Experiences and Nursing Support of Relatives of Persons with Severe Mental Illness

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Akershus
universitetssykehus

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A person never has something to do with another person without also having some degree of control over him. It may be a very small matter, involving only a passing mood, a dampening or quickening of spirit, a deepening or removal of some dislike. But it may also be a matter of tremendous scope, such as can determine the very course of his life.

Knud Ejler Løgstrup

ABSTRACT

Experiences and Nursing Support of Relatives of Persons with Severe Mental Illness

Aim: The overall aim of this thesis was to illuminate experiences of relatives of persons with severe mental illness, and their need for support from formal care. Furthermore, to illuminate nursing support of relatives of persons with severe mental illness.

Methods: A mixed methods design was used. In study I, data was collected with a questionnaire responded by 226 relatives and analysed with statistics. In study II, data was gathered with interviews with a strategic sample of 18 relatives, analysed with phenomenography. Study III gathered data from 216 relatives using open-ended questions in the questionnaire (I), analysed with qualitative content analysis. In study IV, data was collected by means of focus-group interviews with 4 groups of nurses, working in mental healthcare and analysed with phenomenography.

Main findings: The relatives experienced that their lives were intertwined with the life of their severely mentally ill next of kin. The relatives experienced burden and a poor health, and there were associations between burden and health (I). The relatives had to balance between multiple concerns and make choices on behalf of others and themselves, constantly struggling between opposing feelings and between reflections (II). Relatives' encounters with mental health personnel were mainly negative, although some had positive experiences. They strived for involvement in mental healthcare for the sake of their severely mentally ill next of kin, and wanted inclusion and support for their own sake, but mostly felt left alone with straining but inescapable responsibilities (III). The nurses conceived that their responsibility was first and foremost the patient and to develop an alliance with him or her. The nurses often felt they had to exclude relatives, but were sometimes able to support them (IV).

Conclusions: Relatives' lives are intertwined with the life of their severely mentally ill next of kin. Relatives' overall demanding life situation means that the mental health services must involve relatives for the sake of the severely mentally ill person but also include them for their own sake. They need practical and emotional support. Guidelines must be designed to address relatives' needs, and support must be adapted to the individual relative.

Key words: Burden, everyday life, health, mental healthcare, relational ethics, relatives of persons with severe mental illness, support of relatives

SAMMENDRAG

Pårørende til personer med alvorlig psykisk lidelse – deres erfaringer og støtte fra sykepleiere

Hensikt: Avhandlingens overordnete hensikt var å belyse erfaringer med å være pårørende til personer med alvorlig psykisk lidelse, og deres behov for støtte fra helsevesenet. Videre å belyse støtte fra sykepleiere til pårørende til personer med alvorlig psykisk lidelse.

Metode: Mixed methods design ble benyttet. I studie I ble data samlet med spørreskjema besvart av 226 pårørende, og analysert med statistikk. I studie II ble data samlet ved hjelp av intervju med et strategisk utvalg av 18 pårørende, analysert med fenomenografi. I studie III ble data samlet gjennom åpne spørsmål i et spørreskjema (I), besvart av 216 pårørende og analysert med kvalitativ innholdsanalyse. I studie IV ble data samlet ved hjelp av fokusgruppeintervju med 4 grupper sykepleiere fra psykisk helsevern, analysert med fenomenografi.

Hovedfunn: Pårørende opplevde at deres liv var sammenvevd med livet til den som hadde en alvorlig psykisk lidelse. De pårørende opplevde byrde og dårlig helse, og det var sammenheng mellom byrde og helse (I). De pårørende måtte balansere en rekke hensyn, gjøre valg på vegne av andre og seg selv, og samtidig kjempe med motstridende følelser og motstridende tanker (II). Pårørendes erfaringer med møter med helsepersonell i psykisk helsevern var hovedsakelig negative, men noen hadde positive opplevelser. De strevde for å bli involvert i behandlingen for familiemedlemmet med den alvorlige psykiske lidelsen sin del, de ønsket å bli inkludert og motta støtte for egen del, men følte seg overlatt med strevsomt ansvar som de ikke kunne unnslippe (III). Sykepleierne anså at deres ansvar først og fremst var overfor pasienten, og å skape en allianse med vedkommende. Sykepleierne opplevde ofte at de måtte ekskludere pårørende, men var noen ganger i stand til å støtte dem (IV).

Konklusjoner: Pårørendes liv er sammenvevd med livet til den som har en alvorlig psykisk lidelse. Pårørendes krevende livssituasjon innebærer at psykisk helsevern må involvere dem for den som har den alvorlige psykiske lidelsen, samt inkludere pårørende for deres egen del. De har behov for praktisk og emosjonell støtte. Retningslinjer må på plass for å ivareta pårørendes behov, og støtten må tilpasses den enkelte pårørende.

Nøkkelord: Byrde, dagligliv, helse, nærhetsetikk, psykisk helsevern, pårørende til personer med alvorlig psykisk lidelse, støtte til pårørende

TABLE OF CONTENTS

Papers I-IV

ORIGINAL PAPERS

This thesis is based on the following papers, which will be referred to by their Roman numerals:

I. Weimand, B.M., Hedelin, B., Sällström, C. & Hall-Lord, M.L. (2010). Burden and health in relatives of persons with severe mental illness: a Norwegian cross-sectional study. *Issues in Mental Health Nursing, 31: 804-815.*

II. Weimand, B.M., Hall-Lord, M.L., Sällström, C. & Hedelin, B. Life-sharing experiences of relatives of persons with severe mental illness – a phenomenographic study. *Scandinavian Journal of Caring Sciences, doi: 10.1111/j.1471-6712.2012.01007.x*

III. Weimand, B.M., Hedelin, B., Hall-Lord, M.L. & Sällström, C. (2011). "Left alone with straining but inescapable responsibilities:" relatives' experiences with mental health services. *Issues in Mental Health Nursing, 32: 703-710.*

IV. Weimand, B.M., Sällström, C., Hall-Lord, M.L. & Hedelin, B. Nurses' dilemmas concerning support of relatives in mental health care. *Submitted. A revised version has been accepted for publication in Nursing Ethics.*

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INTRODUCTION

The deinstitutionalization of persons with severe mental illness during the past decades has been pointed out as one major reason for the increased responsibilities and greater burden put on their relatives (e.g. Baronet 1999; Doornbos 2002). In Norway, the average 24-hour stay per in-patient decreased from 41 in 2002 to 26 in 2010, while the outpatient consultations increased (Statistics Norway 2012a). Accordingly, these changes have led to new demands on the mental health services and professionals, especially in terms of offering proper treatment at the right place and at the right time (Norwegian Ministry of Health and Care Services 2009).

Norwegian authorities report that three per cent of the population has a severe mental illness (Norwegian Ministry of Health and Care Services 2012) which equals approximately 150,000 persons in Norway. Based on this figure 3-600,000 relatives could be involved. The supportive network of people with severe mental illness is often entirely made up by relatives (Norwegian Ministry of Health and Care Services 2006; Sartorius, Leff, López-Ibor, Maj, & Okasha 2005). They can be a resource, both for the person concerned and for the mental health services. Still, the situation clearly affects relatives' lives in terms of objective and subjective burdens. Relatives experience limitations on their social life and activities, as well as financial burden. Being a relative may also include positive and meaningful experiences, such as contributing positively in the next of kin's life. Social support and a satisfactory social network may contribute to diminish the experience of burden (Engmark, Alfstadsæther, & Holte 2006; Kuipers & Bebbington 2005).

Since relatives often face challenges connected with the severe mental illness of the next of kin, they may be in need of own support from health personnel. According to Norwegian legislation (Norwegian Ministry of Health and Care Services 1999a; Norwegian Ministry of Health and Care Services 1999b) relatives should receive support and information from the health services in order to handle the situation in relation to the mentally ill next of kin. The mental health services must consider if the relatives get the necessary support to deal with the situation (Norwegian Ministry of Health and Care Services 2006, p.11). Nurses are one major health profession within the mental health care services for adults (Norwegian Ministry of

Health and Care Services 2012; SINTEF 2009) in Norway and thus should be in a position to support the patients' relatives.

Based on my experiences as a mental health nurse and a nurse lecturer in the field of mental health for many years, my impression was that the patients were treated, cared for and followed up with minimal contact between health personnel and the patient's relatives. This can be understood as a contradiction, given nurses' claim of holistic approaches to mental health care (International Council of Nurses 2012). My experience of how the patients' symptoms and behaviour could be stressful and challenging to health personnel made me curious about how those close to the patients perceived their situation. Altogether, this made me want to contribute to increased knowledge about relatives' life situation in relation to their severely mentally ill next of kin, as well as how nurses can support these relatives.

BACKGROUND

Severe mental illness in the family

When someone suffers from severe mental illness, this is not an individual problem, but will probably impact on the other family members. To relate to persons with severe mental illness means to relate to someone for whom inhibition of psychosocial functioning is a challenge[1]. In a relational perspective, and regardless of differences in responsibilities and functions towards the person concerned, such challenges may affect the relatives in many ways. Burdens and negative health outcomes, but also positive experiences such as having a fulfilling role have been reported (Ohaeri 2003).

From a relational perspective, family is a "complex relational experience" (Doane & Varcoe 2005, p.43). Transferred to mental health and nursing, this implies that severe mental illness will influence the family (cf. Doane & Varcoe 2005; Lefley 2010). "Severe mental illness" is understood in line with Kirkehei et al. (2008) who claim that the term does not represent a precise group of illnesses[2]. The person's capability of having human relations and self-care are examples of severely inhibited psychosocial functioning.

Based on the view that mental illness is considered a contextual and social phenomenon, nursing to persons with severe mental illness should include relatives (Doane & Varcoe 2005), not only for the sake of the mentally ill person, but with the starting point that the relatives' lives are affected in such a way that support from health personnel may be needed.

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[1] Some of the following challenges/ problems are described as more or less being parts of their lives: hallucinations, delusions, thought disorders, depression, mood swings, apathy, helplessness, problems in cognitive functioning, inactivity, or disturbed behaviour (Barrowclough 2005; Rose, Mallinson, & Walton-Moss 2002).

[2] The term "severe mental illness" often refers to diagnoses such as schizophrenia, schizotypal disorder, paranoid psychosis, schizoaffective disorder and other psychoses, manic and bipolar disorder, and major depressive disorder (NOU 2010, p.221). Others include a wider range of diagnoses (e.g. Levy-Frank, Hasson- Ohayon, Kravetz, & Roe 2011).

Being a relative of someone with severe mental illness

Several terms are used in the literature regarding those close to the one with severe mental illness. The term caregiver is widely used. However, it applies to both health personnel and non professionals. Furthermore, the impact on relatives' lives does not derive solely from a range of tasks (Harvey et al. 2008). In this thesis the terms relatives and family members are thus used with regard to the relatives involved, and includes transferable terms used in the literature[3], irrespective of which terms have been used in the studies referred to. To care about another person means to be somehow involved, and the following definition of carers sheds light on the term relative in this thesis: *"individuals whose own happiness is entwined with the well-being of people who are dear to them"* (Lefley 2001, p.141).

There has been a growing body of studies aiming to describe and understand the impact from severe mental illness on relatives' lives. The main picture shows that the relatives' situation is interconnected with that of their severely mentally ill next of kin[4]. One example that indicates the connection between the relatives' and mentally ill person's lives is that interventions to support relatives seem to be influenced by the follow-up that the mentally ill person receives from formal carers (Macleod, Elliott, & Brown 2011; Magliano et al. 1998; Roick et al. 2007). The situation of relatives may be exhausting (Saunders 2003), and result in perceived burdens, and health deterioration (Macleod et al. 2011). Many experience an overall demanding situation, without sufficient support from health services. Although the main picture seems negative, there are relatives who function

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[3] The terms carers, caregivers, family caregivers, informal caregivers, relatives, family members, or next of kin are used in research literature on the matter (e.g. Budd, Oles, & Hughes 1998; Chang & Horrocks 2006; Ewertzon, Lützén, Svensson, & Andershed 2010; Lefley 2001; Møller, Gudde, Folden, & Linaker 2009; Sjöblom, Pejlert, & Asplund 2005; Sreeja, Sandhya, Rakesh, & Singh 2009; Thara, Padmavati, Kumar, & Srinivasan 1998) whereas the term "user" does not always distinguish between patients and relatives.

[4] Since relatives' experiences come from everyday life, the severely mentally ill person is referred to as such, alternatively as next of kin, or the severely mentally ill next of kin when described from the perspective of relatives in this thesis. When described from the perspective of nurses in study IV, mentally ill persons are referred to as patients, since this was the term used by the informants.

well and who experience satisfying relationships with their mentally ill next of kin (Engmark et al. 2006; Veltman, Cameron, & Stewart 2002). The situation, however, probably reflects a continuum rather than a static state of dealing with the situation. Deterioration of physical health has been pointed at (Winefield 2000) and significantly worse emotional well-being than the general population has been reported (Fleischmann & Klupp 2004). A Norwegian study with 50 informants found associations between relatives' burden and their mental well-being (Møller et al. 2009). Several studies have shown that these relatives experience significant burdens, financially, practically and emotionally (e.g. Lowyck et al. 2004; Rose et al. 2002; Schulze & Rössler 2005).

In order to understand burden and health among relatives of persons with severe mental illness, different factors have been explored. Negative effects on physical health when living with someone with severe mental illness, was reported as early as in 1975 (Creer & Wing 1975). The relatives' burden does not seem to depend on the patient's diagnosis (Angermeyer, Liebelt, & Matschinger 2001; Baronet 1999; Hadryś, Adamowski, & Kiejna 2011; Lowyck et al. 2004; Stengård 2002; Östman, Wallsten, & Kjellin 2005) nor whether the patient was voluntarily or compulsory admitted (Hansson & Östman 2000). Furthermore, relatives worry more or less, depending on the duration of the treatment received by the mentally ill person (Lowyck et al. 2004).

Divergent results regarding background variables, aspects of everyday life, and burden have been found. While relatives' age has been found to not show significant differences in burden (Møller et al. 2009; Rudnick 2004; Stengård 2002), older age has however showed to be associated with higher burden (Hadryś et al. 2011). While some studies have reported no gender differences (Chadda, Singh, & Ganguly 2007; Stengård 2002), others have found significantly higher burdens in women (Møller et al. 2009; Rudnick 2004). It has also been reported that higher burden was associated with kinship to the mentally ill person, the closer the relation, the higher the burden. Parents showed higher burden (Hadryś et al. 2011), and took on more financial responsibilities than partners (Lowyck et al. 2004). Another study found that spouses showed more burdens than other relatives' subgroups (Östman et al. 2005). A review found that relatives' everyday life is affected, such as reduction in leisure activities, negative impact on social relationships, restrictions in occupation, financial difficulties, and amount of

time spent on caring (Schmid, Spiessl, Vukovich, & Cording 2003). Whether or not sharing household with the mentally ill person has showed similar stress level (Laidlaw, Coverdale, Falloon, & Kydd 2002), but also increased burden when living together has been reported (Östman et al. 2005). Furthermore, it has been showed that relatives who shared household with the mentally ill next of kin more often had to give up own leisure time and occupation (Östman 2007). Higher burden have also been associated with the number of hours spent together per week (Hadryś et al. 2011). One study showed that everyday life was demanding for all family members, and that responsibilities shifted within the family when living with someone with major depression (Ahlström, Skärsäter, & Danielson 2009). The divergent results may be explained by for example different definitions, operationalization of relatives' burden, and a variation of time periods in different studies, and the use of different variables (Lowyck et al. 2004).

It has also been suggested that influences on these relatives' burdens, are cultural factors, e.g. support from professional and social network (Magliano et al. 1998; Magliano et al. 2002), the deinstitutionalization of mentally ill persons (Bachrach 2012; Doornbos 2002), along with differences in organization of mental health care (WHO 2011). This indicates that it is important to study relatives' situation from the perspective of multiple contexts, in addition to their need for support from health professionals.

Studies from the past decades about relatives' need for support from professionals have shown that although relatives generally wish to cooperate with mental health personnel in connection with the treatment of their severely mentally ill next of kin, they find this difficult to achieve (Cleary, Freeman, Hunt, & Walter 2005; Cleary, Freeman, & Walter 2006; Doornbos 2002; Holden & Lewine 1982; Jubb & Shanley 2002; Winefield 2000). It has been described that these relatives find themselves alienated from professional care (Ewertzon et al. 2010). Although it is stated that support from professionals will contribute to an ease of their burden (Magliano et al. 2002), relatives receive little support from mental health personnel (Engmark et al. 2006) including nurses (Kaas, Lee, & Peitzman 2003; Sjöblom et al. 2005). Nurses' view of family needs influence their perceived value of working with relatives (Sjöblom et al. 2005).

A grounded theory model of mental health professionals' support to families with severe mental illness found that the four supportive strategies

of being present, listening, sharing, and empowering would be beneficial to relatives (Gavois, Paulsson, & Fridlund 2006). A review showed that effective approaches to support relatives of persons with schizophrenia were intensive community outreach, and programmes addressing stressful relationships (Saveman 2010). Furthermore, support groups showed some evidence of reducing burden and improving coping, and a need for studies that address hindrances and facilitators in delivering support from practitioners and from the health systems was suggested (Macleod et al. 2011).

As shown, to be a relative of a person with severe mental illness involves relational experiences which affect the relatives' well-being and burden and induce a need for support. Furthermore, appraisal, being present, and listening have been found essential to nursing support. These relational aspects may be seen in line with relational ethics, one way of approaching supportive professional practise from a nursing perspective.

Relational ethics

Relational ethics is based on the uniqueness of each person, as well as understanding him or her in a social context (Henriksen & Vetlesen 2001; Nyeng 1999) and applies to people in general. The uniqueness means we cannot fully understand a person, nor can we determine whether an action is ethically good based on general principles. The reciprocal responsibility of taking care of another is unlimited and unconditional, and can neither be regulated, nor limited by rules (Nyeng 1999). Relational ethics as described by Knud Ejler Løgstrup (1905 - 1981) and the caring philosophy of Kari Martinsen will serve as a means of reflecting on the findings in this thesis.

Relational ethics according to Løgstrup

The writings of the Danish theologian and philosopher Knud E. Løgstrup revolve around morality that does not evolve from rules, but emanates from the ethical demand from the other person, meaning that his important matters, or what is of significance for him in the situation, should be valued and taken care of. In his writings Løgstrup argues that the unique phenomenon of "the other person" is the basis of the ethical demand posed upon human beings. Being in the world together makes us reciprocally responsible for one another in the way that we *"constitute another's world and destiny"* (Løgstrup 1971, p.17). This demand of taking care of the other

person's important matters is silent or unspoken, deriving from the very being of the other person, and implies not violating his dignity. Since the demand is unspoken it requires interpretation which is challenging since the risk of misinterpretation, violation and misuse of power is present. The interpretation must be carried out from each and every person (Løgstrup 2000). Løgstrup states that there are some sovereign expressions of life, such as trust, mercy, love, compassion, and open speech. Our ability to interpret the other is based on these sovereign expressions, which also are spontaneous (Løgstrup 1996). They are fundamental to life since we could not survive[5] without them. We are already delivered, meaning that these sovereign expressions of life are fundamental to our destiny. They are fundamental to life, but can be destroyed. For example, trust may easily turn into distrust by violation. That is why Løgstrup (1971) claims that we hold the other person's life in our hands.

The ethical demand of Løgstrup is radical in the sense that it should be followed no matter whether it comes from our loved ones, strangers or even our enemies, and expects nothing in return. It is radical also in the sense that the responsibility *"intrudes disturbingly into my own existence"* (Løgstrup 1971, p.47). The radicality also has to do with having to decide what is in the best interest of the other person, also when this turns out the opposite of what he himself asks for.

The ethical demand is unconditional by nature and may thus be understood as limitless. Yet Løgstrup (1971) discusses the line between radicality and limitlessness. Radicality does not mean unlimited responsibility, and although it may involve selflessness, the responsibility and responsive actions may bring content or meaning into our own life. A danger of limitlessness is the possibility of coercing people against their own will by maintaining that it is for their own good. This means that we must be aware of the power inherent in each relationship in order not to violate the other person. Løgstrup (1971, p. 56) emphasizes that we must decide whether to

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[5] Survival is to be understood literally and metaphorically. Literally, since we in certain situations depend on others; e.g. infants or critically ill persons, or understood metaphorically concerning to be and to express our authentic self. Løgstrup poses that experiencing that our sovereign expressions of life are being met, is vital. Furthermore, he claims (Løgstrup 2007) that the sovereign expressions of life are a realization of oneself.

use the power in the interest of the other person or ourselves. Another aspect is that social conventions may be considered a hindrance to the ethical demand, since they regulate the degree to what we can expect from others, and thereby, from ourselves. These conventions will among others regulate what is considered acceptable expressions of wishes and demands. This may in turn lead to a reducing in trust, or even distrust, since the outcome may be that the (unspoken) demand is not accepted (Løgstrup 1971).

Løgstrup discusses the moral responsibility which humans face when meeting someone whose life conditions are altered. The ethical demand of taking care of the other person has a general validity, but may be of particular importance to persons in vulnerable positions, and who experience that their possibilities to lead full lives are at stake (Weimand 2004). As described, studies have shown that being a relative of someone with severe mental illness means to relate to a person whose life is altered due to the illness. The relatives' own lives may be altered accordingly and hence their own freedom of leading full lives is at stake.

Relational ethics in nursing care

The Norwegian nursing philosopher Kari Martinsen has developed her caring philosophy especially inspired by Løgstrup. Her caring philosophy challenges how the ethical demand of taking care of the other person can be specified in a nursing context. Martinsen's reflections about the essence of caring are based on the universal principle of morality that *"everyone should have the opportunity to live the best life possible"* (Martinsen 1991, p.43). According to Martinsen, people are interdependent, and both their autonomy and their dependence should be cared for. Nursing care is characterized by generalized interdependence. Hence, it is asymmetric and essentially unselfish. Like Løgstrup, Martinsen uses the story of the Good Samaritan as an example of how to respond to the ethical demand from the other. In Martinsen's writings, the story serves as an example of how caring holds a moral, a relational and a practical dimension which are intertwined, and where the moral dimension sets the frames (Martinsen 1991). The nursing care should neither be dominated by sentimentality or paternalism, nor by sins of omission. Since caring relations have inherent power, nurses need to be aware of this as well as the possibility of abusing their power. Relational ethics is about taking care of what is important to the other person.

Martinsen has claimed that today's health services are characterized by efficiency and productivity, as opposed to caring based on the universal principle of the responsibility for the weak (Martinsen 1998a; Martinsen 1998b; Martinsen 2004). This poses challenges to nurses in responding to the ethical demand from a relational ethics perspective, but also regarding whom to understand as the weak, and with regard to limited resources in the health services. Among other things, Martinsen's caring philosophy implies that the relatives' lives should not be unnecessarily limited due to lack of care.

In nursing practise, one ethical demand is to take care of patients' and relatives' threatened life possibilities (Alvsvåg 2006). The ethical demand includes looking beyond rules and procedures arising from diagnoses, treatments and routines (Weimand 2004). The ability to express own concerns depends on trust, hence trust from relatives is essential for nurses in order to understand and take care of their concerns. Relatives of persons with severe mental illness probably experience that their basic conditions of life are altered and thus relatives' hope of being taken care of can be interpreted as an unspoken demand. Nurses meet these relatives in connection with the caring of severely mentally ill patients. The ethical demand implies that the nurses' responsibilities towards relatives in mental health care should not be limited by routines, but given according to the relatives' sovereign expressions of life and the ethical demand of taking care of the other person. Martinsen (2012) claims that we must shape the norms, rules, and society in order to make sure that the expressions of life have the necessary space, so that we can clearly see our caring responsibility[6].

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[6] However, Martinsen claims that these rules and norms never should be expressed restrictively in order not to destroy life. It is not trust that needs to be reasoned, but the situational aspects that makes it problematic for trust to occur. The ethical demand may be used to reflectively try out a situation, but cannot be used as a norm. It is not obvious how we are supposed to act in order to respond to the demand. Cultural norms and ideals, as well as standards, and scientific methods, may lead to being locked up in one way of thinking and acting (Martinsen 2012, pp. 54-55). Furthermore, Martinsen (2012, p. 103) explains that there is a complicated interaction between the "should" of the ethical demand and the "should" of our norms, which also may conflict with each other. It is the sensibility that makes us able to experience the other person's situation as ethically loaded that makes us able to let the "is" and the "should" come together (Nortvedt & Grimen 2004).

According to the ICN (International Council of Nurses 2012), mental health problems must be understood contextually and thus include support for the families. However, nursing within mental healthcare has emphasized the relationship between nurses and patients (e.g. Barker 2001a; Barker 2001b; Hummelvoll 1996; Peplau 1952). An alliance between nurse and patient is among others of importance to the patient's possibilities of examining their own feelings (Nyström & Lützén 2002). In my experience, developing such an alliance requires e.g. attention, endurance and dedication from the nurse.

The need to develop knowledge of a relational approach in nursing from a professional perspective as well as from the perspective of different family members has been advocated (Doane & Varcoe 2005). This brings about a need for knowledge about the life situation and need for support from the perspective of a variety of groups. One such group of individuals is relatives of persons with severe mental illness.

Rationale for the thesis

Relatives of persons with severe mental illness take on great responsibilities for their severely mentally ill next of kin. These relatives experience burden, and their physical and mental health, as well as their everyday lives, may be negatively affected. Their demanding life situation means that they may need support. To study these relatives' situation and relation to mental health care is significant. Studies from a Norwegian perspective are scarce, also with regard to nursing support of these relatives. It is relevant to reflect and discuss these relatives' life situation with their severely mentally ill next of kin and their need for support, as well as nurses' support of the relatives in mental health care from the perspective of relational ethics.

AIMS

The overall aim of this thesis was to illuminate experiences of relatives of persons with severe mental illness, and their need for support from formal care. Furthermore, to illuminate nursing support of relatives of persons with severe mental illness.

The specific aims were:

- to describe and investigate the burden and health of relatives of persons with severe mental illness in relation to background variables, everyday life with the mentally ill person, and sense of coherence. *(I)*

- to describe life-sharing experiences from the perspective of relatives of someone with severe mental illness. *(II)*

- to describe experiences of encounters with mental health services from the point of view of relatives of individuals with severe mental illness. *(III)*

- to describe conceptions of nurses in mental health care about supporting relatives of persons with severe mental illness. *(IV)*

METHODS

Study design

This thesis has a partially mixed sequential dominant design (Leech & Onwuegbuzie 2009). Partially mixed, as opposed to fully mixed refers to the level of mixing which means that the qualitative and quantitative elements were conducted before mixing. Sequential, as opposed to concurrent, refers to time orientation which means that the quantitative and qualitative studies were performed at different stages. Dominant, as opposed to equal, refers to the emphasis of the approaches, which was on the qualitative studies. A mixed methods design integrating quantitative and qualitative designs may be used in "*single studies and in multi-phased studies to investigate the same underlying phenomenon*" (Leech & Onwuegbuzie 2009, p.267) which in this thesis is the life situation of relatives of persons with severe mental illness. This thesis includes four papers (I-IV). For an overview of the studies, see Table 1.

Table 1: Overview of the studies; design, method, informants, data collection, and data analysis

STUDY	DESIGN	INFORMANTS	DATA COLLECTION	DATA COLLECTION PERIOD	DATA ANALYSIS
I	Descriptive Cross-sectional Quantitative	226 relatives	Postal survey Questionnaire	November 2008-January 2009	Descriptive and inferential statistics
II	Descriptive Qualitative	18 relatives	Qualitative, individual interviews	April 2009-June 2009	Phenomenographic analysis
III	Descriptive Explorative Qualitative	216 relatives	Postal survey Two open-ended questions	November 2008-January 2009	Qualitative content analysis
IV	Descriptive Qualitative	26 registered nurses	Qualitative interviews with focus groups	March 2008-January 2009	Phenomenographic analysis

Study context

In Norway, the central government is responsible for the specialist health services for mental health for adults. There are four Regional Health Authorities (RHAs), each responsible for specialized health services to the residents in the region. Regarding the mental health, the RHAs provide

services through hospital trusts, consisting of hospitals with acute wards and specialized functions, and also District Psychiatric Centres (DPCs), which provide out- and inpatient clinics on a more decentralised level. In addition to these specialized mental health services, the municipalities are responsible for primary healthcare services, with responsibilities towards persons with severe mental illness in the local community (Norwegian Ministry of Health and Care Services 2012)

Health personnel within in- and outpatient health services for adult persons with severe mental illness include a wide range of professions: educational therapists, educators, nurses, occupational therapists, physiotherapists, social workers; some of which provide specialist education in mental health or psychiatry, and psychiatrists and psychologists. These professions have partially similar, partially different responsibilities and tasks as well as interdisciplinary cooperation towards the patients. Registered nurses, including mental health nurses, make up a large proportion of the personnel in the mental health services for adults[7].

Informants

The informants in study I, II, and III were recruited from an association for relatives of persons with severe mental illness, the Norwegian National Association for Families of Mentally Ill Persons (NNAFMP). The informants in study IV were registered nurses from the mental health services for adults, and from different parts of Norway. For an overview of the number of informants, see Figure 1.

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[7] The proportion of registered nurses among health personnel in the mental health services for adults was 36.6 % in 2008 (SINTEF 2009, p.136). In 2003, 23 % of the personnel were mental health nurses, and 14 % were registered nurses (Norwegian Ministry of Health and Care Services 2012).
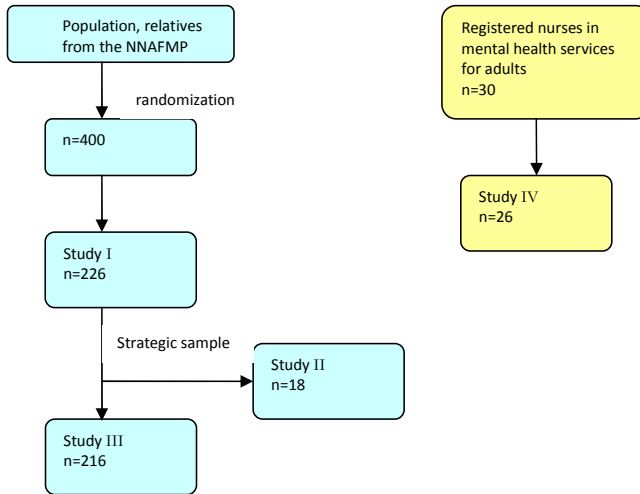
Figure 1: Overview of the numbers of informants in Studies I-IV

In study I, a simple random sample of 400 informants was selected from the study population of 2330 personal members of the NNAFMP, representing approximately 35 local units across Norway. The sample size was calculated to be sufficient by a consulting statistician, assuming a drop-out rate of approximately 50 %. Inclusion criteria were individual members from the age of 18, who considered themselves to be relatives of a person with severe mental illness. A response rate of 57 % with 226 informants participated in this study.

Study II included 18 informants of different kinship to a person with a severe mental illness. Inclusion criteria: The informants were strategically selected among the informants in study I, to secure variation in sex, age, and kinship to the severely mentally ill person, years of experience as a relative, sharing household or not with the person concerned, experiences from different levels of mental healthcare services in relation to the severe mental illness of their next of kin, and frequency of contact with the mental health services. In addition the selection was based on being satisfied or not with received support from the health services for their own sake in relation to the severe mental illness of their next of kin, and place of residence. The selected informants had from four to 38 (median 14) years of experience as a relative. Four shared household with the severely mentally ill person. The informants had experiences from all levels of the mental health care services

(hospital, district psychiatric centre, local community healthcare) and at several occasions. They should also understand and speak Norwegian.

<u>In study III</u>, 216 of the 226 informants from study I who answered two open-ended questions were included.

For an overview of the informants' background in study I, II, and III, see Table 2

Table 2: Description of the informants, (I, II, & III)

	STUDY I		STUDY II	STUDY III	
	N	%	N	N	%
Total	226	100.0	18	216	100.0
Sex					
Men	54	23.9	7	53	24.5
Women	172	76.1	11	163	75.5
Age					
21-35	8	3.5	0	8	3.7
36-50	50	22.1	8	48	22.2
51-66	107	47.3	6	102	47.2
67-85	57	25.2	4	54	25.0
Missing	4	1.8	0	4	1.9
Marital status					
Spouse/cohabitant	153	67.7	13	145	67.1
Single/divorced/widowed	73	32.3	5	71	32.9
Education					
Compulsory comprehensive school	24	10.6	2	21	9.7
Upper secondary school	76	33.6	4	72	33.3
University	124	55.9	12	121	56.0
Missing	2	0.9	0	2	0.9
Occupation					
Employee	110	48.7	9	105	48.6
Sick leave/ disability pension	39	17.3	4	36	16.7
Retirement pension	61	27.0	4	60	27.8
Other	14	6.2	1*	13	6.1
Missing	2	0.9	0	2	0.9
Kinship					
Parent	162	71.7	7	155	71.8
Sibling	29	12.8	2	27	12.5
Spouse/ cohabitant	17	7.5	7**	17	7.9
Child (adult)	10	4.4	2	10	4.6
Other	6	2.7	0	5	2.3
Missing	2	0.9	0	2	0.9

* Housewife. ** Two of whom were former spouses with common children with the severely mentally ill person

<u>In Study IV</u>, 26 registered nurses from all parts of the mental healthcare services and from all four Health regions were strategically selected for variation. Inclusion criteria were registered nurses or mental health nurses with a minimum of two years of experience from in – or outpatient wards in

hospitals, district psychiatric centres, or local community health services for adult patients with severe mental illness. They should also understand and speak Norwegian. The informants were divided in four groups.

For an overview of the informants in study IV, see Table 3.

Table 3: Description of the informants, study IV

		GROUP 1	GROUP 2	GROUP 3	GROUP 4
Sex					
	women	5	5	5	6
	men	2	2	0	1
Age					
	median	45.5	44	55	50
	range	27- 52	37- 54	42- 65	40- 57
Mental health nurse		7	7	5*	7
Years of experience in profession with severe mental illness					
	median	18	15	12	20
	range	3-30	6-20	10-34	17-24
Current work place					
District Psychiatric Centre					
	inpatients	1	2	0	2
	outpatients	0	0	0	5
Hospital					
	inpatients	5	5	0	0
	outpatients	1	0	0	0
Local community					
	outpatients	0	0	5	0

* Of whom 1 registered nurse without specialist education in mental health nursing

Data collection

Procedure (I, III)

The data collection took place from November 2008 until January 2009. A questionnaire was sent by mail. Two reminders were sent, by approximately two weeks of intermission.

Between the first and the third mailing, 17 persons informed that they were no longer relevant as relatives. Eight surveys were returned due to unknown address. These 25 were considered random drop-outs. A new random sampling of 25 persons was performed, and these 25 received two reminders similar to the description above. During the last period eight additional persons had informed that they were not relevant as relatives

anymore, and four additional surveys were returned due to unknown address. These were not replaced, nor were the ten who informed that they did not wish to participate from reasons stated in the ethical considerations section.

The questionnaire (I, III)

The questionnaire with 88 items consisted of three instruments about relatives' health, burden and sense of coherence, in addition to background data, questions of everyday life with the severely mentally ill person, and experiences with the health services. As shown in the following, some of the items were used in relation to the strategic sampling (II).

Background data (I, II, III) concerned sex (I, II, III), age (I, II, III), ethnic origin (three items) (I), marital status (spouse /cohabitant, or single /divorced /widow /widower) (I), education (compulsory comprehensive school, upper secondary school, university) (I), occupation (employee, sick leave/disability pension, retirement pension or other) (I), kinship to the severely mentally ill person (parent, sibling, spouse, child, or other) (I, II, III), years of experience as a relative to the person concerned (I, II, III), place of residence (rural districts, cities, villages) (II).

Aspects of everyday life with the severely mentally ill person (I, II) concerned contact in person and by phone with the severely mentally ill person (several times per day, daily, weekly, or monthly or more seldom) (I), financial problems related to the severely mentally ill person (yes or no) (I), and someone with whom to share caregiving (yes or no) (I), sharing household (yes or no) (II).

Experiences with the mental health services (II, III) concerned number of times in total of own contact with the health services related to the mental illness of the person concerned (1-5, 6-10, 11-15, >15) (II, III), in contact with which parts of the mental health services in total, related to the mental illness of the person concerned (hospital, district psychiatric centre, local community healthcare) (II, III), received the needed follow-up or help from the health service to handle one's own situation in connection with the person's mental illness (yes or no) (II, III).

The Short Form Health Survey, version 2 (SF-36) (Ware, Snow, Kosinski, & Gandek 1993) was used to measure physical and mental health aspects (I). The instrument is widely used, and was chosen since it profiles functional

health and well-being (Ware 2012) and is also well suited for comparisons between generic and specific populations (Ware et al. 1993). The instrument includes four subscales on physical health: Physical Functioning (PF), Role Physical (RP), Bodily Pain (BP), and General Health (GH); and four subscales on mental health: Vitality (VT), Social Function (SF), Role Emotional (RE) and Mental Health (MH). The response scores were calculated for each subscale. The score of each subscale could range from 0-100, with higher scores indicating better health.

The Burden Assessment Schedule (BAS) (Sell, Thara, Padmavati, & Kumar 1998) is a short version which was used to measure the relatives' burden related to their relation with the severely mentally ill person (I). The original 40 item instrument (Thara et al. 1998) was developed to assess the subjective burden of primary caregivers to persons with chronic mental illness, specifically schizophrenia and mood disorders, and measures both positive and negative aspects of being a relative. The short version (Sell et al. 1998) included 20 items, and consisted of five factors: Impact on well-being, Marital relationship, Appreciation for caring, Impact on relationship with others, and Perceived severity of the disease. The factor Marital relationship applies to relatives who are spouses or cohabitants with the severely mentally ill person. In the present study, this factor with four items was excluded since only 17 informants were spouses or cohabitants of the mentally ill person. A three-point response scale (not at all, to some extent, and very much) ranged from 1-3. In addition, "not relevant" was an option. Each factor consisted of four questions. The scores were calculated for each factor (subscores could range from 4- 12) and for the total score (ranging from 16 to 48), with higher scores indicating higher burden.

The Sense of Coherence scale/ instrument (SOC) (Antonovsky 1987), the short version was used to measure to what extent the relatives found life to be comprehensible, manageable, and meaningful (I). The original instrument includes 29 items, and measures peoples' health ease/disease continuum and is suitable across cultures (Antonovsky 1993). Sense of coherence has showed to be a mediator between stressful life events and self reported health (Richardson & Ratner 2005). The short version consists of 13 items. The response scale with the anchors defined ranged from 1-7. A sum score was computed by adding the scores of all items, ranging from 13 (weakest sense of coherence) to 91 (strongest sense of coherence).

Two open-ended questions were used to collect the informants' experiences of help and support from the health services for their own sake (III). The questions were: "Please write something about what you are satisfied with and what you would like to have more of", and "please write what you have been missing and what kind of help/support/follow-up you would like to have". The hand-written notes varied from a few sentences to several pages, and altogether consisted of approximately 16,500 words. They were transcribed by the author (BW).

Instrument translation: The SF-36 (Loge, Kaasa, Hjermstad, & Kvien 1998) and the SOC (Guldvog 1996) scales existed in Norwegian translations which were used in study I. In order to translate the BAS for use in research, permission was obtained from the World Health Organization. Then the following steps were used in the process of translating the instrument from English into Norwegian (Brislin 1970). The items were translated from English to Norwegian by a bilingual and experienced professional within the discipline of psychology. This translation was scrutinized and commented on by two persons, blinded to the original version. One of the reviewers is bilingual and an experienced mental health nurse, the other an experienced reader of English professional texts within the discipline of psychology. The next step was to translate the Norwegian version into English by a bilingual and experienced psychiatrist, blinded to the original version. The two versions were scrutinized by the author in order to identify differences and in which stage they had occurred. A final version was referred to the research team (BW, BH, MLHL), and agreement was reached. The research team found the translated version to be linguistically accurate and sufficiently relevant culturally. Finally, the translated version was scrutinized by a group of experienced researchers within the field of mental health, who found it acceptable and relevant.

A pilot-test (I, III) for clarity was performed for the entire questionnaire. A local unit of the NNAFMIP administered the questionnaires to 20 adult relatives of different sex, age and kinship to severely mentally ill persons, of whom 15 responded and returned the questionnaire. In addition to answering the questionnaire, the relatives were asked to comment on the form with regard to clarity, length and relevance, and if they had any additional remarks.

As a result of pilot testing with relatives, the phrase "patient" was replaced by "the person concerned" in the BAS instrument, since the items were to

be answered by relatives. Furthermore, the item "is the patient's illness preventing you from looking for a job?" was altered to "is the mental illness of the person concerned hindering you from working?" since this was believed to provide a broader catchment. One optional answer, "not relevant", was added to every item. For example, the item about work situation would not be relevant to the senior citizens. This optional answer matched that of a similar instrument (Reinhard, Gubman, Horwitz, & Minsky 1994) which is translated and has been used in Sweden (Bogren 1996; Ivarsson, Sidenvall, & Carlsson 2004). Apart from the changes described above, the questionnaire as a whole was considered relevant and acceptable with regard to length and clarity by the relatives in the pilot study. The responds from the pilot-test were not included in the studies (I, III).

Procedure (II)

The data collection took place from April to June 2009. The data collection procedure consisted of a first request sent to 13 relatives of whom seven gave consent to participate. After four weeks a second request was sent to 13 new relatives, of whom eight gave their consent to participate. After another four weeks a third request was sent to five new relatives, of whom three gave consent. After four more weeks a last request was sent to four new relatives, of whom no one gave consent. The remaining kinship role was brothers, but despite request to every brother in the sample no consent was achieved. One of the relatives later withdrew from participation before the interview took place.

The individual interviews (II) consisted of altogether 17 qualitative interviews (cf. Marton & Booth 1997). One turned out to become a pair-interview since the informant, a mother, wished that her husband (the father of their severely mentally ill, adult child) should participate, which he did, and was thus included as an informant.

The interviews took place according to the informants' wishes, in the informant's home, or workplace. One interview took place in a quiet, undisturbed office in the interviewer's (BW) workplace, and another in a quiet, undisturbed office in a university college. Before the interviews started, time was spent to chat informally and to ease the atmosphere and get a little acquainted.

Interview guide (II)

An interview guide with a few open-ended questions (cf. Baker 1997), was used. There was one introductory question. In addition, questions which followed the informant's story and probing questions were used to illuminate variations in conceptions, and to get the informants' meta awareness (Marton & Booth 1997). The introductory question was: *"What are your thoughts about your own situation as a relative to someone with severe mental illness?"*. The additional questions were: *"Has the situation affected your own life in any ways?", "What are positive aspects of being a relative?",* and *"What has been challenging/ difficult about being a relative?"*. Furthermore, probing questions were used.

At the end of the interviews the informants were asked to share any thoughts they found relevant that had not been covered. All interviews were transcribed verbatim by the author (BW). Each informant was interviewed once. The interviews lasted between 70 and 160 minutes. The transcripts counted approximately 260,000 words.

One pilot study (II) was performed (BW) prior to the interviews, with a relative from a local unit of the NNAFMIP. After the interview, the informant was asked to share comments on the questions, regarding time spent, relevance and possible ethical aspects. The informant's feedback included only positive remarks to these issues, and had nothing additional or negative to report. The pilot interview was audio recorded and transcribed verbatim by the author (BW), with a subsequent discussion in the research team (BW, BH, MLHL, CS). The pilot study was not included in the study.

Procedure (IV)

In study IV, the data collection took place from March 2008 to January 2009. Focus group interviews are well suited to study complex phenomena in the health services (Barbour & Kissinger 1999), and also to mutually discover understanding of the question under study (Manning 1997).

Permission to perform focus group interviews was received from the respective head managers of the four hospital trusts/ municipality health services. The relevant head nurses shared information about the study to the personnel. Information letters and letters of consent were distributed to all registered nurses. The written consents were collected in a pre-stamped

envelope, witch was returned to the author (BW). The author also shared oral information to the groups by visiting once prior to the interviews, emphasizing that withdrawal would be acceptable at any time prior to the analyzing process.

When selecting informants for one of the focus groups, one nurse, who was a former student of the moderator (BW), was excluded. Three others were excluded as well, due to logistical problems, and that variation in the sample would still be achieved.

In the focus group interviews (IV), each focus group was interviewed three times, with approximately two weeks in between. Several meetings may be beneficial to deepen understanding of the question under study (Thornton 2002). An experienced mental health nurse participated as an observer in seven of the 12 interviews in order to give feed-back to the moderator (BW) about interview technique and to be available to the informants at the end of the interviews. The observer was ill during the last interviews, but was not replaced since the moderator was able to carry them out on her own due to experiences from the first interviews and feedback from the observer. To use an observer in a restricted number of focus group interviews has been described (Høye & Severinsson 2008). In order to keep track of who said what, the moderator (BW) mapped the informants with numbers which then were noted in the same order as they made comments, to facilitate the transcription of the interviews.

The first interview within each group started with presentations of the informants, the moderator (BW) and the observer (when relevant), and by underlining the importance of an open dialogue where nothing was considered "right or wrong". These first interviews were mostly spent to illuminate the phenomenon under study, i.e. what the informants' understood by cooperation with and supporting relatives they would meet in relation to their working with severely mentally ill patients. At the end of each interview the informants were encouraged to share comments about the discussion and their own participation. At the beginning of each groups' second and third interviews, the moderator (BW) shared a summary of topics discussed in the prior interview, and encouraged the informants to share comments from the latest interview.

Interview guide (IV)

An interview guide with open-ended questions was used. The opening question was *"What are your thoughts about cooperation with relatives for their own sake"*. Additional question were: *"In what ways do you/ how can you cooperate with the relatives for their own sake?"* Probing questions were posed in order to stimulate reflections and variations in conceptions. From time to time, some issues were illuminated by asking two informants together to discuss and reflect on the issues while the others listened. The others were then invited to reflect on and give feed-back on the discussion.

The interviews were audio-recorded and transcribed verbatim by the author (BW). They lasted between 70 and 120 minutes. The transcripts counted approximately 180,000 words.

Two pilot interviews (IV) were performed (BW) with a group of three informants (one man, two women), with more than five years of experience of working with patients with severe mental illness (two mental health nurse assistants, one social educator). The pilot interviews lasted between 60 and 90 minutes, with one week of intermission. The head nurse shared information about the pilot study to the personnel, and those wishing to participate gave oral consent to the head nurse and the researcher (BW). The group shared consent of confidentiality. After each interview, the informants were given time to share comments regarding relevance, group discussion and ethical aspects. The interviews were audio-recorded and transcribed verbatim by the author (BW), with a subsequent discussion of the material in the research team (BW, BH, MLHL, CS). The pilot testing was helpful in moderating the actual focus group interviews in terms of balancing the informants' opportunity to participate. The pilot interviews were not included in the study.

Data analyses

Statistics (I)

The data analyses of Study I was carried out with descriptive and inferential statistics, by the use of the Statistical Package for the Social Sciences (SPSS), versions 15-17, by SPSS Inc., Chicago, Illinois, USA. Non-parametric tests were used. Significance level was set to $p < .05$ for all statistical tests (Altman 1991).

The statistical analyses used in Study I are shown in Table 4.

Table 4: Statistical tests in study I

STATISTICS	PURPOSE OF ANALYSES
Frequencies, percentages, mean, standard deviation, median, and range	Description of data.
Pearson's Chi-square test	To test differences in proportions between men and women for background and aspects of everyday life variables.
Mann-Whitney *U*-test	To analyse for differences between relatives' health (SF-36 subscales) and burden (BAS subscales and total scale), respectively, in relation to (two independent groups) background (sex, marital status) and everyday life with the mentally ill person (financial problems, and someone with whom to share caregiving). Sub-group comparisons when Kruskal Wallis tests showed a statistically significant difference.
Kruskal-Wallis analysis of variance	To analyse for differences between relatives' health (SF-36 subscales) and burden (BAS subscales and total scale), respectively, in relation to (three independent groups or more) background (educational level) and everyday life with the mentally ill person (in-person and phone contact).
Spearman's rank order correlation	Examine associations between the subscales and total scale of BAS, the subscales of SF-36, and SOC.
Cronbach's alpha	To test internal consistency (reliability test) of the total scale of BAS, the subscales of SF-36, and SOC.

One missing or "not relevant" response per subscale for the BAS instrument was replaced by each respondent's mean score for the remaining three items per subscale, the case mean substitution technique (Fox‒Wasylyshyn & El‒Masri 2005). This resulted in a variation from 196 to 216 valid cases in the subscales and for the total scale.

Phenomenography (II, IV)

The analyses of Study II and IV were carried out using phenomenography, a research method described by Marton (1981). Phenomenography has its' basis in educational research and cognitive psychology (Marton 1981; Marton & Booth 1997; Uljens 1989), and aims at discovering different ways of conceiving phenomena in the world around us. Phenomenography takes a second-order perspective, meaning that it is the different ways of conceiving the phenomena that is of interest: *what* is in the informants' focus when describing the phenomenon under study and *how* is it described (Marton & Booth 1997).

According to Dahlgren and Fallsberg (1991), the difference between conceptions is the core of results. The variation of conceptions may be understood as a "collective mind", and thus representing variations of conceptualizing that also may exist outside of the chosen sample (Marton 1981). Dahlgren and Fallsberg (1991) described seven steps of analyzing data which were followed in study II and IV:

Familiarization: After all the interviews had taken place in each study, they were listened to several times and transcribed verbatim by the author (BW). The research team (BW, BH, MLHL, CS) read the transcripts several times. Condensation: Significant statements of interest to the research focus were identified from the transcripts, looking for what the informants focused on and how it was described. A condensation of the meaning units was performed and further scrutinized and discussed in the research team. Comparison: Meaning units were compared and contrasted. Grouping: Seemingly similar statements were put together. Differences and similarities were compared within the meaning units, and possible categories were tested by comparing them with the interviews. Articulating: A description of an essential meaning of each group of answers was made. Labelling: Suitable expressions were found to cover the essential meaning of the categories. Contrasting: Finally, comparisons of the categories with regard to similarities and differences were made. The last three steps were repeated several times (cf. Stenfors-Hayes, Hult, & Dahlgren 2011). The categories were organized in a hierarchical and horizontal outcome space (Uljens 1989).

In study II, the data material was large, and in order to make the data manageable the material was divided into two parts (cf. Åkerlind 2005, p.68) (interview 1-9 and 10-17), after the transcripts had been read several times. The steps from condensation to a preliminary labelling were made for each two parts. When including the second part, these steps were repeated, the categories reconsidered, and new labels were found before the contrasting step was done.

Qualitative content analysis (III)

The analysis in study III was carried out with qualitative content analysis, according to Elo and Kyngäs (2008) in order to describe the relatives' experiences with the mental health services. Elo and Kyngäs (ibid.) described three main phases of content analysis: the preparation phase, the organizing phase, and the reporting phase. The preparation phase included collecting the informants' written notes about their experiences with the health services in relation to the person with the severe mental illness (the unit of analysis). These notes were transcribed verbatim (BW) and read several times by the research team (BW, BH, MLHL, CS) to get an overview of the content. The organization phase concerned open coding of the text, which was transferred into coding sheets (BW) and thoroughly discussed in the research team in order to start the initial grouping of the codes. The grouping initiated the work with generating mutually exclusive categories. The subcategories emerged as we arranged the content into generic categories, and named them according to their content. Throughout the analyzing process the research team secured that relevant content were placed in the right categories by going back to the original data. The main category emerged, and was named after the content was transformed into generic categories and subcategories. The reporting phase concerned describing the three levels of categories and supporting the categories with excerpts from the original material.

Validity, reliability and trustworthiness

To strengthen the quality of the studies, steps were made throughout the research processes to establish validity and reliability in the quantitative study, whereas trustworthiness was sought in the qualitative studies. Reliability of an instrument refers to its consistency to measure the construct, its accuracy and stability (Polit & Beck 2004). Validity concerns the evidence of the degree to which an instrument is assessing what it is supposed to assess (Polit & Beck 2008). According to Guba, trustworthiness in qualitative research includes credibility, transferability, dependability and confirmability (Guba 1981).

Validity and reliability of the instruments (I)

The SF-36 instrument has been widely used in research. It has been documented to demonstrate high validity and reliability, and may be used

for comparisons between generic and specific populations (Ware et al. 1993). The Norwegian edition of the questionnaire showed a Cronbach's alpha (Cronbach 1951) ranging from .80 to .93 (Loge & Kaasa 1998). In the present study, Cronbach's alpha ranged from .90 to .92.

The SOC scale has been developed to be applicable across cultures (Antonovsky 1993) and has shown acceptable validity and reliability (Eriksson & Lindström 2006). The Cronbach's alpha values in 127 studies with the 13-items version ranged from 0.70 to 0.92 (Eriksson & Lindström 2006). In the present study, Cronbach's alpha was 0.85.

The BAS instrument has been used in several studies in the original version. Validity and reliability have been described as acceptable for the original 40-item version (Thara et al. 1998) and the later 20-item version (Sell et al. 1998). Internal consistency showed an alpha coefficient of 0.81 for the 40-item version (Rammohan, Rao, & Subbakrishna 2002). No alpha coefficient for the 20 item version has been found. The 16 items used in the present study showed a Cronbach's alpha of 0.88.

Trustworthiness (II, III, IV)

In studies II, III, and IV, Guba's four actions to ensure trustworthiness were used (Guba 1981). Credibility was strengthened with the use of open-ended questions, since the informants were free to express their own views, and in their own words. The research team's (BW, BH, MLHL, CS) insight and understanding of the material were repeatedly tested against the informants' statements, and the condensation and coding was discussed until all aspects of the content were found to be covered. Throughout the analyzing process, individual and mutual interpretations were discussed until agreement was reached within the research team. Transferability was sought by the description of data collection, the informants and the analyzing process. In study III, dependability was ensured by all informants answering the same, open-ended questions. In studies II and IV, interview guides were used to secure dependability. Furthermore, accounts of the analyzing processes were described in order to establish "audit trails" (Guba 1981). To strengthen confirmability, the understanding of the findings of each study was compared with other relevant studies. Moreover, the possibility of preconceived notions with regard to the material was thoroughly discussed within the research team, which was balanced in terms of professional experience. Interpretations were supported by quotations.

Ethical approval and considerations

The Regional Committee for Medical Research Ethics for Southern/ Eastern Norway approved studies I-III: ref 08-167-07242d, 2008/9489. Studies I-IV were also approved by the Norwegian Social Science Data Services: ref 17465. The head of NNAFMIP gave consent to conduct the relatives' studies. The head of each health trust, institution or municipality healthcare services gave consent to conduct the focus group interviews with nurses. The studies were carried out in accordance with Ethical guidelines for Research in the Nordic Countries (Northern Nurses' Federation 2003). The written information followed the norm of the Regional Committee for Medical Research Ethics for Southern/ Eastern Norway (I-III) and the Norwegian Social Science Data Service (IV), including the opportunity to withdraw unconditionally from participation until data was included in the analyses or in publications (I-IV).

Consent of participation was considered granted from those informants who returned the questionnaire (I, III). A request for participation in an interview (II) was sent to a sample of informants from study I. A request was sent on four occasions to different groups of relatives (II), in order to avoid asking too many from some of the groups. The nurses who wished to participate (IV) signed and returned a letter of consent to the researcher. The researcher contacted the informants (II) or a nurse pointed out as a contact (IV) by phone to make further arrangements about time and place for the interviews. Prior to each interview (II, IV), the informants were additionally informed orally according to the information letters described above.

Illuminating burden, health problems and life situation of relatives of persons with severe mental illness (I-IV) may cause extra strain on mentally ill persons. On the other hand, relatives' situation needs investigation and description. In the questionnaire there were no direct questions about the severely mentally ill person. Names were sought to be avoided in the interviews (II, IV), and if any occurred, they were made anonymous in the transcripts.

The questionnaire may have been disturbing to the relatives, since it revolved around health, burden and everyday life with the severely mentally ill person. No direct negative remarks about the items were reported from the informants, but of the 400 relatives who were asked to participate (I,

III), three persons contacted the author and refused participation due to concerns about the possibility that the study could put extra strain on mentally ill persons in general. Two stated that the emphasis on relatives' health was irrelevant, and two had concerns about the possibility that participating might jeopardize their relation with the severely mentally ill person. One relative was dissatisfied because the members' association had given consent to perform the study. Two informants contacted the author after filling in the questionnaire, to share some experiences, although stating that further follow-up was unnecessary. The author contacted all those having regrets, either by phone or by mail, in order to make sure that their comments were noted and that no further contact with them would take place.

The interviews with relatives revolved around issues which might be conceived emotional or sensitive to the informants. The informants were told that the audio recorder would be turned off at request, and that it was possible to take breaks during the interviews. In some of the interviews, the recorder was turned off at the informant's request, or by the researcher due to e.g. the informant bursting into tears. In such cases, the informants were given time to calm down, and given the opportunity to end the interview. No one wished to end the interviews, but instead stated that it was important for them to share these experiences. To avoid interrupting the interviews was a way of acknowledging the informants' experiences. At the end of each interview the informants were asked if any questions had been too sensitive or difficult emotionally, which they all stated was not the case. Time was spent to ensure that the informants felt safe and had someone to address. They were also told that they could contact the researcher (BW), who in turn would put them in contact with the relatives' member association or health personnel if they later on needed follow-up. None of the informants contacted the researcher about this. Although the questionnaire and the qualitative interviews could be disturbing to the informants, several informants noted at the end of the questionnaire or during the interviews that this was the first time they had been asked about their experiences, and that they were grateful for the opportunity to share experiences.

Taking part in focus group interviews involves exposing one's opinions to others, and the informants may discover latent meanings, which implies a

risk of feeling vulnerable (cf. Maunsbach & Dehlholm-Lambertsen 1997). The moderator was conscious about not pressuring the informants.

The questionnaire was punched by the author (BW). The information was stored electronically in the hospital's research server. Audio-taped material was stored encrypted in an area particularly for this purpose in the hospital's research server. Written material was stored anonymously by the use of cross-lists, coding lists, and coding key stored in separate areas, safely locked away separately in the research department. Transcripts from the audio recorded interviews were made anonymous.

MAIN FINDINGS

The main findings are presented in relation to the burden, health, and everyday life of relatives of persons with severe mental illness, their life-sharing experiences and need for support from formal care, as well as nurses' conception of support of relatives of persons with severe mental illness.

Relatives' burden and health (I)

The relatives' experienced burden and health are shown in Tables 5 and 6.

Table 5. The relatives' experienced burden

IMPACT ON WELL-BEING		APPRECIATION FOR CARING		IMPACT ON RELATION-SHIP WITH OTHERS		PERCEIVED SEVERITY OF THE DISEASE		TOTAL SCORE 16 ITEMS	
Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
8.97 [1]	1.97	6.12[1]	1.60	6.68[1]	2.11	7.72[1]	1.98	29.61[2]	4.11

[1] Each factor consisted of 4 items with responses ranging from 1-3. The sub scores could range from 4 to 12 per factor. [2] The total score could range from 16 to 48. Higher scores indicate higher burden.

The total sample experienced burden. The highest burden was shown in the factor Impact on well-being, while the factor Appreciation for caring showed lowest burden.

Table 6. The relatives' experienced health

PHYSICAL HEALTH SUBSCALES	PHYSICAL FUNCTIONING	ROLE PHYSICAL	BODILY PAIN	GENERAL HEALTH
Mean (SD)	83.5 (19.76)	70.9 (28.57)	62.4 (26.57)	64.4 (23.15)
MENTAL HEALTH SUBSCALES	VITALITY	SOCIAL FUNCTIONING	ROLE EMOTIONAL	MENTAL HEALTH
Mean (SD)	42.8 (23.27)	68.8 (27.38)	72.1 (28.39)	67.2 (20.08)

The sub scores could range from 0-100, with higher scores indicating better health.

The total sample showed poor health. Regarding physical health, the best health was shown in the subscale Physical Functioning, while the worst health was shown in the subscale Bodily Pain. Regarding mental health, the

best health was shown in the subscale Role Emotional, while the worst health was shown in the subscale Vitality.

The statistically significant differences in relatives' burden and health in relation to background variables are presented in Table 7.

Table 7. The relatives' burden and health in relation to marital status, and educational level

	MARITAL STATUS			EDUCATION			
	Spo/Coh	Sing/ Div/Wid		C	US	U	
	Mean (SD)	Mean (SD)	*p-value*	Mean (SD)	Mean (SD)	Mean (SD)	*p-value*
BAS	29.02 (4.16)	30.87 (3.74)	.003	-	-	-	-
PF	-	-	-	74.2 (23.77)	81.5 (20.88)	86.6 (17.49)	.006
BP	-	-	-	45.8 (23.51)	58.2 (26.83)	68.1 (25.32)	.000
GH	66.8 (23.11)	59.4 (22.57)	.017	51.7 (20.49)	64.7 (23.69)	66.56 (22.75)	.015
SF	-	-	-	53.8 (24.55)	71.1 (27.40)	70.5 (27.09)	.011
MH	69.2 (19.29)	62.9 (21.21)	.028	55.2 (21.42)	68.0 (19.50)	69.0 (19.65)	.017

Spo/ Coh= Spouse/ Cohabitant, Sing/ Div/ Wid= Single/ Divorced/ Widowed. C= Compulsory comprehensive school, US= Upper secondary school, U= University. BAS= Burden Assessment Schedule. The following abbreviations refer to subscales of SF-36: PF= Physical Functioning, BP= Bodily Pain, GH= General Health, SF= Social Funcioning, MH= Mental Health.

The burden was greatest for those being single, divorced, or widowed. Regarding health, the subscales General Health and Mental Health showed the lowest scores for those being single, divorced or widowed. For those with the lowest educational level all the health subscales showed significantly lower scores. There was a significant difference in burden between men and women; mean 28.36 (SD 3.86) and mean 30.00 (SD 4.12), *p*= .019, respectively, but no differences between men and women regarding health were found (not shown in the table).

The statistically significant differences in burden and health related to aspects of the relatives' everyday life are presented in Table 8.

Table 8. Relatives' experienced burden and health regarding frequency of contact by phone with the severely mentally ill person, financial problems related to the severely mentally ill person, and whether having someone to share the caregiving with

		BAS	PF	RP	BP	GH	VT	SF	RE	MH
Frequency of contact by phone										
S	Mean (SD)	30.76 (3.91)	73.26 (24.21)	56.53 (34.07)	-	53.28 (27.20)	32.73 (23.62)	51.67 (28.65)	55.00 (35.51)	56.94 (21.49)
D	Mean (SD)	28.51 (3.78)	85.54 (17.55)	73.79 (27.18)	-	69.67 (20.59)	45.83 (22.01)	77.41 (20.92)	77.58 (26.93)	73.43 (16.82)
W	Mean (SD)	29.32 (4.06)	89.04 (14.14)	79.03 (20.93)	-	66.38 (21.29)	43.67 (23.63)	72.89 (27.46)	77.41 (20.76)	68.47 (19.59)
M	Mean (SD)	30.73 (4.92)	78.68 (25.40)	65.30 (31.72)	-	64.14 (24.21)	48.75 (21.05)	70.97 (24.24)	74.19 (25.94)	69.33 (17.90)
	p-value	.030	.002	.003	-	.016	.012	.000	.003	.001
Financial problems										
Yes	Mean (SD)	30.54 (3.86)	80.1 (19.34)	63.0 (26.81)	52.5 (25.54)	55.7 (21.55)	34.4 (21.62)	57.4 (28.17)	61.5 (30.26)	58.8 (20.53)
No	Mean (SD)	28.78 (4.10)	88.0 (17.23)	78.4 (27.11)	70.7 (24.76)	71.8 (21.34)	49.8 (22.37)	78.1 (23.31)	81.3 (23.94)	73.6 (17.77)
	p-value	.006	.000	.000	.000	.000	.000	.000	.000	.000
Shared care-giving										
Yes	Mean (SD)	29.25 (4.11)	-	70.6 (27.76)	-	-	-	-	-	-
No	Mean (SD)	30.72 (3.94)	-	63.0 (25.57)	-	-	-	-	-	-
	p-value	.049	-	.034	-	-	-	-	-	-

S = Several times per day, D = Daily, W = Weekly, M = Monthly or more seldom. BAS= Burden Assessment Schedule. PF= Physical Functioning, RP= Role Physical, BP= Bodily Pain, GH= General Health, V= Vitality, SF= Social Functioning, RE= Role Emotional, MH= Mental Health.

Having very frequent or very little contact by phone showed greater burden compared to daily or weekly contact. Financial problems related to the severely mentally ill person, and not having anyone to share the caregiving with, showed greater burden. The health subscales and particularly Vitality (VT) were lower for those who had contact by phone with the severely mentally ill person several times per day, and for those who had financial problems. There were no significant differences in burden and health regarding contact in person with the severely mentally ill person (not shown in the table).

The correlations between the relatives' health (SF-36), burden (BAS), and sense of coherence (SOC) are presented in Table 9.

Table 9: Correlations between relatives' health, burden, and sense of coherence

SF-36	PF	RP	BP	GH	VT	SF	RE	ME
	RHO	*RHO*	*RHO*	*RHO*	*RHO*	*RHO*	*RHO*	*RHO*
	P	*P*	*P*	*P*	*P*	*P*	*P*	*P*
BAS	-.144	-.194	-.177	-.208	-.183	-.201	-.253	-.205
	.046	.007	.014	.003	.010	.005	.000	.004
SOC	.240	.329	.367	.473	.520	.479	.465	.634
	.001	.000	.000	.000	.000	.000	.000	.000

SF-36= Short Form Health Survey. PF= Physical Functioning, RP= Role Physical, BP= Bodily Pain, GH= General Health, VT= Vitality, SF= Social Functioning, RE= Role Emotional, ME= Mental Health. BAS= Burden Assessment Schedule. SOC= Sense of Coherence.

There were negative correlations between all SF-36 subscales and BAS total scale, meaning that when one increased, the other decreased. The correlations between the SF-36 subscales and SOC were positive, meaning that when the one increased, so did the other. There was no correlation between total BAS and SOC (not shown in the table).

Relatives' life-sharing experiences and need for support (II, III)

The relatives' experiences of sharing lives with a severely mentally ill next of kin (II) were conceived as *The art of balancing between multiple concerns.* This was experienced as a challenging process in terms of balancing a complexity of considerations and dilemmas. Two descriptive categories emerged: *"Making choices on behalf of others and oneself",* and *"Constantly struggling between opposing feelings and between reflections"* meant that the relatives' life-sharing experiences were characterized by facing dilemmas concerning their relationships with the severely mentally ill person.

"Making choices on behalf of others and oneself" included the conceptions "manoeuvring between different ways to act", and "prioritizing between wishes and between needs". Relatives' choices between ways to act concerned what to say, and what to do. They needed others to understand their situation, but had doubts about being open. Loyalty and respect towards the severely mentally ill person prevented them from revealing too many details. The relatives had to tune into the state of the mentally ill person to decide how to communicate, depending on the severity of symptoms in him or her. Furthermore, to let the severely mentally ill person be in control of his or her own life might seem to enhance his or her freedom, but often resulted in negative outcomes. Regarding their meetings

with health personnel, the relatives conceived that they had to balance their own behaviour carefully, since any unwanted approach could easily turn health personnel against them. Furthermore, they had to manage their dialogue within the personnel's professional confidentiality. Prioritizing between wishes and between needs, concerned having to choose between the other family members and the severely mentally ill person and between the severely mentally ill person and oneself. These choices were difficult, since those involved often had competing or contradictory wishes and needs. For the relatives, keeping up their own activities was a wanted and necessary offload. This was nevertheless difficult to achieve, and even if they did, the worries about how the severely mentally ill next of kin were doing, remained in the back of their heads.

"Constantly struggling between opposing feelings and between reflections" included the conceptions "Facing a wide range of strong feelings", and "Searching for hope and meaning". Relatives feared what others might think and say about them, and they sometimes feared the severely mentally ill next of kin. Fearing one's next of kin was associated with unpredictability and a mixture of feelings. The relationship with a severely mentally ill next of kin made the relatives vulnerable in other relationships. Furthermore, their unpredictable situation, experiences of often being unable to get help in critical situations and changes in the severity of the mental illness, describe a feeling of powerlessness. The relatives often wanted to give up or to escape the situation, and some had considered suicide a resort. The relatives' searching for hope and meaning was wavering between never giving up hope and feeling that there was no hope. They searched for meaning through religion, a spiritual dimension regarding a higher purpose of the situation, their own family values, and political or philosophical views. Lost opportunities and an uncertain future for oneself and the severely mentally ill person sometimes resulted in feelings of meaninglessness. On the one hand, they had learned to be patient, to appreciate small pleasures in life and their own health, and to grasp the moment and look for opportunities. Furthermore, they felt wiser, more generous towards people's differences, and had gained a broader perspective on life due to the situation. They found it meaningful to help the person concerned, and some relationships had become closer. However, the overall description was that the costs were too high, and the reward could never be worth the price.

The relatives' experiences with the mental health services (III) in connection with the treatment and care of their severely mentally ill next of kin were essentially described as negative, but some relatives had positive experiences. The relatives described that they had to shoulder the overall responsibilities for their severely mentally ill next of kin, mostly without support to manage the situation. The relatives experienced that they were *Left alone with straining but inescapable responsibilities.* Two generic categories emerged: "Striving for involvement for the sake of the mentally ill person", and "Wanting inclusion for the sake of oneself".

"Striving for involvement for the sake of the mentally ill person", concerned tensions between the relatives' attempts to be involved by health professionals in relation to the treatment and care for the severely mentally ill next of kin, and being excluded despite their useful resources. Relatives' striving for cooperation with health personnel was first and foremost for the sake of their severely mentally ill one, but also for themselves. There were examples of health personnel who had met relatives in a respectful and inviting manner, which seemed to be the exception. The relatives wanted to share their knowledge, which was based on experiences with the next of kin from his or her periods of well functioning, as well as from periods with severe symptoms. They often experienced that their knowledge was unwanted, and felt excluded and even burdensome to health personnel when trying to be involved. The relatives felt powerless, further underlined by being unable to receive necessary help from the mental health services, and when facing severe psychosis in the mentally ill next of kin. The relatives tended to feel lost and without hope. To be invited by health personnel to share experience, was defined as positive. However, the common description was that the relatives repeatedly had to ask for involvement, and had to take charge of any cooperation themselves. In particular, relatives described that health personnel tended to maintain that confidentiality regulations prevented them from cooperating with relatives. In relatives opinion did the health personnel hide behind confidentiality (III).

Wanting inclusion for the sake of themselves" concerned that the relatives' responsibilities tended to be exhausting and overwhelming. They had to be there when the mental health system was not, and they found it difficult to give priority to their own needs. They needed attention and confirmation about their straining situation. They faced difficult feelings, related to their

relationship with the severely mentally ill next of kin, as well as from negative experiences with the mental health services. The relatives were left in an inescapable situation since the person concerned was dependent on help and support, sometimes around the clock. The responsibilities were overwhelming, and an endless, exhausting battle, and were likely to induce a worsened financial situation for the relatives. Altogether, the relatives' situation was demanding and they needed support, which they rarely had received. Not receiving support sometimes resulted in discouragement and shattered hope, and a kind of loneliness. Their need for support varied along with changes in the severity of the mental illness, and their own changing capacity to care for the severely mentally ill person. The support relatives asked for was connected to learning how to navigate through the mental healthcare system, and about the severe mental illness of their next of kin. They also needed acknowledgement, offload, and support in order to deal with their own emotions. Some demanding emotions derived from their relationship with the severely mentally ill person, while others were related to negative experiences with the mental health services.

Nurses' conceptions of support of relatives (IV)

The nurses' conceptions about supporting relatives, expressed as *"Our responsibility is first and foremost the patient"*, revealed a fundamental premise to the nurses' possibilities of supporting relatives. Three descriptive categories emerged, and showed areas of importance to this premise: "The context framing the nursing care", "Aspects of the actors", and "Relational concerns". A major argument was that the alliance with the patient was the corner stone of the nursing care, but could easily be broken if the patient did not experience to be the nurses' priority. Although this made it challenging for the nurses to support relatives, they sometimes managed to do so.

"The context framing the nursing care", concerned that the common view on mental illness within mental health care, the routines, and legislation affected the nurses' opportunity to support relatives. The treatment culture was based on a medical and patient directed view. Routines and resources available to support relatives were scarce. Still, the nurses sometimes managed to share some information and give relatives emotional support by listening to them. Confidentiality was a major concern, which sometimes made it difficult or impossible to inform relatives, although there were

examples where nurses meant that they broke confidentiality in order to support relatives.

"Aspects of the actors" concerned that several issues tied to the patients, relatives, and nurses, mattered to the nurses' possibility to support relatives. Concerning the patients, the severity of symptoms was important. In particular, paranoia could make it impossible for the nurses to have contact with relatives, although they acknowledged the relatives' need for support in these situations. Furthermore, the relatives were expected to behave in certain ways. It was considered challenging when relatives were negative, complaining, in opposition, or distrusting. Preferably, they should not be in opposition or challenge the units' rules. The nurses found it demanding to support relatives who were accused of for example sexual abuse of the patient. Furthermore, relatives from other cultures were viewed as challenging since the nurses lacked the knowledge needed to understand their points of view. The nurses found it appropriate to expect that relatives took responsibility since they were family. The nurses' general and individual view upon relatives was influenced by their personal and professional experiences. Maturity and courage could make them share information and listen to relatives, even those who were considered difficult to deal with.

"Relational concerns" showed that the relationships between patients and relatives, as well as between nurses and relatives, influenced the nurses' possibilities of supporting relatives. In particular, competing or contradicting interests between relatives and patients negatively affected the nurses' possibility to support relatives. The nurses' loyalty was firstly towards the patient, but there were situations when they prioritized relatives' needs before the patients' needs. To support relatives was balanced against their own alliance with the patient, and was also thought of as secondary to patient work. Also, the nurses found that establishing a positive relationship with relatives was a mutual responsibility. Receiving accusations or complaints from relatives might jeopardize any such relationship, although the nurses found it understandable from the relatives' point of view. The nurses found information from relatives about the patient useless if they were not allowed by the relatives to share it with the patient concerned. It was considered negative to receive information that might colour the way they understood the patient.

COMPREHENSIVE UNDERSTANDING OF THE FINDINGS

The findings showed that the relatives' life was intertwined with the life of their severely mentally ill next of kin and hence induced a demanding life situation for relatives. Their life situation included burdens and possible deterioration of health, as well as facing competing or contradicting demands from those involved. It was a challenge to constantly balancing between multiple concerns. The relatives had to shoulder the overall responsibilities for the severely mentally ill person. They experienced to be left alone with straining, but inescapable responsibilities, and often without any hope of improvement of the situation. They needed, and asked for, involvement in mental health care for the sake of the mentally ill person, as well as inclusion and support for themselves. Instead, they often found themselves excluded and felt abandoned by mental health care. Nurses in mental healthcare found their responsibility first and foremost to be the patient and their own therapeutic alliance with him or her, which further complicated relatives' possibility of receiving support.

DISCUSSION

Methodological considerations

Nursing profession draws on knowledge from a diversity of sciences and scientific methods, about general features of health and illness, and about individual experiences. The use of mixed methods corresponds to the different epistemological perspectives connected to nursing practice and may contribute to compensating the weakness of each method and may be performed in a variety of designs (Foss & Ellefsen 2002; Polit & Beck 2012). A partially mixed, sequential and dominant design (Leech & Onwuegbuzie 2009, p.268) was used in this thesis. The research questions guided the choice of methods including data collection, selection of participants, and analyses. The partial mixing meant that the studies were conducted before being interpreted as a whole. Performing the quantitative study (I) prior to the qualitative studies (II, III, IV) meant a sequential design, and the dominance was on the qualitative studies. Performing the quantitative first made it possible to gain a deepened insight of the relatives' experiences and nurses' conceptions, through the following qualitative studies (cf. Polit & Beck 2012). While quantitative designs can be generalized to a broader population, they lack the deepened insight of phenomena that qualitative designs provide. Hence, the mixing was well suited in relation to the overall and specific aims of this thesis.

The quantitative study (I) served well to describe relatives' burden, health and everyday life in order to gain an overview and discover specific areas of interest. It was thus well suited as entrance to further studies with qualitative designs. The qualitative studies (II, III, IV) provided deeper insight from individual interviews about life-sharing experiences (II), and from open-ended questions in a questionnaire about encounters with the mental health services from relatives' perspective (III). To perform focus-group interviews with nurses from all parts of mental health care (IV) provided insight to nurses' conceptions about supporting relatives.

Validity and reliability of the quantitative study (I)

Concerning the internal validity of the study, a random selection of the sample was carried out in order to avoid selection bias (Polit & Beck 2012). The informants consisted of 226 members of NNAFMIP, which at the time

applied to relatives of someone with severe mental illness. To perform data collection in a festive season may have influenced the informants' assessment of their situation. However, most of the questionnaires were returned before and after Christmas time. On the other hand, one cannot rule out bias concerning the possibility that some were filled in keeping in mind good as well as challenging experiences from the festive season.

Some issues should be noted regarding the external validity of the study. Firstly, the sample consisted of members of a relatives' association, and hence caution should be taken regarding generalizability to non-members. On the other hand, the informants came from all health regions of Norway, and regardless of membership, the results point out some areas that deserve attention in relation to relatives of persons with severe mental illness. Secondly, the response rate should be considered. The informants represented 57 % of the randomly selected sample, which was fairly good, considering reported response rates from 40 - 75 % in similar samples (e.g. Borg & Hallberg 2006; Ewertzon et al. 2010; Ivarsson et al. 2004; Rapaport, Bellringer, Pinfold, & Huxley 2006). However, the response rate might involve a risk of bias, since more than 65 % response rate is required to ensure a relatively small risk of bias (Polit & Beck 2012). Thirdly, uncertainty about drop-outs may affect the external validity (Cormack 2000) and hence, drop-out analysis is recommended regarding age, sex and ethnicity (Polit & Beck 2012). After having sent two reminders to the study sample, we decided not to send a request about these questions to show respect for the non-respondents. A Swedish study of a similar sample also showed an uneven distribution of sexes: 24 % men and 76 % women (Ewertzon et al. 2010). According to oral information from the NNAFMIP, the association had a majority of members above 50 years of age, which is consistent with this study's informants. Fourthly, the educational level in the study sample showed that 54.9 % had a university education, compared to 26.7 % in the general population (Statistics Norway 2012b). Whether the high educational level represents an elite bias (Sandelowski 1986) or perhaps is a correct representation of the members' association remains uncertain. Lastly, the studies were performed in Norway. Mental healthcare service provision differs across countries, which should be taken into account in terms of the generalizability of the results.

Regarding the instruments, both the SF-36 and SOC instruments have repeatedly been tested and found valid and reliable, and applicable across

cultures (Eriksson & Lindström 2005; Ware et al. 1993). Regarding reliability, the internal consistency showed Cronbach's alphas between .90 and .92 for SF-36, .85 for SOC, and .88 for BAS. All values are acceptable internal consistency (Cronbach 1951). Regarding construct validity of the Norwegian version of BAS, factor analysis was not performed. However, Spearman's rho test showed no correlations between the instrument's factors which mean they are measuring different areas of the construct. The Norwegian version of BAS should be further tested due to anticipated cultural differences (Polit & Beck 2012). Replacing missing data with substitutions, which was performed for BAS, is debated since it underestimates variance (Polit & Beck 2012, p.468). Missing substitutes were performed manually using "the case mean substitution technique" (Fox−Wasylyshyn & El−Masri 2005). This technique is considered to be an acceptable method for performing imputations (Fox−Wasylyshyn & El−Masri 2005; Polit & Beck 2012).

Concerning statistical methods, non-parametric tests were considered appropriate (cf. Polit & Beck 2012). Sum scores from ordinal level instruments may be considered continuous, given normal distribution of data, which did not apply for the current data. In addition, some of the subgroups were small, and the three-graded response alternatives in BAS indicate that the distance between them may very well be different (cf. Streiner & Norman 2008). Furthermore, since multiple tests were performed, Bonferroni corrections could have been performed. Deciding on a stricter level of significance might reduce the risk of falsely rejecting the null hypothesis (type 1 error), but on the other hand increases the risk of type 2 error (Polit & Beck 2012).

Trustworthiness of the qualitative studies (II, III, IV)

The four actions to enhance trustworthiness in qualitative studies (Guba 1981) were followed. *Credibility* was sought by the use of open ended questions (II, III, IV), and the informants were encouraged to add any relevant additional experiences (II, IV). During the analyzing processes (II-IV), the interpretations were tested against the data material, and the research team openly discussed possible interpretations until agreement was reached. Regarding *transferability*, descriptions of the informants, data sampling and analyses have been accounted for in the articles (II, III, IV). Furthermore, since mental health care may differ across countries, the

Norwegian mental health care system is described in the methods section. The fact that the informants were members of a relatives' association, should also be taken into account regarding transferability of the findings. However, the informants in study II were selected with regard to multiple variations that might strengthen transferability. *Dependability* was sought by using the same, open ended questions (III), and introductory and additional questions (II, IV) to all informants within each study. All interviews were conducted by the author (II, IV). Concerning *Confirmability,* the research team was conscious about being open-minded and set aside possible preconceived notions to the material. The balance of professional experiences within the research team was thus considered positive. Quotations were used to strengthen confirmability of the categories. Regarding relatives' experiences with the mental health services (III), there were only 33 of 216 respondents who described solely positive experiences with the mental health services, and 50 who both reported positive and negative experiences. The remaining 133 did solely report negative experiences. The mainly negative image of relatives' experiences with the mental health services presented (III) was thus assumed sufficiently supported. This finding is contradicted by an interview study from one Norwegian hospital (Nordby, Kjønsberg, & Hummelvoll 2010), which found mainly positive experiences of relatives' encounters with mental health personnel. It might have been an advantage that the informants in study III expressed their experiences in writing, and outside of the mental health services. Furthermore, although study III does not represent the entire population of relatives of persons with severe mental illness, the fact remains, that these negative experiences exist. Furthermore, comparisons of the included studies confirmed several findings.

A qualitative content analysis (III) according to Elo and Kyngäs (2008) may be deductive or inductive. In order to be open to the informants' own statements, an inductive approach was chosen. Since the analysis dealt with written responses of varying length and depth from open-ended questions, a manifest content analysis was considered appropriate. Although the length of the written materials varied, the material as a whole was rich in content. Several informants stated that this was the first time they had been asked to share their experiences as relatives and this may have lead to the richness in content.

Both individual (II) and focus-group (IV) interviews were carried out based on phenomenographic method. Individual interviews were found suitable since they revolved around emotional issues and explored personal experiences. The one pair-interview, although not planned in advance, proved to be a useful supplement since it provided an additional informant. Several informants openly expressed their emotions during interviews. However, emphasis was put on exploring both positive and demanding aspects of their situation.

Focus group (IV) interviews are found suitable to explore complex issues in health services (Barbour & Kissinger 1999; Barbour 1999), and are in general considered suitable to illuminate conceptions within a culture (Wibeck 2000). Furthermore, focus group interviews can access many viewpoints in an efficient way (Polit & Beck 2012, p.538), and turned out to be a fruitful way of collecting data. On the other hand, some individual statements may be lost, and thus it was important for the moderator to encourage an open environment for sharing thoughts and examples. The risk of biased discussions in focus groups due to possible difficulties in addressing divergent statements (cf. Krueger 1994) did not seem to be significant during these interviews. Efforts were made to ensure that all points of view were welcome (cf. Krueger 1994). The informants stated that the discussions had been open and that opposing views were considered stimulating. This may have been positive in terms of getting variations of conceptions, which is a goal in phenomenography (Marton & Booth 1997). Focus group interviews have repeatedly been used in phenomenographic studies (Fatahi, Mattsson, Hasanpoor, & Skott 2005; Hyrkäs & Paunonen‑Ilmonen 2001; Lepp, Ringsberg, Holm, & Sellersjö 2003; Ringsberg & Krantz 2006; Salomonsson, Wijma, & Alehagen 2010; Struksnes et al. 2012). In study IV, the informants had relevant experiences or conceptions about support of relatives for their own sake. In the outcome space, conceptions represent a variation on a collective level and individual conceptions are not the focus of attention (Marton & Booth 1997).

Phenomenographic interviews should seek to move from unreflected material to a state of meta-awareness, at which both researcher and informants are learning (Husén & Postlethwaite 1994; Marton 1994, p.4427; Marton & Booth 1997, pp.129-31). To perform three interviews with the focus groups (IV) was well suited, since the informants needed time and

discussions to grasp the meaning of the phenomenon under study. The informants provided variations of conceptions that were further scrutinized by the other participants, and more variations of perceptions appeared in the second and third interviews. The probing questions and tentative interpretations of earlier statements were useful in order to reach a metalevel of awareness (cf. Marton 1994, p.130)

Discussion of the findings

The findings concerning the relatives' health, burden, and everyday life, their life-sharing experiences with the severely mentally ill person, and their encounters with mental health services are discussed in this chapter. What kind of support the relatives need, and how nurses do and may support them in connection with the care of the severely mentally ill patient, will also be discussed. Reflections of the findings from a relational ethics perspective are also included.

Relatives' burden and health (I)

The findings (I) showed that the relatives were burdened, and their health was poor compared to the general Norwegian population (Loge & Kaasa 1998). In particular the mental health subscale Vitality was poor (I) which may indicate exhaustion. That burden negatively affected relatives' mental health status was also found in a review of measurements, findings and interventions (Schulze & Rössler 2005). The reported high frequency of phone calls with the severely mentally ill person was one example of an experience that might contribute to relatives' exhaustion. Being frequently involved or disrupted might induce a feeling of never being able to relax or have the freedom to live one's own life. However, to have seldom contact was also associated with burden, possibly due to worrying (Laidlaw et al. 2002) about how the severely mentally ill person is doing. It should also be noted that burden was higher for those who had financial problems related to the severely mentally ill next of kin. The fact that many of the relatives experienced financial problems related to the severely mentally ill next of kin indicates e.g. that the financial situation of severely mentally ill persons needs further attention from the health- and social services. Those who did not have anyone to share the responsibilities with experienced greater burden poorer health, and thus they should be offered support. More than half the sample had a university education, which is twice as many as in the general population (Statistics Norway 2012b). The general poor health should be noted with regard to the highly educated sample, which has been shown to protect health (Cavelaars et al. 1998).

In this thesis, burden and health showed negative correlations (I). Health and sense of coherence correlated positively, and strongest regarding the mental health subscales, which is in line with Eriksson and Lindström

(2006). A connection between the overall straining life situation of the relatives and the severe mental illness of their next of kin is shown. The relatives experienced burdens, sometimes to the extent of exhaustion, which indicates that their health was at risk. Altogether, these relatives need attention and support from health personnel, in order to handle their situation and sustain health.

Relatives' life-sharing experiences and need for support (II, III, IV)

This thesis shows that the relatives' lives were intertwined with the life of their severely mentally ill next of kin. Human relationships involve a moral dimension, which was evident (II, III, IV). The relatives responded to the ethical demand from their severely mentally ill next of kin, to the extent that their own life circumstances were altered and their possibilities of leading full lives seemed threatened. Love, compassion, worry and a bad conscience made them stretch beyond the limit (II, III). The way relatives met their severely mentally ill next of kin, seems in line with the generalized reciprocity which is the basis of the nurse- patient relationship in Martinsen's philosophy (Alvsvåg 2006; Martinsen 1990). The generalized reciprocity might pose challenges to relatives if there is no one else there to unburden them. The nurses that Martinsen address can share responsibilities, difficult situations, and dilemmas with colleagues, and also live a private life, apart from the patients. Relatives do not have this opportunity; their responsibilities are around the clock and never-ending (II, III), and often lead to a kind of loneliness (II). Løgstrup poses, on the other hand, that we cannot claim anything in return when acknowledging the ethical demand, since life is a gift and we are interdependent (Løgstrup 1971; Løgstrup 2007). However, a kind of reciprocity for relatives was visible in terms of rewards from a strengthened relationship between the relative and his or her next of kin, and the pleasure of knowing that he or she was better off with their help (II).

The relatives faced a range of competing ethical demands, and they had to balance multiple concerns (II). Having to choose between different demands or needs from the severely mentally ill next of kin, other family members or their own wishes and needs implies a double-bind situation, like the one nurses report about being in a double-bind situation between patients and relatives (Sjöblom et al. 2005). Moral choices must *"account for the web of relationships, the relational networks and responsibilities that are an essential*

part of particular moral circumstances" (Nortvedt, Hem, & Skirbekk 2011, p.192). To balance these multiple choices might induce moral distress to relatives (cf. Kälvemark, Höglund, Hansson, Westerholm, & Arnetz 2004; Lützén & Kvist 2012). It seemed as they did not escape the dilemmas, but often put themselves last. They had to be there when no one else was, including the mental health services. However, they sometimes felt the need to escape – for some, to the extent that suicide was considered a way out of the hardship (II). Possible suicidal thoughts among these relatives should be noted by health personnel.

The relatives need someone who can understand their situation and support them, among others in dealing with multiply directed demands (II). A Norwegian study showed that relatives' preunderstanding was that they would be offered support and help from health personnel (Tranvåg & Kristoffersen 2008). This, in addition to relatives' mixed emotions regarding their own situation (II, III) shows that they may initially meet health personnel with tension and anxiety, but also with confidence of being affirmed. Daring approaching the other person based on the assumptions that he or she will do me good is the basic phenomenon of ethics (Martinsen 2012). Transferred to this thesis, this implies that relatives' mistrust against mental health personnel (II, III) derives from not being met in a way that affirms their "authentic selves" (Løgstrup 2007). To express our inner wishes and hopes means becoming vulnerable. Not being met leads to accusations and reproach (Løgstrup 1971; Løgstrup 2007).

The relatives could feel lost and without hope (II, III). Nevertheless, they still searched for hope and tried to find some meaning to the situation (II) (cf. Tranvåg & Kristoffersen 2008). The relatives were uncertain about own judgements, in particular when facing severe symptoms in the mentally ill person (II). To have doubts about one's own judgement was also described by Tranvåg and Kristoffersen (2008). While hope has been found essential to families' coping with the impact of mental illness (Bland & Darlington 2002), this thesis showed that hopelessness and meaninglessness was tied to uncertainties of the future for one self and the one with the severe mental illness (II). This supports the importance of relatives' believing that improvements of the situation will occur in the future (Tranvåg & Kristoffersen 2008). Health professionals may also be a source of hope in addition to family and friends (Bland & Darlington 2002), e.g. by relieving them from burden, which has been found to build hope in relatives

(Jönsson, Skärsäter, Wijk, & Danielson 2011). Another source of hope is religious beliefs (Bland & Darlington 2002). The spiritual dimension seems recognizable in this thesis since the relatives to some extent found meaning by accepting a higher purpose to the situation, something they needed to learn (II). The lessons learned were found valuable in the sense that relatives became more understanding and generous to others. Furthermore, the situation had made them learn to appreciate the simple things in life. However, they stated that the rewards could never be worth the prize (II).

The relatives wanted their severely mentally ill next of kin to receive sufficient treatment and follow-up from mental health care (II, III), which supports the findings of other studies (Cleary, Freeman, Hunt, & Walter 2006; Schulze & Rössler 2005). However, the relatives felt *left alone with overwhelming responsibilities* (III). Since the relatives' lives were intertwined with their severely mentally ill next of kin, they strived for *involvement* in mental healthcare for the sake of him or her and for *inclusion* for the sake of themselves. Relatives experienced that their resources mainly were unwanted by mental health personnel (III). Their resources were in terms of an understanding of their severely mentally ill next of kin which was based on a wholeness of life-sharing experiences with him or her, and in terms of wanting to engage as a supportive part of his or her life. The relatives experienced that the personnel lacked interest in their knowledge, which have been previously shown (e.g. Muhlbauer 2002). Saveman and Benzein (2003) pose the question whether nurses only see relatives as providers and receivers of information. However, in this thesis, it seemed to be that relatives were not even considered so, at least not in general (III, IV). The conception of nurses that information from relatives about the patient sometimes was unwanted, since it might colour their own impression of him or her (IV), can illuminate this. One interpretation is that the nurses find relatives' knowledge distracting instead of enriching in the sense of providing them with a more holistic view of the severely mentally ill person. Relatives also experienced that health personnel found their own knowledge superior to relatives' (III).

Sharing any communication with mental health personnel has shown to be a common problem for relatives (e.g. Ewertzon et al. 2010; Kaas et al. 2003; Muhlbauer 2002; Nicholls & Pernice 2009). The informants (II, III) have experiences with mental health professionals from a long period of time and their overall descriptions confirmed this communication problem. Although

some stated that the climate had improved somewhat over the years, the main picture remained negative. Confidentiality in particular has been pointed at as an obstacle to relatives, but also that relatives recognize the need for confidentiality for the mentally ill persons (Rapaport et al. 2006). This thesis shows that in relatives' opinion did health personnel use confidentiality as an excuse to avoid communicating with them and claimed that the personnel hid behind confidentiality (III). The relatives had to balance their communication within mental health professionals' confidentiality. Confidentiality was confirmed by the nurses as a challenge regarding their possibility to include relatives (IV).

Not being offered support and help made relatives disappointed, their ability to handle their situation might decrease, and might increase their burden (cf. Tranvåg & Kristoffersen 2008). This seems applicable to the relatives in this thesis. Not receiving help, but instead feeling rejected by, and burdensome to mental health personnel (III), might to some extent explain the increased burden mentioned. Relatives' experiences of rarely receiving support from mental health personnel (II, III) is in line with several other studies (e.g. Cleary, Freeman, & Walter 2006; Kaas et al. 2003; Winefield 2000). Furthermore, the relatives experienced that it was necessary to approach health personnel in certain manners. They should not be "too pushy or clever" (II, III). There is an inherent dimension of power in a praxis that expects that relatives do not speak their minds (cf. Lundstøl 1999). This thesis showed that although the nurses were able to understand relatives' negative emotions, they found them challenging (IV). Tranvåg and Kristoffersen (2008) found that relatives experienced that health personnel did not understand that their anger was rooted in despair. Relatives' despair may again be understood in line with Løgstrup's (1971, 2007) argument that not being met when being vulnerable leads to accusations and reproach.

This thesis has shown that the relatives found several obstacles to receiving the support they wished for (II, III) but provides insight in what kind of support relatives ask for (II, III). Their need for support can be divided in two main parts: practical and emotional support (Nordby et al. 2010; Schröder, Wilde Larsson, & Ahlström 2007). Relatives of persons with severe mental illness need both (I-III). This thesis has also shown that practical and emotional supports often are two sides of the same coin.

Being involved for the sake of the severely mentally ill person and being included for one's own sake (III) were two sides of support that the

relatives needed, and may include both practical and emotional support. For instance does practical support concern that mental health personnel should answer questions, share information, guidance, and advice. Support also means involving relatives in the shaping of treatment and follow-up of the severely mentally ill person (III). At the same time, these supportive interventions may also serve as emotional support since the relatives may feel that matters of importance to them are being affirmed. A further example is that support should include to balance the relatives' responsibilities against their need for off-load and private time (II, III), bearing in mind how the situation as a whole influenced the relatives (I, II, III). Although advice and education were found to be important aspects of support (II, III), it has been shown that these relatives would benefit from a combination of mutual support groups and education, as well as to learn coping strategies (Macleod et al. 2011). Emotional support concerns being met in a respectful manner, being affirmed, and being given the opportunity to share experiences and knowledge with mental health personnel (Goodwin & Happell 2007), which hopefully will contribute to prevent loneliness, shattered hope and the feeling of being devaluated (II, III). Not being able to share thoughts and emotional reactions and experiencing exclusion by mental health personnel (III), increases relatives feeling of loneliness (cf. Tranvåg & Kristoffersen 2008). Relatives' loneliness was linked with the experience that no one else was able to understand their situation (II). To attain supportive relationships with health personnel thus includes having someone to address, to solve dilemma, deal with difficult emotions, and find balance, hope, and meaning.

Nurses' conceptions about supporting relatives

This thesis shows that relatives' lives are affected inasmuch as it cannot be overlooked. Nurses are considered to be in a good position to offering support to relatives (WHO 2012), the extent to which they actually do so, is a concern (Macleod et al. 2011). Patients' life possibilities, which may be threatened due to illness, pose ethical demands on nurses of taking care of what is of importance to the patient (Alvsvåg 2006; Martinsen 1990). What about similar demands from relatives the nurses meet in connection with the treatment and care for the severely mentally ill patient (II, III)? Although relatives formally are part of nurses' responsibilities (Norwegian Ministry of Health and Care Services 1999a; Norwegian Ministry of Health

and Care Services 1999b), there were issues pulling in the opposite direction (IV).

The nurses faced competing ethical demands between patients and their relatives. Since the nurses' main priority was the patient, they found it challenging to support relatives, although they described that they were aware of relatives' needs. To respond to one of the parties demands could mean to turn down the other. Although the nurses mostly prioritized the patients, they acknowledged the demand from the relatives, which may be considered a double-bind situation (IV) (cf. Sjöblom et al. 2005). An interpretation is that in order to handle the moral distress (Kälvemark et al. 2004; Lützén & Kvist 2012) of this situation the nurses found two main paths concerning support of relatives in mental health care: whether to see the relative in the shadow of the patient, or as an individual person. To manage seeing him or her as an individual person depended on contextual aspects like whether there was a patient or family oriented view in the care culture, if there were sufficient resources present, as well as different aspects of relatives, patients or nurses and the relationships between them (IV). Power is inherent in all human relationships, and Martinsen's moral dimension includes being aware of dilemmas related to power (Martinsen 1991). This was evident in the nurses' concrete descriptions of competing ethical demands from patients and relatives, and when they tried to find ways to act in order to protect both parties' rights. The nurses sometimes followed their own conscience and conviction, sometimes even when they thought they violated confidentiality. The other choice was to follow the rules, which in this respect seemed to be a deontological ethics' stance (IV) (cf. Henriksen & Vetlesen 2001). A problem with deontological ethics is how to relate to contradictory rules or duties (ibid., p. 157). However, this thesis has shown that challenges from competing demands are not ruled out by a relational ethics stance, but derive from the reciprocal dependence which gives us the responsibility of taking care of the other person. Relatives and their severely mentally ill next of kin may have competing demands (II, III, IV).

Being excluded (III) has been shown to be a source of strain to relatives (Tranvåg & Kristoffersen 2008). One possible explanation is the basic view among nurses that *"Our responsibility is first and foremost the patient"* (IV). Furthermore, there were issues from *the context framing the nursing care*, *aspects of the actors*, and *relational concerns* which, as a whole, made it difficult to

support relatives. The nurses found their relationship with the patient fundamental, since it was the basis of being able to fulfil the responsibilities for him or her (IV). Social conventions of the nursing context (cf. Løgstrup 1971) including rules and routines, but also lack of such, pose challenges to nurses regarding support of relatives. Especially when, as in this thesis, there are multiple ethical demands that call for action, and multiple choices of how to act (cf. Nortvedt 2001). Martinsen (2012) poses the question of "how the nurse can be aware of the demand from the patient of being taken care of, among all other tasks that calls upon her" (p. 55). The nurses conceived that their main responsibility was the patient (IV). Furthermore, to care for the patient was perceived as depending on their ability to foster a therapeutic relationship with him or her, which has long been considered fundamental to mental health nursing (e.g. Barker, Jackson, & Stevenson 1999; Barker 2001a; Barker 2001b; Hummelvoll 1996; Peplau 1952). It was evident that the nurses were concerned about anything that might jeopardize their own relationship with the patient. However, this might imply that the patient's other relationships came in the shadow from the nurses' point of view. Another issue was that nurses took patient's autonomy and to act as patients' advocates seriously (IV). This might mean to exclude relatives (IV), particularly when there were contradicting views and wishes from patients and their relatives. To seeing the alliance with the patient their main priority thus became the basis for their decisions about supporting relatives or not, although the importance of including relatives in the care and treatment has been emphasized for years (e.g. Barker 2001a). Even though the organization of mental health care has changed and the large institutional settings are no longer relevant, the alliances between nurses and patients are still important. However, the therapeutic alliances between nurses and patients no longer need to be primary to nurses, but should be supplemented by relationships between nurses and relatives (Rowe 2010). Other explanations have also been set forth concerning why implementation of family nursing has been hindered, namely organizational issues, personal issues and professional experiences (Benzein, Johansson, Årestedt, & Saveman 2008; Saveman 2010, p.37) which are all recognizable in this thesis (II, III, IV). One example which may be understood as related to these issues, was that the relatives on the one hand were excluded (II, III, IV) from formal care, on the other hand did the nurses expect relatives to be involved and take responsibilities for their severely mentally ill next of kin (IV).

There were also examples, both from the relatives and the nurses, showing that the relatives received support, although the degree to witch seemed limited (II, III, IV). To meet relatives relationally, practically, and morally (IV), is understood as being supportive. These are three dimensions of caring, of which the moral dimension sets the frames (Martinsen 1991). It is by meeting the relative relationally in the practical settings that nurses may be able to engage morally to his or her needs, - which may be understood as emotional and practical support. Examples of meeting relatives *relationally* were to actively approach them, to listen, confirm them[8] and to acknowledge their needs. The nurses described that they could manage to do so despite lack of routines. It was a question of taking the time, and making the space in terms of unscheduled "meetings in the doorway" (IV). Although such unscheduled meetings might be seen as examples of being present and approaching relatives, being welcomed in a well prepared way may lead to feeling involved and included in a more profound way. According to Martinsen, time is a necessity for care, and care requires time and space to approach each other wondering[9] (Martinsen 2000; Martinsen 2004; Martinsen 2012). Examples of meeting relatives *practically* were to offer them offload by prolonging patients' hospital stay more than required, to invite them to meetings or to offer them general information and participation in family groups, to refer relatives if they needed follow-up, and to invite to family groups (IV). Family groups were mentioned as being supportive (III). Peer family meetings as a means to building hope has been advocated (Jönsson et al. 2011). The *moral* dimension was recognizable through nurses' respect[10] of relatives' wishes, when they tried to understand relatives' points of view, and when they made decisions based on consideration to all parties (IV).

An interpretation of the findings (II, III, IV) is that by seeing relatives as explicit, individual persons, the nurses become capable of relating morally to them, which seems to require attention, directed approach and time.

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[8] In the sense of being met as an authentic self (Løgstrup 2007).

[9] "undrende" in Norwegian.

[10] Respect from health professionals has been described in terms like being open, to cooperate, and to confirm (Andershed & Ternestedt 2000; Andershed & Ternestedt 2001). These descriptions concerned intensive care units, but should have general value to nursing care.

However, they managed to find loopholes, which showed that to respond to the ethical demand from relatives to a great extent depended on the individual nurse inasmuch as the frames allowed them. The nurses experienced to be hindered by the system, such as the contextual emphasis on the alliance with the patient, lack of routines, and confidentiality (IV). The felt responsibility and consciousness of each nurse may thus to a large extent determine the outcome for relatives. Furthermore, the nurses might exclude relatives in order to avoid moral distress from existing competing ethical demands. Although the nurses (IV) sometimes managed to "own the space and time" and support relatives, the relatives felt excluded from formal care, overwhelmed with the responsibilities of their severely mentally ill next of kin. It seems that support of relatives cannot be left up to each individual nurse, but ought to be considered a collective responsibility. However, the individual responds from nurses of relatives' need for support (III, IV), are examples of individual pressure to the context of nursing care. The ontology of relational ethics may thus serve as a means of pressure to a practice that have multiple ethical demands to serve (cf. Martinsen 2012).

The need for support varies among relatives, may change, and must therefore be designed accordingly. Taking relatives seriously and supporting them according to their needs seems consistent with relational ethics. However, to describe the kind of support relatives in general need as common rules is a contradiction to relational ethics (Andersen 1996; Henriksen & Vetlesen 2001; Løgstrup 1971). Relational ethics does not suggest common rules as a basis of choices (Nortvedt 2001; Nortvedt 2011). Still, situations are both unique and typical which means that some content is recognizable and may be transferred from one situation to another (Martinsen 2012, pp.46-47). Hence, there should be guidelines and routines concerning involvement from, and inclusion of relatives in mental health care as well as general knowledge about their situation (I, II, III, IV). According to the nurses, guidelines, routines, and general knowledge, however, are not sufficient, but may serve as frames to direct nurses' approach towards relatives (IV). Each relative's life is unique, and should be addressed with an open approach (II, III).

This thesis have shown that the unspoken and even the spoken demands from relatives are generally ignored by mental health personnel, which in the ethical perspective of Løgstrup (1971, 2007) and the caring philosophy of Martinsen (e.g. Martinsen 1998a; Martinsen 1998b) is destruction. Martinsen

(2012, p. 103) poses the question if the culture we are part of, allows us to become spectators and thereby avoiding seeing the other person's distress, which again mean avoiding to feel guilt and shame for not acting according to the ethical demand of the other person. This thesis shows that the context framing the nursing care made it possible for nurses to look the other way. To consider relatives as outsiders, in the sense of not being their concern, stands in contrast to the radicality of the ethical demand (Løgstrup 1971). The relatives did not look the other way - they were touched by the ethical demand from their next of kin – who never could be considered an outsider.

Conclusions and implications for mental health services

In conclusion, this thesis shows that relatives find their own lives intertwined with the life of their severely mentally ill next of kin, whereas the nurses mostly found it appropriate to approaching them as separate individuals.

Conclusions from the thesis

> ➤ Relatives of persons with severe mental illness experienced burden, their health was poor, and there were associations between the relatives' burden and health.

> ➤ The relatives experienced strains, demanding responsibilities, and challenging ethical demands related to the severe mental illness of their next of kin.

> ➤ The relatives wanted to be included by mental health professionals in relation to the care of their next of kin; to share their understanding of him or her, to engage as a supportive part in his or her life, but also in order to receive own support.

> ➤ The relatives had some positive experiences with mental health personnel, but mostly felt excluded or abandoned with overwhelming responsibilities.

> ➤ The nurses conceived that their main responsibility was the patient; to develop an alliance with him or her was the basis for caring for the patient.

> ➤ The nurses faced practical problems and ethical dilemmas which made it difficult to support relatives. Whenever the nurses were able to support relatives, it seemed as a personal initiative rather than a systematic approach.

Implications for nursing care and the mental health services

> ➤ Relatives of persons with severe mental illness need practical and emotional support.

> ➤ Mental health services need to involve relatives for the sake of the severely mentally ill person, and include them for their own sake.

➢ Reflections and discussions among mental health professionals related to collaboration with relatives for their own sake need to be prioritized.

➢ On a system level, guidelines should be designed, and implemented in order to address relatives' needs. At the individual level, support must be adapted to the individual relative.

Future research

➢ A systematic review of the literature regarding relatives' health and life situation should be performed.

➢ Relatives' burden and health should be further investigated with multivariate analyses in order to explain their complex connections.

➢ In particular, there is a need for further research of the life situation of male relatives and children.

➢ More studies on mental health personnel's attitudes towards patients' relatives should be performed.

➢ Most important is research aiming to develop, implement and evaluate guidelines for support of these relatives, in cooperation with relatives' representatives.

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