same time this only became clear in the process, and each of the other concepts also opened doors to central issues related to dignity and dignity-promoting practices, and these may have been lost if the frames of reference were more narrow.
8 CONCLUSION

Focus on dignity means focus on the core of humanness. It is about experiencing to be worthy of respect as a human being, and being given space to live a meaningful human life. Recognition of a person’s dignity and personhood moves the focus from what we can do and how we can do something, to who we can be. When mental health workers ask: “What can I do for you?” or, “What do you want?” he or she has passed the crucial point, which is to relate to the service user in a way that opens his or her life opportunities. “Who we can be” is about involvement and engagement, about being changed by the other, about sensing and experiencing with the other, and of recognising oneself in the other. The knowledge needed to know “who we can be” is knowledge that understands rather than knowledge that defines. Ability to be a person who recognises and promotes the dignity of the other person can only be developed in relationships with other persons. To recognise service users as human beings is an ethical demand. And developing ability to be in order to respond to this demand is an ongoing process of development induced by recognising and being recognised.

The main aim for dignity promoting practices is not development or change in the service users, it is to recognise and value the service users here and now, in their present state. This way of being becomes a gift to the other person, allowing him or her to be a person who is included in human fellowship, who is significant for other people, and who makes a difference in the world. This kind of recognition can lead to development and change even if the goal was only to recognise the person in a relationship.

Mental health workers and other health professionals work to respect and protect service users’ integrity. Even so service users experience that their boundaries are invaded and experience lack of respect in the services. Faced with the accusation of humiliation, the health worker can avoid listening, minimise the problem or defend him or herself. This is a natural reaction as admitting to contribute to humiliate other persons is a threat to the image the health worker has of him or herself as a moral subject who acts to help and be good to other people. Being open to the accusation about humiliation is humiliating. Thus working to be open and to promote dignity can be a painful process.

At the same time, being worthy of trust from the service user and experiencing to contribute to facilitate his or her life opportunities is rewarding. To receive the other person, to be moved and engaged by his or her presence, and to acknowledge him or her as a valued and significant human being contributes to both service user’s health workers’ self-respect. Thus working to be open and to promote dignity can open life opportunities for health workers as well as service users.
9 SAMANDRAG PÅ NORSK

Bakgrunn: Stabile relasjonar mellom brukarar og helsearbeidarane er ein viktig del av tenestetilbodet i dei kommunale psykiske helsetenestene i Noreg. Denne oppgåva ser nærare på korleis brukarar opplever å bli stadfesta og få rom som menneske i desse relasjonane. Forskinga har fokus på omgrepa ”Recovery” (å vera i betringsprosess) og ”omsorgsetikk”.”Sosial verdighet” er brukt som perspektiv.

Hensikt: Det overordna målet var å utforske brukarane sin erfaringsbaserte kunnskap om å bli anerkjent, sett og høyr, og så sjå nærare på korleis denne kunnskapen er eller kan bli ein del av dei psykiske helsearbeidarane sitt kunnskapsgrunnlag. I artikkeli I var målet å utforske korleis brukarane beskriver og forstår av sine møter og relasjonar med andre menneske. Artikkel II beskriver brukarane si forståing av å vera i relasjonar med profesjonelle helsearbeidarar, og korleis desse relasjonane var til hinder for eller kunne fremje betringsprosesser. Ut frå helsearbeidarane sine erfaringar med å vera i stabile relasjonar med brukarar, var målet i artikkel III å vise og uttrykke kunnskap om kva det inneber å anerkjenne, sjå og høyre brukarane som heile menneske. Artikkel IV utforskar eksempel på helsearbeidarane sine prosesser av utvikling og læring.


Funn: Brukarane sine opplevelser av å vera anerkjend, sett og høyr, hang i hop med å erfaringar av å bli verdsett, og av at hans eller hennar bidrag i relasjonen vart teke omsyn til av helsearbeidarane. Brukarane levde med eit strev for å vera seg sjølv eller akseptera seg sjølv, og eit strev for å bli anerkjent, sett og høyr av andre. Og det å oppleva å vera i relasjonar der ein vart anerkjend, sett og høyr letta dette strevet (Artikkel I). Strevet for å bli anerkjend av andre var eit dilemma mellom på den eine sida å vera open og risikere å misse retten til å fortelje si eiga historie, og på den andre sida å skjule kven ein var og slik risikere å bli isolert og åleine. Erfaringar av å ha tillit til, og av å vera i opne relasjonar til helsearbeidarar var med på å styrke faktorar som har vist seg å vera til hjelp i betringsprosessor (Artikkel II). Helsearbeidarane si tilnærming, eller måte å vera på, påverkar brukaren sitt høve til å vera open i relasjonen til helsearbeidarane. Det å vera i relasjonar med mål om fremje verdighet førte til auka sjølvsrespekt både hjå brukar og
helsearbeidar (Artikkel III). Openheit og vilje til å la vera å avgjera (å vera ubestemt - indecisiveness) var eit viktig grunnlag for å kunne utvikle kunnskap. Utviklings- og endringsprosessar kan fremjast ved å evaluere erfaringar og delta i samtalar om korleis verdiigheitsfremjande praksisar kan bli utvikla og oppretthaldne (artikkel IV).

Konklusjon: Å inkludere brukarkunnskapen i helsearbeidaren sitt kunnskapsgrunnlag, krev at helsearbeidaren er open for og ”berørt” av brukaren i kvart nye møte; brukaren må få vera forfattar i eige liv; og helsearbeidaren må vera klar over at brukaren sine perspektiv og erfaringar representerer ein unik innsikt som har verdi. Målet for verdiigheitsfremjande praksisar er ikkje å utvikle eller endre brukaren, men å sjå og anerkjenne han eller henne slik han eller ho er no. Ved å vera i relasjon med brukaren kan helsearbeidaren anerkjenne brukaren som eit aktivt, deltakande subjekt og slik vera med på å gje brukaren oppleving av å vera verdsett og at hans eller hennar deltaking gjer ein skilnad i andre sine liv. Openheit og tillit kan fremjast ved å sjå den strevande personen; ved å forstå tilbaketrekking og stemmehøyring (og andre ”symptom”) som menneskelege erfaringar heller enn teikn på sjukdom; og ved å anerkjenne menneskeverdet. Kvart nytt møte mellom helsearbeidaren og brukaren opnar möglegheit for å anerkjenne, sjå og høyre. For å få til å stadfesta og gje rom for brukaren i kvart nytt møte må helsearbeidarane så vel som psykisk helsepraksisar engasjera seg i utviklingsprosessar der ein jobbar mot praktisk visdom om kva det er å vera i verdiigheitsfremjande relasjonar.
ACKNOWLEDGEMENTS

I am very grateful to the participants in both projects for sharing their experiences, knowledge and wisdom, and for joining me in parts of my research process.

To co-researcher Bengt Sundfør: I treasure our friendship and our continued dialogues. Working with you made research interesting, exciting, and less stressful. Thank you for organising, speaking to the right people, sharing, and your ongoing interest and enthusiasm for our shared work.

Thank you Maria Arman for guidance in the academic world: for keeping me on the track and showing me the goal, for perseverance and patience when I did not progress, and for structure and containment when I was astray.

Thank you Bengt Karlsson for inspiration to keep thinking that (almost) anything goes, for opening doors in the mental health field, and for continued support and patience when I thought I would not make it.

Thank you to Stord Haugesund University College (HSH) for financing my degree. And for allowing “mature” women to do a PhD.

Mentor Gro Steensnæs Håvåg was there when I needed it, and was ready to talk about the various challenges to me as a person in the PhD-process. Thank you for joining me on mental swimming trips, marathon running, and on memory-lanes to my past.

I would also like to thank Larry Davidson and his colleagues at “Program for Recovery and Community Health” at Yale School of Medicine, for receiving me, for sharing and allowing me to share, and for making me believe I was doing something worthwhile.

Thank you to my colleagues at HSH for creating an atmosphere of goodwill, support and openness in which it has been comforting and a great inspiration to work. Thank you for listening, for reading, for supporting, for giving me attention, and for believing that I would make it.

Thank you to my family for inspiring me to achieve, for making my life worthwhile, and for all your love and support. I know I have been self-centred, and I’m afraid I cannot promise that it will change. And a special thank you to Gunvor who reads my mood and who (I’m ashamed to write) may also have postponed or skipped her teenage rebellions in regard for her mother. And last, but not least Tor Egil for keeping the “in spite of” promise, for making me laugh, for food on the table, and for your “being in relationship” with me.
11 REFERENCES


Davidson, L. (2009). Purposes and goals of service user involvement in mental health research. In Walcraft, & Schrank & Amering (red) (Eds.), *Handbook of service user involvement in health research*. (pp. 87-98) Wiley.


Nasjonalt kunnskapssenter for helsetjenesten.(2009). Seksjon for kvalitetsutvikling - GRUK. *Og bedre skal det bli, ved å involvere brukerne og gi dem innflytelse* Kunnskapssenteret.


