



Everyday life of relatives of persons suffering from severe depression

Experiences of health, burden, sense of coherence and encounters
with psychiatric specialist health services



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Whatever affects the ill person's relatives affects the ill human being, and the reverse is also true.

Joyce Travelbee

Abstract

Aim: The overall aim of this thesis was to investigate and describe everyday life among relatives of inpatients with severe depression and their encounter with the psychiatric specialist health services (PSHS).

Methods: A descriptive design with qualitative and quantitative approach was used. Data were collected from 68 relatives by a questionnaire consisting of background information, questions from the Quality from the Patient's Perspective modified to relatives and psychiatric settings and the Burden Assessment Scale, General Health Questionnaire and Sense of Coherence. The data were analysed with statistics (I, III). Individual interviews with 24 relatives were carried out with two main questions: "Please tell me about your experience as a relative of a person with depression" and "Please tell me about your experiences when encountering the PSHS as a relative of a person hospitalized with depression." The data were analysed with phenomenography (II, IV).

Main findings: The everyday life of relatives to persons suffering from severe depression was strained. They reported objective and subjective burden, their health was affected to various degrees and more than half of the relatives were worried about their future (I). The relatives experienced that they were, "Living on the other person's terms". They described ambivalent relationships, had to adjust their daily life and tried to manage the situation by balancing their own and the next-of kin's needs, in addition to other family members' needs (II). Before they encountered the PSHS, a long period of worries and struggles for help was described. The relatives wanted to be a resource and a participant and to be confident about health care (IV). The need for support from the PSHS was greater than what they received. Relatives who reported less received information had higher burden scores than the others (III).

Conclusions: Everyday life of relatives of persons suffering from severe depression is demanding with health problems, burden and worries. To be acknowledged as a resource in the treatment and care is important. Being present at the wards 24 hours a day, the mental health nurses are in a unique position to support the relatives. A person- and family-centred perspective may contribute to strengthening the reciprocal relationship between the relatives and the patients.

Sammendrag

Hensikt: Avhandlingens overordnede hensikt var å undersøke og beskrive dagliglivet til pårørende til pasienter innlagt med alvorlig depresjon, og deres møte med psykiatrisk spesialisthelsetjeneste.

Metode: Et deskriptivt design med kvalitativ og kvantitativ metode ble brukt. Data ble innhentet ved hjelp av et spørreskjema med bakgrunnsinformasjon, spørsmål fra Kvalitet Ur Patientens Perspektiv tilpasset pårørende i en psykiatrisk setting, Burden Assessment Scale, General Health Questionnaire og Sense of Coherence. Data ble analysert med hjelp av statistikk (I,III). Individuelle intervjuer av 24 pårørende ble gjennomført med to hovedspørsmål: «Kan du fortelle meg om din erfaring ved å være pårørende til en person som lider av depresjon?» og «Kan du fortelle meg om dine erfaringer i møte med psykiatrisk spesialisthelsetjeneste som pårørende til en person innlagt på grunn av en depresjon.» Data ble analysert ved hjelp av fenomenografi (II, IV).

Hovedfunn: Dagliglivet til pårørende av personer som lider av alvorlig depresjon er utfordrende. De rapporterte objektiv og subjektiv merbelastning, at helsen var påvirket, og halvparten av de pårørende var bekymret for framtiden (I). Pårørende opplevde at de «Levde på den andres premisser». De beskrev ambivalente relasjoner, de måtte tilpasse dagliglivet, og forsøkte å håndtere sin situasjon i balansegang mellom egne, personen som lider av depresjon og andre familiemedlemmers behov (II). Pårørende beskrev en lang periode med bekymringer før de fikk hjelp fra den psykiatriske spesialisthelsetjenesten. Tillit til helsepersonell var viktig og de ønsket å være en ressurs i behandling og pleie. (IV). Behovet for støtte fra PSHS ble ikke alltid tilfredsstilt. Pårørende som rapporterte at de hadde fått mindre informasjon enn de hadde behov for scoret høyere på merbelastning enn de andre (III).

Konklusjon: Dagliglivet til pårørende av personer som lider av alvorlig depresjon er krevende med helseproblemer, merbelastning og bekymringer. Å bli anerkjent som en ressurs i behandling og pleie er viktig. Sykepleietjenestens døgntilstedeværelse på sengepostene gjør at sykepleiere er i en unik posisjon til å gi hjelp og støtte til de pårørende. Et mer person og familie sentrert perspektiv vil bidra til å styrke de gjensidige relasjonene mellom de pårørende og den som lider av depresjon.

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Study I-IV

Original Papers

The thesis is based on the four following studies referred to by Roman numerals.

- I. Skundberg-Kletthagen, H., Hedelin, B., Wangensteen, S. & Hall-Lord, ML. (2015). Burden, Health and Sense of Coherence among Relatives of Depressed Inpatients. *Open Journal of Nursing*, 5, 163-172.
- II. Skundberg-Kletthagen, H., Wangensteen, S., Hall-Lord, ML. & Hedelin, B. (2014). Relatives of patients with depression: experiences of everyday life. *Scandinavian Journal of Caring Sciences*, 28, 564-571.
- III. Skundberg-Kletthagen, H., Hall-Lord, ML., Hedelin, B. & Wangensteen, S. Relatives of persons suffering from severe depression. Experiences of burden and encounters with the psychiatric specialist health services. *Manuscript*.
- IV. Skundberg-Kletthagen, H., Wangensteen, S., Hall-Lord, ML. & Hedelin, B. (2014). Experiences of the psychiatric specialist health services – The perspective of relatives of inpatients with severe depression. *Journal of Nursing Education and Practice*, 5, 117-123.

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Introduction

As a result of deinstitutionalization, it has been reported that relatives, rather than the mental health service, have become the major provider of care to persons with mental illness in the Western hemisphere (Novella, 2010). The number of beds in Norway for psychiatric specialist health services has decreased and the average hospital stay has decreased, while outpatient consultations have increased (Statistisk sentralbyrå, 2012). This increases the possibility that the person will be in need of care before and after hospitalization, thus imposing a responsibility on relatives that may lead to an experience of burden and health problems among relatives (Møller et al., 2009).

As a mental health nurse employed in the psychiatric specialist health service in acute wards, as well as in outpatient clinics for many years, I have met relatives in different trajectories of their next-of-kin's mental illness. During these years, an increasing focus on the relatives' situation has been required from the health authorities (Helsedirektoratet, 2008, Sosial- og helsedirektoratet, 2006). The legislation has stated the relatives' rights to be included and to receive information as to whether the patient agrees (Helse- og omsorgsdepartementet, 2001). Nonetheless, my impression is that the relatives are not included as a matter of course, and when the patients are discharged from the hospital, relatives are left with a great responsibility. In Norway, patients with affective disorders constituted the largest number among those treated in mental health services within hospitals, community specialist health centres and outpatient clinics in 2011 (Pedersen et al., 2012). Since these patients are frequently represented in the specialist health service, I became interested in how their relatives perceive the everyday life, and I wanted to contribute to the knowledge about their situation.

Background

Being the relative of a person suffering from severe mental illness

During the past few decades, there has been an increasing body of studies concerning the consequences for relatives of persons with severe mental illness such as schizophrenia, major depression and bipolar disorder. These studies are most often concerned with the burden of the family, caregiver strain, distress, coping and received social support (Beentjes et al., 2012, Loukissa, 1995, Maurin & Boyd, 1990, Saunders, 2003), while only a few studies have been concerned with the positive aspects of caregiving (Hunt, 2003, Weimand et al., 2013).

The severity of the symptoms and the duration of the mental illness are found to be what places the greatest burden on relatives (Karp & Tanarugsachock, 2000, Rose et al., 2006, Schulze & Rössler, 2005), and an association between caregiver burden and adversely affected health has been reported (Schulze & Rössler, 2005, Shah et al., 2010). Moreover, high levels of mental distress have been associated with low sense of coherence (Suresky et al., 2008).

Support in terms of being seen, confirmed and invited to cooperate with the mental health service is found to be of importance for how the relatives perceive the situation when their next-of-kin is suffering from a severe mental illness (Ewertzon et al., 2011, Johansson et al., 2013). Even so, a gap between relatives' expectations and what they actually receive from the mental health service has been reported (Weimand et al., 2011).

Even though the caregiver burden is mostly attached to the kinship to the patient and the hours spent together per week (Hadry et al., 2011, Östman et al., 2005), there might be important differences concerning burden due to the patient's diagnosis. Van Wijngaarden et al. (2009) compared the consequences for the caregivers of persons suffering from schizophrenia to the caregivers of persons suffering from depression. In the case of depression, the caregivers often experience a more strained atmosphere, such as a lack of energy and lack of emotion, in addition to less social support and less coping abilities. The caregivers of persons suffering from schizophrenia were most often elderly mothers, whereas it was mostly spouses caring for their partners suffering from depression. It is reported that mental health was more affected among the relatives of persons with major depression than the relatives of persons with bipolar disorder (Zendjidian et al., 2012). Hence, to be the

relative of a person with depression is reported as contributing to a strained situation.

Being the relative of a person suffering from depression

The impact of depression as a health problem reaches beyond the person suffering from depression, and many relatives are affected. In order to be able to understand the influence on relatives' everyday life, it is important to understand the characteristics of depression. In this thesis everyday life is understood as the life that is lived, and includes all daily activities, tasks and responsibilities that people have (c.f Gullestad, 1989).

Persons suffering from depression

The World Health Organization (WHO) ranks depression as one of the ten global diseases entailing the greatest loss of life quality and years of life, and will be the second leading cause of the burden of disease in 2020 (Murray & Lopez, 1996, Üstün et al., 2004). In Norway, one out of five persons is estimated to be affected by depression during their lifetime (Mykletun et al., 2009).

Depression is divided into three main groups: mild, moderate and severe, which is dependent on the number and severity of the symptoms and the degree of functional disability (World Health Organization, 2010). The general symptoms of depression are lowering of mood, reduced energy and capacity for activity and enjoyment. Things that have previously been of importance to the person are no longer important. Self-esteem and self-confidence are reduced, and there are many struggles with ideas of guilt and worthlessness. Additionally, pessimistic thoughts and thoughts of death and suicide are common. The depression impairs cognitive functions and the person's ability to concentrate is reduced, while many have difficulties with reading and remembering, as well as difficulties in simply having a conversation. Most persons experience increased fatigue, insomnia and waking up several hours before their usual time. Psychomotor retardation or agitation occurs, and many have a loss in libido, appetite and weight, whereas others gain weight because of an increased appetite (Hummelvoll, 2012, Malt, 2012, World Health Organization, 2010). There may be some gender differences, with men reporting more symptoms of anger, aggression, irritability, substance abuse and risk-taking behaviour than women (Martin et al., 2013).

Concerning severe depression, the aforementioned symptoms are extensive and it is unlikely that the person will be able to continue with work, social or domestic activities, and hospitalization is also often necessary (Malt, 2012). Furthermore, a significantly higher risk of cardiovascular death and stroke mortality is reported to be associated with the severity of the symptoms (Gump et al., 2005, Lépine & Briley, 2011). Depression is also reported to be the primary risk factor for suicide (Miret et al., 2013). A higher severity in illness has been associated with increased risks of relapse, and the number of patients with recurrent severe depression is found to be high in psychiatric specialist health services (Hardeveld et al., 2010).

Consequences for relatives' everyday life

When considering the aforementioned symptoms of depression, including a considerable risk for relapse, imposes burden and health problems also for the relatives.

Burden may be defined as a multidimensional negative consequence of caregiving (Rose et al., 2006), and it is common to distinguish between objective and subjective burden (Hoening & Hamilton, 1966). The objective burden is understood as the observable consequences of the person's illness, whereas the subjective burden is the psychological consequences for the relatives (Hoening & Hamilton, 1966, Maurin & Boyd, 1990, Reinhard et al., 1994, Schene, 1990). Despite this, caregiving may also be rewarding in that the relatives find it meaningful to ensure that their next-of-kin's needs are met in the best possible way (Heru & Ryan, 2004).

Health is understood as a process constantly in motion between the two poles: "total ill health" to "total health", and not as static or a constant condition (c.f. Antonovsky, 1987). Antonovsky describes the salutogenic perspective which search for causes of health rather than causes of disease. From this perspective he developed the sense of coherence (SOC) comprising how people perceive everyday life as comprehensible, manageable and meaningful. It is considered that a strong SOC is a coping resource to protect health and that it is of importance when handling difficult life situations.

The relatives of persons with depression represent different relationships, ages and phases of life, which may colour their experiences. These experiences contain different phases of their next-of-kin's depression from onset to recovery and periods with recurrence. There may be a long period of time from the onset of the depression until the person receives professional help.

Muscroft and Bowl (2000) found that the person with depression was not taken to a general practitioner (GP) before there were physical consequences of the illness, such as sleep disturbance or changes in appetite. Relatives' lack of knowledge is found to be one barrier for the early detection of their next-of-kin's depression (Hansen et al., 2011), while another reason for delay may be the lack of acceptance of the illness (Radfar et al., 2013). Some relatives recognize the depression in hindsight because the onset of depression is a gradual process that occurs over time (Highet et al., 2005), with the caregiver role found to entail added burden and responsibilities that affect many areas of the caregiver's lives (Stjernswärd & Östman, 2008). The depression is described as an "intruder" into the family, making everyday life unpredictable (Ahlström et al., 2009) and being a continuous stressor for the entire family, thereby reducing the relatives' level of subjective well-being (Radfar et al., 2013). Some family members experience the risk of suicide as a constant threat, and that they always therefore have to be in a state of readiness to monitor changes in the next-of-kin's behaviour (Nosek, 2008).

When comparing the caregivers of outpatients to inpatients diagnosed with depression, the caregivers of inpatients reported more extreme tiredness, sleeplessness and a lack of appetite, whereas some felt so distressed that they had to visit a mental health practitioner for their own mental well-being (Van Wijngaarden et al., 2004).

Depression among parents has been found to be associated with poorer health in their children, who may be at considerable risk for developing their own mental afflictions, e.g. depression (Beardslee et al., 1998, Garber et al., 2011). Furthermore, anxiety and concern for the depressed parent may affect children, even after they have become adults and moved away from home (Ahlström, 2009).

Rehman et al. (2008) found that depression influenced the relationship between spouses, and that communication was characterized by accusations and verbal aggression, in addition to withdrawal and a lower frequency of positive communications. Idstad et al. (2010) reported higher levels of symptoms of depression and anxiety, as well as a lower degree of subjective well-being, among the spouses of persons suffering from anxiety and depression compared to the spouses of persons not suffering from mental illnesses. This is supported by Wang and Zhao (2012), who found that spouses experienced a reduced quality of life and a high degree of emotional burden.

It has been reported that relatives experienced not being taken seriously and included by healthcare professionals (Stjernswärd & Östman, 2008), and that they were left with all the responsibility for the depressed person's care (Hansen & Buus, 2013). This type of experience with the healthcare services are reported to compound the difficulties faced by the relatives (Highet et al., 2004). Hence, the family members need support for their own sake (Radfar et al., 2013). The importance of gaining more knowledge about the impact on health and the perceived burden in relatives of persons suffering from depression was reported ten years ago (Leff, 2005) and is still being highlighted (Gandhi & Thennarasu, 2012, Ildstad et al., 2010).

Despite a common focus on relatives of persons suffering from depression in the aforementioned studies, there are disparities concerning design, recruitment and diagnosis that need to be considered. In qualitative studies relatives were recruited via outpatient clinics (Ahlström, 2009), or recruited after the patients were discharged (Hansen & Buus, 2013, Nosek, 2008). The diagnosis of depression was not defined (Radfar et al., 2013) in addition, recruitment via support groups has been used (Highet et al., 2004, Muscroft & Bowl, 2000, Stjernswärd & Östman, 2008) that also provides uncertainty concerning the diagnosis, since depression may not be assessed and stated by a specialist. In quantitative studies, the diagnosis of depression was not defined (Hadry et al., 2011, Ildstad et al., 2010), or there were not described if the relatives were recruited via inpatient or outpatient clinics (Zendjidjian et al., 2012), and characterized by small samples (Gandhi & Thennarasu, 2012, Heru et al., 2004, Van Wijngaarden et al., 2004).

Mental health nursing

Mental health nursing is grounded in nursing philosophy, and is influenced by historical context, legislation and ethical guidelines.

Joyce Travelbee (1971) was a psychiatric nurse and nursing theorist who built her theory on humanistic existentialism. Travelbee was concerned with the emotional aspect of nursing, and the relationship between the nurse and the individual. She argued that the nursing goals and purpose can only be achieved through the establishment of a truly human-to-human relationship, in which both the nurse and the patient have to overcome the stage where they see each other solely as roles. Travelbee defined nursing as “an interpersonal process whereby the professional nurse practitioner assists an individual, family, or community to prevent or cope with the experience of illness and

suffering and, if necessary, to find meaning in these experiences” (p. 7). Travelbee’s definition of the interpersonal process corresponds to the three phenomena in the Client-Nurse domain described more than 40 years later by Kim (2010). The three phenomena that occur in the encounter between the client and the nurse are contact, communication and interaction. The client can be understood as a person who meets a nurse in a context in which nursing care is provided. The client may also be the relative of a person suffering from a mental illness.

Mental health nursing is grounded on the core values of humanism, and emphasizes the importance of collaboration and cooperation in the encounter with the person in need of mental health nursing, and that the illness must be understood holistically in the context in which it occurs (Hummelvoll & Granerud, 2010). Due to deinstitutionalization, the relatives have become an important provider of care to persons with serious and persistent mental illness (Hummelvoll, 2012, Novella, 2010), and there is an agreement that relatives are not only important resources, but also in need of support for themselves (Helsedirektoratet, 2008, Nordby et al., 2010).

The nurses’ responsibility for the relatives is also stated in the patient’s rights act, which imposes an obligation on healthcare professionals to inform the relatives about the patient’s health status and the care provided after agreement from the patient (Helse- og omsorgsdepartementet, 2001). These responsibilities are also stated in the Ethical Guidelines for Nurses (International Council of Nurses, 2012).

Rationale

The relatives of persons suffering from depression are experiencing a great responsibility and their everyday life is affected. When the relatives encounter the psychiatric specialist health services, they perceive not being included and taken seriously. The number of persons with severe depression in psychiatric specialist health services is found to be high, however few studies include relatives recruited via hospital wards. There is reason to believe that persons hospitalized suffering from a severe depression affect their relatives' everyday life. Moreover in previous studies the main focus has not been their experiences with the mental health care. There are also uncertainties concerning the depression diagnosis, the sample size and the recruitment procedure. It is therefore of great importance to acquire more knowledge about how relatives of inpatients with severe depression experience their everyday life, health and burden, in addition to experiences of encountering the psychiatric specialist health services.

Aims

The overall aim of this thesis was to investigate and describe everyday life among relatives of inpatients with severe depression and their encounter with the psychiatric specialist health services (PSHS).

The specific aims were:

- to describe burden, health and sense of coherence with regard to background variables among relatives of inpatients with severe depression. Furthermore, to investigate relatives' burden in relation to their health and sense of coherence (I).
- to describe experiences of everyday life as a relative of a person diagnosed with depression (II).
- to investigate relatives of inpatients with severe depression – their perceptions of encountering psychiatric specialist health services and burden (III).
- to describe experiences of encountering the psychiatric specialist health services as a relative of an inpatient suffering from severe depression (IV).

Methods

Study design

Nursing science is developed from various research traditions, and requires different perspectives for understanding (Kim, 2004). The world is assumed to be subjective and complex, which requires different inquiries. Quantitative methods are for the purpose of discovery, explanation and validation, while qualitative methods are for the purpose of exploration and understanding (Kim, 1993, Polit & Beck, 2012). Hence both quantitative and qualitative approaches were used in this thesis. The studies with quantitative approach aimed to investigate relatives' burden, health and their encountering with the psychiatric specialist health services (PSHS), whereas the studies with qualitative approach aimed to acquire a deeper understanding of the relatives' experiences of everyday life and their encountering with the PSHS in relation to their next-of-kin suffering from depression. An overview of the studies in the thesis is presented in Table 1.

Table 1. Overview of the four studies: design, participants, data collection and data analysis.

Study	Design	Participants	Data Collection	Data Analysis
I,III	Descriptive quantitativ Cross-sectional	68 relatives	Questionnaire	Descriptive and inferential statistics
II,IV	Descriptive qualitative Phenomenographic	24 relatives	Qualitative individual interviews	Phenomenography

Cross-sectional studies (I, III)

Cross sectional studies with a descriptive design are often used in population studies and are suitable when data is collected at one point in time, with the purpose to describe the relationship among phenomena or the status of a phenomena (Polit & Beck, 2012). In this thesis, data was collected once for each participant.

Phenomenographic studies (II, IV)

Phenomenography is a qualitative empirical research approach. The most essential feature of phenomenography is descriptions of qualitatively various ways that a phenomenon can be experienced and understood in the world around us (Marton & Booth, 1997, Marton, 1981). Phenomenography is grounded in a non-dualistic ontology, in which the idea is that the human world is experienced and the only world we can communicate about.

The researcher is interested in how a phenomenon is conceived, which is known as the “second-order perspective,” distinguished from what a phenomenon is that we can observe from outside, known as the “first-order perspective.” Epistemologically, it is assumed that there are a limited number of qualitatively different conceptions of a phenomenon that can be described. The conceptions are conceived in relation to both context and time, and may therefore vary not only between people, but also for the same person over time (Barnard et al., 1999). In phenomenography, the terms understand, experience, perceive, conceive, conceptualize and apprehend are used (Marton & Booth, 1997). In this thesis the phenomena are relatives’ everyday life and their encountering with the PSHS.

Study context

In Norway, the regional health authorities are responsible for the provision of psychiatric specialist health care. This is provided in psychiatric hospitals and Distrikts Psykiatrisk Senters (DPS) (Norwegian Ministry of Health and Care Services, 2012). The DPS are organized into outpatient clinics, day care, and 24 hour wards. In this thesis, these DPS are named community specialist health centres. The participants consisted of relatives of inpatients with severe depression hospitalized in psychiatric specialist health services (PSHS) in one hospital trust in Norway, in total 13 wards. Six community specialist health centres (24-hour wards) and three hospitals wards agreed to participate in the study. Before a referral to PSHS can be done, a GP located in the municipality assesses the severity of the patient’s depression.

Recruitment procedure

One health professional (mental health nurse, nurse, psychologist, social worker) from each of the nine wards was responsible for the recruitment. This person was responsible for giving information about the studies to the patients and the relatives. The recruitment took place in two stages.

Firstly, inpatients were asked consecutively, both verbally and in writing, for permission to ask their closest relative to participate in the study. Inclusion criteria for the patients were to be admitted with one of the following diagnoses: Depressive episode (F 32.0-32.9) or Recurrent depressive disorder (F.33.0-33.9) following the ICD-10 criteria (World Health Organization, 2010), being aged 18 years and older and assessed as having the capacity to give informed consent. Exclusion criteria for the patients were: bipolar disorders, personality and behavioral disorders, substance abuse and serious somatic illnesses, as well as psychotic disorders, with the exception of psychotic depression.

Secondly, relatives were asked both verbally and in writing about participation in the study. Inclusion criteria for the relatives were: to be the person the patient regarded as his/her closest relative, being aged 18 years and older, and being able to read and understand Norwegian.

The recruitment took place during a period of 12 months from 2010 to 2011 (II, IV), and during a period of 24 months from 2010 to 2012 (I, III).

Sample

The sampling was consecutive during a period of 24 months. A total of 223 patients with the included depression diagnoses were admitted, and out of these 125 patients were asked for permission to ask one of their relatives to participate in the study. Ninety-one patients gave their written consent to ask one of their closest relatives to participate and 71 relatives agreed, see Figure 1.

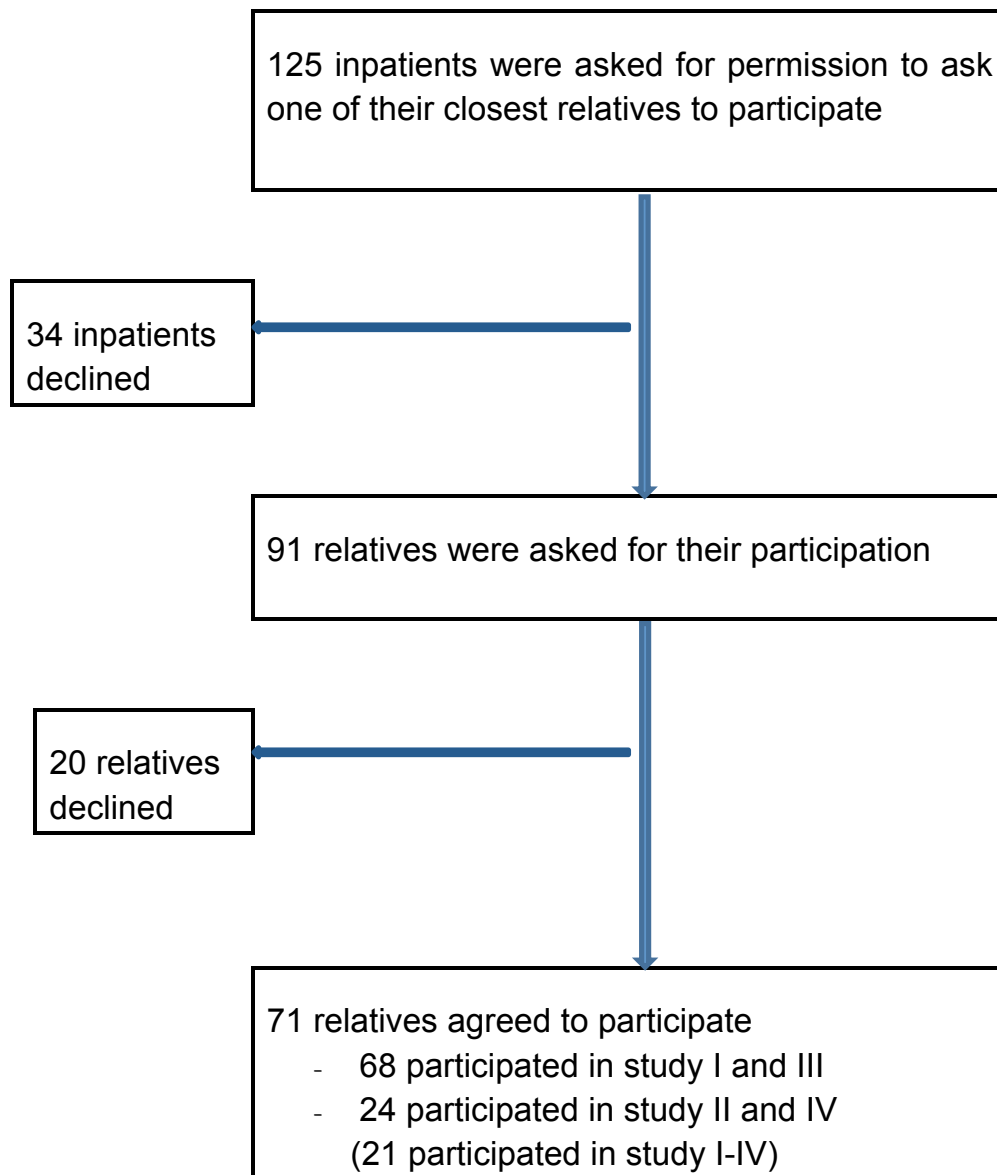


Figure 1. Overview of recruitment (I-IV)

Participants

The response rate was 75% in study I and III. Sixty-eight relatives of inpatients with severe depression were included, and out of these approximately half (35) were recruited via hospital wards. There was a predominance of women. The age ranged between 19-81 years (Md=50), most of the relatives did not have children under the age of 18 and most were married or cohabitating. With regard to educational level, half the relatives represented upper secondary school. According to their relationship with the person suffering from depression, most were adult children. Less than half of the relatives lived together with the person suffering from depression (Table 2).

Table 2. The background of the participants (I-IV).

	Study I-III n (%)	Study II-IV n (%)
Total	68	24
Recruited via		
Hospital wards	35 (51)	9 (38)
Community specialist health centres	33 (49)	15 (62)
Sex		
Male	27 (40)	8 (33)
Female	40 (60)	16 (67)
Age		
18-39	11 (16)	6 (25)
40-59	43 (63)	16 (67)
60-81	14 (21)	2 (8)
Children under 18		
Yes	16 (24)	3 (13)
No	50 (76)	21 (87)
Marital status		
Married/cohabitant	54 (79)	19 (79)
Divorced/single	14 (21)	5 (21)
Education		
Compulsory comprehensive school	11 (16)	2 (8)
Upper secondary school	33 (50)	14 (58)
University	22 (34)	8 (33)
Relationship		
Spouse/cohabitant	25 (38)	6 (25)
Children	31 (47)	12 (50)
Other ¹	10 (15)	6 (25)
Living together with the depressed person		
Yes	27 (41)	8 (33)
No	39 (59)	16 (67)

Parent, sibling, friend ¹

Twenty-four relatives of inpatients with severe depression were included in study II and IV, and out of these 15 were recruited from the community specialist health centres. Most of the participants were females, between the ages of 40-59, did not have children under the age of 18 and were married or cohabitating. More than half of the relatives had an upper secondary school education. According to relationship with the person suffering from depression half represented adult children, and one third lived together with the next-of-kin suffering from depression (Table 2).

Data collection

Procedure

The health personnel responsible for the recruitment gave oral and written information about the studies and distributed the questionnaires. This person sent written consents from both patients and relatives to the researcher. The participants (I, III) returned completed questionnaires by post to the researcher. Each questionnaire was systematically pre-numbered to indicate from where the participant was recruited. One reminder was sent after approximately two weeks.

Concerning the interviews (II, IV), the researcher contacted each participant to agree on a time and place for the interview. The interviews were carried out according to the participants' wishes, in their homes, in the wards where the relatives were recruited via, or at the researcher's office. Fourteen out of the 24 relatives were interviewed while the next-of-kin was still hospitalized. Before the interview started the researcher repeated the aim of the study, and the participant had the opportunity to pose questions regarding the study. The interview was held in a relaxed atmosphere in a quiet and undisturbed place (c.f. Kvale & Brinkmann, 2009).

The questionnaire (I, III)

The questionnaire consisted of questions regarding the relative's health, burden, sense of coherence and their perceptions of encountering the PSHS. Moreover, there were questions concerning the relative's background (sex, age, children under the age of 18, marital status, education, relationship and living together with the depressed person). One question (III) concerned the number of contacts with the health-care services in connection with the person's depression during the past 12 months.

Two global questions (I) were used concerning perceived physical health and mental well-being: “How do you consider your physical health right now?” and “How do you consider your mental well-being right now?” each with a five-point response scale ranging from 1 (Very bad) to 5 (Very good).

To measure the relatives’ mental health (I), the General Health Questionnaire, GHQ-12, was used (Goldberg & Williams, 1991). On each of the 12 items, the person was asked whether he or she had experienced mental distress over the past two weeks (e.g. lost sleep over worry, been unable to face problems). For each question, four response options were provided: “Less than usual”, “As usual”, “More than usual” or “Much more than usual”. In this study, the 0-0-1-1 (Goldberg & Williams, 1991) was used for calculating the GHQ total score ranging between 0 (Most favourable) and 12 (Least favourable). Persons marking 4 or more are considered as having an experience of mental distress (Goldberg & Williams, 1991, Nerdrum et al., 2006).

To measure the relatives’ burden (I, III), the Burden Assessment Scale (BAS) was used (Reinhard et al., 1994). BAS consists of 19 items in five dimensions representing: Disrupted Activities (six items), Personal Distress (four items), Time Perspective (three items), Guilt (three items) and Basic Social Functioning (two items). The item concerning “Financial problems” is not included in any of the dimensions, but represent objective burden. The objective burden consists of the dimensions of: Disrupted Activities and Basic Social Functioning, whereas the other dimensions of Personal Distress, Time Perspective and Guilt constituted the subjective burden. The response options ranged from 1 (Not at all) to 4 (A lot), and each item had the alternative of Not applicable (NA). A sum score was calculated for the total burden, ranging from 19 (No burden) to 76 (A lot of burden).

To measure relatives’ sense of coherence (I), Antonovsky’s Sense of Coherence scale (SOC) was used (Antonovsky, 1987). In this study, the short version with 13 items was chosen (Antonovsky, 1993). The scale is based on the salutogenic perspective and measures to what extent the relatives found life manageable, comprehensible and meaningful. A strong SOC is considered as a coping resource to protect health and is of importance for managing difficult life situations. The items have a seven-point response scale with the anchors defined, and a sum score was calculated for the total SOC score, ranging from 13 (Weaker SOC) to 91 (Stronger SOC).

To measure relatives’ perceptions of encountering the PSHS (III) a modified version of the questionnaire, Quality from the Patient’s Perspective (QPP) was

used. QPP consists of 24 items in four dimensions: the medical-technical competence of caregivers (four items), the identity-oriented approach (12 items), the physical-technical conditions of the care organization (three items) and the sociocultural atmosphere of the care organization (five items) (Wilde Larsson & Larsson, 2002). In this thesis, two of the dimensions: Identity oriented approach and Socio-cultural atmosphere were used. Ten items were used from the dimension Identity-oriented approach concerning information, empathic skills of the health personnel when meeting the relative as a unique person, as well as their ability to show interest and commitment to the relatives. In addition, two items were included from the dimension Socio-cultural atmosphere, concerning if the relatives could speak with the health personnel in a private room. The 12 items were modified to the context of current interest, i.e. relatives in a psychiatric setting. Each of the items was to be answered in two ways: perceived reality (PR) and subjective importance (SI). A four-point response scale was used, for PR ranging from 1 (Do not agree at all) to 4 (Fully agree) and for SI ranging from 1 (Of no importance) to 4 (Of the very highest importance). Each item also had the alternative, "Not Applicable" (NA).

Translation of BAS

The BAS scale (Reinhard et al., 1994) was translated from English to Norwegian with permission from Reinhard. The translation process was inspired by Yu et al.'s (2004) description of back translation, and the following steps were used:

1. The instrument was translated from English to Norwegian by a bilingual nurse lecturer whose native language was Norwegian.
2. The translation was reviewed by an expert group of three mental health nurses. Minor suggestions with regard to some linguistic changes were also discussed and approved by the research team (HSK, BH, MLHL).
3. The Norwegian version of BAS was translated back into English blinded to the original version by a bilingual person whose native language was English.
4. Possible differences between the translated and the original version were searched for by the research team (HSK, BH, MLHL), and only minor differences were found.

Furthermore the Norwegian version of the instrument was assessed for face- and content validity (Polit & Beck, 2012) by ten health professionals and no revisions were suggested.

Interviews (II, IV)

A phenomenographic interview has few pre-defined questions, and aims at being a dialog (Marton & Booth, 1997). The relatives were encouraged to speak freely about their experience as a relative of a person diagnosed with depression, and two main questions guided by the aims were posed in each interview: "Please tell me about your experience as a relative (specified relationship) of a person with depression" (II) and "Please tell me about your experiences when encountering the psychiatric specialist health services as the relative of a person hospitalized with depression" (IV). The aim was to unfold *what* the relative meant with the phenomenon and *how* they described it. Follow-up questions such as "what do you mean", "how did this affect you" and "how did you manage" were asked based on the relative's answers and to probe more deeply into the themes and to ensure a correct understanding. The interviews were tape recorded and transcribed verbatim by the researcher. The length varied between 36 and 87 minutes, with an average duration of 53 minutes.

Data analysis

Statistical analysis (I, III)

For the statistical analysis, the IBM SPSS Statistics, version 20, was used. The statistical tests (Altman, 1991, Greene & D'Oliveira, 2005) are shown in Table 3. The significance level was set at $p < 0.05$, two tailed (I, III), and a stronger level of significance ($p < .0167$) was chosen when doing pair-wise comparisons (I) (c.f. Altman, 1991).

Participants with up to five "Not applicable" were included when calculating the BAS total score. Not applicable marks were treated as missing items and replaced by each participant's mean score, i.e. using the case means substitution technique (Fox-Wasylyshyn & El-Masri, 2005). One participant was excluded due to a high number of "Not applicable" marks, and in total, 67 participants were included when calculating the BAS total score (I, III).

According to the relatives total BAS score they were divided into three groups: Group A (≤ 37), Group B ($> 37 - \leq 47$) and Group C (> 47) (I).

A categorical variable based on the relatives' scores on perceived reality (PR) and subjective importance (SI) was created (III). Those who had higher scores on the SI than the PR on four or more of the 12 items constituted "Group 1", while the other relatives constituted "Group 2".

Table 3. The application of the statistical analyses (I, III).

Statistics	Application of statistical analyses
Frequency, percentage, mean, standard deviation, median and range	To describe the descriptive results (I-IV).
Mann-Whitney <i>U</i> -test	To compare for differences between two groups (sex, marital status, having children under the age of 18 and living together with the person suffering from depression) in relation to BAS ¹ , GHQ ² and SOC ³ (I). To compare for differences between relatives recruited via hospital wards and community specialist health centres with regard to PR and for the number of contacts with the health-care services in relation to the person's depression over the past 12 months. To compare the total mean BAS score between "Group 1" and "Group 2" (III).
Kruskal-Wallis test	To compare for differences between three groups (age groups, level of education and the relative's relationship with the person suffering from depression) with regard to BAS, GHQ and SOC. The three groups (A, B, C) were compared with regard to GHQ, SOC, physical health and mental well-being (I).
Wilcoxon's signed rank test	To compare for differences between PR and SI between relatives recruited via hospital wards and community specialist health centres, respectively (III).
Cronbach's alpha	To test for the internal consistancy of the instruments (I, III).

¹Burden Assessment Scale (BAS). ²General Health Questionnaire (GHQ).³Sense of Coherence scale (SOC).

Phenomenographic analysis (II, IV)

A phenomenographic analysis, in which the main purpose is to identify qualitatively different ways to perceive a phenomenon (Marton & Booth, 1997), was performed. In this thesis, the phenomena were experiences of everyday life (II) and experiences of encountering the PSHS (IV) when being the relative of an inpatient suffering from a severe depression.

The data was analysed as a “pool of meaning” with all the transcripts together, insofar as the analysis moved from an individual to a collective awareness (Marton & Booth, 1997), and was performed in seven steps in accordance with Dahlgren and Fallsberg (1991):

Familiarization - Each interview was listened to by the researcher and the transcripts were read carefully through several times by the research group to acquire an overall impression of the material.

Condensation - Significant statements that correspond with the aims of the studies (II, IV) were searched for. These statements were condensed and inserted into tables, with a clear identification to the respondent from whom the statement originated.

Comparison - The condensed statements were compared on the basis of similarities and differences. From this step study II and study IV was analysed separately.

Grouping - Condensed statements were grouped into conceptions based on similarities and differences, and compared in order to ensure that each group had a unique character and the same level of description.

Articulating - Each group of conceptions were compared to describe the essence of the similarities and variations, as well as looking for non-dominant ways of understanding the perceived variations of the phenomenon. A preliminary attempt was made to describe the overall impression of the similarities within each group, and the analysis moved back and forth between the preceding and actual step.

Labelling - As a result of discussions in the research group, the various categories were denoted by constructing descriptive categories that best represented the findings.

Contrasting - The descriptive categories and the concepts were compared with regard to similarities and differences to ensure that they did not overlap and represented the same level of description. One main category with three descriptive categories in study II, and three descriptive categories in study IV were identified.

The final categories were agreed up on after moving between the different steps of the analysis several times, and analytic closure was reached when no new conceptions emerged. The findings were presented in a “hierarchical outcome space” (II) and a “horizontal outcome space” (IV) (c.f. Uljens, 1989).

Ethical approval and considerations

The studies (I-IV) were approved by the Regional Committee for Medical and Health Research Ethics, Norway (South-East) ref. 2010/126 and the head administration of the hospital trust. All the studies were performed in accordance with the ethical guidelines for nursing research, which describe principles of autonomy, beneficence and of non-maleficence and justice (Northern Nurses' Federation, 2003).

The principle of autonomy

The inpatients and the relatives were informed both verbally and in writing following the guidelines from the Regional Committee for Medical Research Ethics for Southern/Eastern Norway (I-IV). Requirements from the ethical committee were to have written informed consent from the patient before relatives could be asked for participation. Furthermore, declining participation would not have any negative consequences for the patient's care and treatment. The principle of autonomy was secured through voluntariness, informed consent, and that the relatives could withdraw unconditionally at any time from participation in the study until the data was included in the analyses or publications.

The principle of beneficence and of non-maleficence

The research group considered the risk versus the benefits of the studies and assessed the advantages of this study to exceed the disadvantages. The relatives had the opportunity to describe their own experiences related to their situation. For some, the interview was the first time they had been asked about their experiences as a relative of a person suffering from depression, which was described as good and that they were grateful for the opportunity to share their experiences. The disadvantages might have been that the questions in the interview and the questionnaire may have aroused difficult feelings among the participants. Concerning the questionnaire, there were no negative remarks with regard to the questions. The relatives were informed that they could request to turn off the digital recorder during the interview, and that it was possible to take a break. On a few occasions, the recorder was turned off by the researcher because the person needed a break. They were given the opportunity to end the interview, though no one did so. After completing the interview, the researcher spent time talking to the relatives, and if the interview awakened any feelings it was assured that they had someone to address this to. Additionally, every participant had the phone number and e-mail address of the researcher if they had any questions, but none contacted the researcher after the interview.

With regard to confidentiality, information given by the participants was not accessible to others than the research group. In the interviews, names were sought to be avoided and only the researcher could identify the participants through a link between a number and the written information, which was kept in separate lockers that only the researcher had access to. No information was to be obtained about the patient's severity of symptoms or depression diagnosis according to requirements from the ethical committee.

The principle of justice

All wards in psychiatric health care that were treating persons with depression in one hospital trust were invited to participate in the study. Patients and relatives that fulfilled the inclusion criteria were asked to participate in the study. This group of relatives has been investigated to a lesser extent.

Main findings

The main findings are presented in two parts: firstly, the relatives' health and everyday life and secondly, their encounter with the psychiatric specialist health services.

Health and everyday life among relatives

The relatives had to adjust their everyday life in various ways with regard to their next-of-kin's depression. They experienced burden and that their health was affected.

Burden, health and sense of coherence (I)

The relatives reported their burden (BAS) with a mean score of 43.34 (SD = 11.16), a mean score on mental distress (GHQ) of 4.77 (SD = 4.18) and a sense of coherence (SOC) mean score of 63.91 (SD = 13.34). No statistical differences were found for these scores in relation to background variables.

The number of relatives who reported 'Some' or 'A lot' of objective and subjective burden at the item level are listed in Table 4. The most frequently items reported were: "Worry about future", "Upset by change in patient", "Less time for friends" and "Reduced leisure time", while the least frequently reported items were: "Guilty for causing illness", "Financial problems", "Friend frictions" and "Embarrassed by patient".

Table 4. Burden Assessment Scale. Frequencies of 'Some' and 'A lot' responses (n=67).

Objective burden "Some" and "A lot"	n	Subjective burden "Some" and "A lot"	n
Less time for friends	37	Worry about future	55
Reduced leisure time	36	Upset by change in patient	39
Upset household routine	33	Guilty in not helping enough	33
Difficulty concentrating	33	Stigma upsetting	27
Felt trapped	31	Family frictions	25
Changed personal plans	31	Resented demands	24
Neglected family's needs	30	Worry about making illness worse	22
Missed work/school	19	Embarrassed by patient	11
Friend frictions	9	Guilty for causing illness	7
Financial problems	8		

The relatives were divided into three groups based on their total BAS mean score. Group A constituted relatives with the lowest scores (≤ 37), group B relatives with the middle scores ($>37-\leq 47$) and group C relatives with the highest scores (>47) (Table 5). The three groups were compared for differences concerning mental distress (GHQ), sense of coherence (SOC), physical health and mental well-being, and there were significant differences between the groups. Further pair-wise comparisons revealed that relatives in group C reported significantly more mental distress ($p < 0.001$), weaker sense of coherence ($p = 0.001$), poorer physical health ($p = 0.002$) and poorer mental well-being ($p = 0.002$) than group A. The relatives in group C reported weaker sense of coherence than group B ($p = 0.005$).

Table 5. Three groups of burden (A, B, C) compared to GHQ, SOC, physical health and mental well-being responses.

	Group A BAS $\leq 37^1$ n=23	Group B BAS $>37-\leq 47^1$ n=22	Group C BAS $>47^1$ n=22	Kruskal- Wallis test	
	Mean (SD)	Mean (SD)	Mean (SD)	χ^2	p
GHQ ²	2.47 (3.21)	5.18 (4.05)	7.00 (4.04)	12.86	.002
SOC ³	68.69 (9.40)	66.45 (12.13)	55.31 (13.92)	13.31	.001
Physical health ⁴	4.04 (0.82)	3.77 (0.75)	3.27 (0.82)	11.13	.004
Mental well-being ⁴	4.13 (0.69)	3.59 (0.85)	3.27 (0.98)	10.02	.007

¹Burden Assessment scale (BAS). Sum scores ranged from 19 (no burden) to 76 (a lot of burden).

²General Health Questionnaire (GHQ) Sum scores ranged from 0 (most favourable) to 12 (least favourable).

³Sense of Coherence Scale (SOC). Sum scores ranged from 13 (weaker) to 91 (stronger).

⁴Physical Health and Mental Well-being, with a response scale ranging from 1 (very bad) to 5 (very good).

Relatives' experiences of everyday life (II)

The relatives experienced that they were “Living on the other person’s terms”, which constituted the main category, thus indicating that their everyday life was highly affected. The relationships in the family were strained, and roles were changed. The challenge in adjusting their daily life and balancing between caring for the person with depression, oneself and other family members, was described. Knowledge about depression and its consequences

enabled them to manage the situation and to better understand how to support their next-of-kin (Table 6).

Table 6. *Experiences of everyday life as a relative to a person diagnosed with depression.*

Main category	Living on the other person's terms					
Descriptive categories	Ambivalent relationship		Adjusting daily life		Managing the situation	
<i>Conceptions</i>	<i>Diversity of feelings</i>	<i>Changing roles</i>	<i>Walking on eggshells</i>	<i>Taking responsibility</i>	<i>Focusing on one's own health</i>	<i>Insight in depression</i>

The descriptive category “Ambivalent relationship” illuminates relatives’ experiences of being close to a person suffering from depression, how they emotionally react to the situation and how they perceive their responsibility.

Diversity of feelings describes how the next-of-kin’s symptoms of depression appeared to have a great impact on how relatives experienced the situation. Their everyday life was coloured by the next-of-kin’s passivity, irritation, pessimism, sombreness and suicidal thoughts. Relatives described ambivalent feelings such as irritation or anger towards the next-of kin. For some of them, this was followed by feelings of bad conscience and guilt, whereas others meant that this was a natural reaction due to the difficult situation. In cases where the mother or father was depressed, the other parent described that the children to a various extent withdrew from contact or became angry at the parent suffering from depression.

Changing roles describes how the relationships in the family were affected. Adult children described that since an early age they had become conversation partners for the sick parent. The healthy parent also used the child as an equal conversation partner to air his/her frustrations and concerns about the sick spouse. Older siblings took care of younger siblings when a parent was depressed. Parents experienced that they were not invited to take part in their adult child’s treatment and some of them did not receive information about treatment and state of health, even though the adult child wanted to include them.

The descriptive category, “Adjusting daily life”, illuminates that to provide care for the person suffering from depression was a challenge because relatives also simultaneously had to attend to other responsibilities. Some of them

experienced that they always were in a state of readiness, which influenced their concentration, and they were worried about what the future might bring.

Walking on eggshells describes how relatives attempted to reduce conflicts by not revealing their own frustrations or negative attitudes toward the person suffering from depression. Some of the relatives tried to live their life as usual while other renounced social intercourse and leisure interests because they did not want to leave the next-of-kin alone. Suicidal threats were met with reactions as anger but also as fear at provoking such thoughts, and they tried to ensure that the person did not have the opportunity to commit suicide.

Taking responsibility describes how relatives sometimes were not working or were on partial sick leave, not because of their own illness but to look after the person suffering from depression. A loss of income when the next-of-kin was on sick leave increased the responsibility for the relatives with respect to the family economy, and had to be taken into account when making plans for the future. Additionally, some relatives described gratefulness to the next-of-kin because he/she previously had supported them, and they wanted to repay this solicitude.

The descriptive category, “Managing the situation”, illuminates that the relative’s own health and well-being was affected. Being a resource for- and support to the person suffering from depression was important, and knowledge about depression was a prerequisite to deal with the situation.

Focusing on one’s own health describes relatives’ experiences of both physical and mental afflictions, which for some of them were serious enough to necessitate sick leave. Some described anxiety, and that they slept poorly because of stress and worries. When the next-of-kin was depressed, relatives felt exhausted and unwell but they were also unwell during better periods since they had underlying worries for the future. To endure the situation, confirmation and acknowledgement from others for the care shown to the next-of-kin was experienced as positive and important.

Insight in depression describes the relatives’ need for counselling and follow-up in order to know how to best help the person suffering from depression. Not knowing how to understand and interpret the next-of-kin’s behaviour was perceived as frustrating. A suicide attempt was described as a breach of trust. Some of the relatives perceived suicide to be difficult to prevent, while others meant this to be the individual’s responsibility and choice. To have knowledge about depression was deemed as important in reducing the feelings of guilt.

Relatives were afraid that difficulties in comprehending the person and what the depression was caused by could lead to an inappropriate approach to their next-of-kin.

Relatives' encounter with the psychiatric specialist health services

Relatives recruited via hospital wards and via community specialist health services perceived their encounter with the PSHS differently. A large span of time between the onset of the depression and the next-of-kin's hospitalization imposed the relatives to struggle for help and they needed to be acknowledged by the health personnel.

Encountering PSHS and burden among relatives (III)

In total, relatives reported from 0 to 100 ($Md = 5$) contacts with the health-care services in relation to the person's depression over the past 12 months. These contacts included the municipal health services (e.g. GP, community specialist health centres and hospitals). The relatives recruited via hospital wards showed significantly more contacts ($M = 16.30$; $SD = 20.13$) compared to those recruited via community specialist health centres ($M = 5.36$; $SD = 9.20$) ($Z = 4.27$; $p < 0.001$).

When comparing perceived reality (PR) and subjective importance (SI) of the 64 relatives who responded, significant differences were found insofar as relatives recruited via community specialist health centres rated the PR lower than the SI on five items concerning information, if the doctor seemed to settle into how the relatives experienced the situation, and if the relatives got to talk to the doctors, nurses and staff in a private room (Table 7). No significant differences were found for relatives recruited via hospital wards.

Table 7. Comparisons between perceived reality (PR) and subjective importance (SI) of relatives recruited via community specialist health centres (n= 30).

Item		PR ¹	SI ²		Wilcoxon signed rank test <i>P</i>
		(n) ³	Mean (SD)	Mean (SD)	
	I got useful information about				
1	-how examinations and treatment should take place	(27)	2.07 (1.04)	2.85 (0.95)	.005
2	-results of examinations and treatment	(26)	1.92 (1.06)	2.85 (1.01)	.001
3	-which doctor was responsible for his/her medical care	(23)	2.30 (1.36)	2.78 (0.95)	.084
4	-which nurses were responsible for his/her nursing care	(26)	2.69 (1.05)	2.81 (0.89)	.552
	The doctors				
5	-treated me with respect	(19)	3.16 (1.07)	3.11 (0.88)	.739
6	-seemed to settle into how I experienced my situation	(20)	2.15 (1.14)	2.60 (0.99)	.013
7	-showed engagement ; “cared about me”	(20)	2.40 (1.23)	2.60 (0.94)	.248
	The nurses and staff				
8	-treated me with respect	(26)	3.42 (1.06)	3.12 (0.82)	.087
9	-seemed to settle into how I experienced my situation	(24)	3.08 (1.06)	2.92 (0.78)	.331
10	-showed engagement ; “cared about me”	(23)	2.96 (0.98)	2.91 (0.73)	.739
	I got talking to				
11	-the doctors in a private room	(11)	1.55 (1.04)	2.73 (1.10)	.027
12	-the nurses in a private room	(13)	2.15 (1.35)	2.85 (0.99)	.047

¹PR ranging from 1 (Do not agree at all) to 4 (Fully agree).

²SI ranging from 1 (Of no importance) to 4 (Of the very highest importance).

³Variation in number is due to the response alternative, “Not Applicable”.

Comparisons between relatives’ responses on PR between those recruited via hospital wards and those recruited via community specialist health centres showed significant differences in nine of the 12 items. Relatives recruited via community specialist health centres reported lower mean scores (Table 8).

Table 8. Comparisons of relatives' perception of perceived reality (PR) between those recruited via hospital wards and those recruited via community specialist health centres.

Item ¹	Hospital wards (n = 34)		Community specialist health centres (n = 30)		Mann-Whitney U-test	
	N ²	Mean (SD)	N ²	Mean (SD)	Z	p
I got useful information about						
1 -how examinations and treatment should take place	34	3.12 (1.08)	28	2.11 (1.03)	-3.55	<.001
2 -results of examinations and treatment	33	2.97 (0.01)	27	1.93 (1.03)	-3.52	<.001
3 -which doctor was responsible for his/her medical care	33	2.94 (1.17)	26	2.19 (1.32)	-2.18	.029
4 -which nurses were responsible for his/her nursing care	33	3.30 (1.01)	28	2.61 (1.06)	-2.68	.007
The doctors						
5 -treated me with respect	32	3.66 (0.70)	21	3.05 (1.12)	-2.24	.025
6 -seemed to settle into how I experienced my situation	31	3.03 (1.08)	22	2.14 (1.12)	-2.77	.006
7 -showed engagement ; "cared about me"	31	3.00 (1.18)	22	2.36 (1.21)	-1.96	.049
The nurses and staff						
8 -treated me with respect	34	3.47 (0.89)	28	3.32 (1.12)	-0.23	.818
9 -seemed to settle into how I experienced my situation	33	3.15 (1.09)	26	3.00 (1.09)	-0.77	.440
10 -showed engagement ; "cared about me"	33	3.09 (1.10)	25	2.88 (1.01)	-1.04	.296
I got talking to						
11 -the doctors in a private room	24	3.21 (1.14)	13	1.62 (1.04)	-3.43	.001
12 -the nurses in a private room	27	3.33(0.96)	16	2.25 (1.34)	-2.68	.007

¹PR ranging from (Do not agree at all) to 4 (Fully agree).

²Variation in number is due to the response alternative, "NotApplicable".

The relatives were divided in two groups. The relatives with higher scores on SI than PR on four or more of the items constituted “Group 1” (n = 16), whereas the rest of the relatives constituted “Group 2” (n = 47). “Group 1” reported lower scores on PR than on SI on items especially concerning information (items listed in Table 8).

The total mean burden score (BAS) for the relatives were 43.34 (SD = 11.16). A significant difference was found in that relatives in “Group 1” reported a higher burden (M = 49.37, SD = 9.37) than those in “Group 2” (M = 41.47, SD = 10.95) ($Z = -2.29, p = .022$).

Experiences of the encounter with the PSHS (IV)

The relatives’ experiences of their encounter with the PSHS are illuminated by three descriptive categories, “Being in need of help”, “Being a resource and a participant” and “Being confident with the health-care”, which embodies two conceptions each.

The descriptive category, “Being in need of help”, illuminates that relatives, the person suffering from depression and health professionals perceived the person’s need for help differently, and getting help when relatives deemed it necessary was experienced as difficult.

Severity of depression describes that the next-of-kin sometimes had difficulty assessing the severity of own depression, while the relative noticed that the depression was getting worse. It was also experienced difficult to agree with health professional concerning the severity.

Access to help implies relatives’ experience of getting expert help which was a relief. To get help was experienced as a struggle, indicating that the situation must be acute before help was given. The first contact with the PSHS was for some after the next-of-kin had been hospitalized due to a suicide attempt. Even though the next-of-kin suffered from a recurrent depression and was known in the system from previous admissions, getting help quickly was not a matter of course. Moreover, relatives described uncertainties about who or where to ask for help.

The descriptive category, “Being a resource and a participant”, illuminates that relatives had knowledge of and experiences with the person and the depression, and wanted to share this with the staff. In addition, they wished to be met with responsiveness and they needed to be informed.

To share experiences describes that the relatives wanted the staff to request how they viewed the situation on admission and to value their experiences in assessment of the patient’s condition and treatment. Some relatives had taken the initiative themselves to inform the staff about what they considered as crucial for both the patient’s treatment and the follow-up.

To be invited describes the importance of being acknowledged when relatives visited the ward. Even though they were encouraged to get in touch if necessary, some feared being regarded as tiresome. The duty of confidentiality was experienced as a hindrance to getting information and being involved in the treatment and care, even though some of them described that their next-of-kin wanted them to.

The descriptive category, “Being confident with the health-care”, deals with relatives’ ability to rely on the treatment and care given to their next-of-kin and the continuity in the different trajectories of care.

To rely on the staff describes the relatives questioning the staff’s competence and continuity when the care was experienced as inadequate and the expected improvement did not occur. Some even feared suicide during the hospital stay. When health personnel were accessible and observed changes in the next-of-kin, the relatives felt secure. It was described as vital to encounter a nurse who knew their next-of-kin and who followed throughout the course of treatment.

To rely on the service describes the importance of the health personell transferring information between wards and institutions. Information had to be passed on to the next health personnel so the relatives did not need to repeat this. Some relatives experienced that the period of hospitalization was too short, that the treatment had not been completed and that the patient was not well enough to be

discharged. Others found that the discharge was well planned, with a smooth transition between the various treating institutions.

Summary of findings

Everyday life of relatives to persons suffering from depression was highly affected. To a various degree, they experienced burden and deterioration of their own health. Everyday life needed to be planned in line with the severity of the next-of-kin's depression, and social intercourse and leisure interests were renounced. The interpersonal relationships were influenced by relatives' ambivalent feelings towards their next-of-kin. The relatives had to take much responsibility for their next-of-kin, simultaneously balancing between their own and other family member's needs. Knowledge about depression reduced the feelings of guilt and enabled them to better understand and support their next-of-kin. When the relatives encounter the PSHS, it may have been a long time of worries and struggles for help from the onset of the depression until the next-of-kin was finally hospitalized. To be invited to collaborate and to share their knowledge about the next-of-kin was of great importance, in addition to receiving information concerning the treatment and care. Relatives who received less information reported higher burden. The staff's ability to be observant concerning changes in the next-of-kin was important for the relatives to feel confident. Moreover, the continuity throughout the trajectories of care was perceived to be essential.

Methodological considerations

Regardless of the methodology chosen to gain empiri several considerations have to be reflected upon from designing to publishing (Polit & Beck, 2012). In this thesis, the methodological considerations are discussed with focus on validity and reliability in the quantitative studies and with regard to trustworthiness in the qualitative studies.

Validity and reliability (I, III)

The recruitment of the participants was consecutively done. To reduce the risk of sampling bias (Altman, 1991), there were strict inclusion criteria for inpatients and relatives. During the recruitment period, a total of 223 patients were admitted with depression diagnoses corresponding to the ICD-10 criteria (World Health Organization, 2010), out of which 125 were asked. The reason for not asking all inpatients may be that they did not have the capacity to give informed consent, having relatives under the age of 18 and/or not being able to speak and understand Norwegian. There are some uncertainties as to whether all the eligible inpatients who fulfilled the inclusion criteria were asked, which is a limitation of the studies. The data collection spanned a period of two years (2010 to 2012), which included two festive seasons and two summers, which may have led to some patients been overlooked or been forgotten to be asked due to more temporary staff.

The questionnaire consisted of many questions, which can be both time consuming and stressful and can affect how the participants responded to the questions (c.f Polit & Beck, 2012). At the end of the questionnaire, an opportunity was given to provide comments, but no one gave any feedback on the questions raised.

Regarding the instruments applied in this thesis, GHQ-12 (I) is a well-known questionnaire, and the validity has been assessed and found acceptable in a numerous of studies within different cultures (Baksheev et al., 2011, Goldberg et al., 1997, Puustinen et al., 2011). The GHQ-12 has also been used in a Norwegian context (Nerdrum & Geirdal, 2014). The Cronbach's alpha coefficient has been reported to

range from 0.81 to 0.86 (Nerdrum & Geirdal, 2014, Nerdrum et al., 2006, Romppel et al., 2013), and the alpha coefficient in this thesis was 0.92.

The Sense of Coherence scale (SOC), which consists of 13 items, was used in this thesis (I). The validity of this scale was found to be acceptable within different cultures (Antonovsky, 1993, Eriksson & Lindström, 2005). The SOC scale has also been used in a Norwegian context (Langeland & Wahl, 2009, Weimand et al., 2010). The Cronbach's alpha coefficient is reported to range from 0.70 to 0.92 (Eriksson & Lindström, 2005, Langeland & Wahl, 2009, Weimand et al., 2010), and the alpha coefficient in this thesis was 0.88.

Quality from the Patient's Perspective (QPP) originally consisted of 56 items (Wilde et al., 1994). The questionnaire was further developed into a short version of 24 items and tested for validity and reliability (Larsson et al., 1998, Wilde Larsson & Larsson, 2002) and was also used in a Norwegian context (Grøndahl et al., 2011). In this thesis, 12 items from the short version were modified to the context of current interest with relatives in a psychiatric setting (III). Several relatives recruited via community specialist health centres replied, "Not Applicable" on the items "I got talking to the doctors/the nurses in a private room." The high number of "Not Applicable" may be due to the items not being perceived as relevant in their situation.

The Burden Assessment Scale (BAS) (Reinhard et al., 1994) used in this thesis (I, III) contains 19 items that capture both objective and subjective consequences for relatives when providing care to a person suffering from a severe mental illness. The objective burden was measured by the dimensions of Disrupted Activities and Basic Social Functioning, whereas the other dimensions of Personal Distress, Time Perspective and Guilt constituted the subjective burden. The structure of the dimensions is found to differ within different samples (Guada et al., 2011, Ivarsson et al., 2004, Reinhard et al., 1994,). The face validity and content validity (Polit & Beck, 2012) of the Norwegian version of BAS was assessed by health professionals and was found to be acceptable. Regarding construct validity, the Norwegian version should be further tested psychometrically due to possible cultural

differences (Polit & Beck, 2012). The Cronbach's alpha coefficient is reported to range from 0.89 to 0.94 (Reinhard et al., 1994, Ivarsson et al., 2004, Guada et al., 2011), and the alpha coefficient in this thesis was 0.88.

There were no missing responses on the BAS scale, although "Not Applicable" marks were treated as missing items. Participants with up to five "Not applicable" marks were included in the analysis when calculating the BAS total score. "Not applicable" marks were replaced by each participant's mean score, i.e. the case means substitution technique (Fox-Wasylyshyn & El-Masri, 2005). Because there may be a risk for bias, "Not Applicable" responses were explored and were found to disperse over the entire scale. To replace missing data has been debated since this underestimate variance (Polit & Beck, 2012), but case mean substitution has been found to be an acceptable method for imputation at the item level (Fox-Wasylyshyn & El-Masri, 2005).

A low internal reliability is regarded as a threat to statistical conclusions (Polit & Beck, 2012). The internal consistency measured with Cronbach's alpha in this thesis exhibited suitable values and were comparable with previous studies. The acceptable values of alpha have been reported to range between 0.70 and 0.95, but a high alpha level may indicate that some items may be redundant (Tavakol & Dennick, 2011).

In this study (I, III), non-parametric tests were chosen to be appropriate due to level of measurements (ordinal) even though sum scores from the ordinal level may be considered as continuous, given a normal distribution of the data (Altman, 1991, Greene & D'Oliveira, 2005). The current data did not represent a normal distribution and the subgroups were relatively small. Moreover, non-parametric tests are based on scores that are ranked from the lowest- to the highest score (Greene & D'Oliveira, 2005).

The significance level was set at $p < 0.05$ (two-tailed), and was used for all tests in this thesis with one exception (I). When multiple comparisons were done, a Bonferroni correction was performed to

reduce the risk of falsely rejecting the null hypothesis, type I error. On the other hand this correction may increase the risk of type II error (rejecting the effect there really is) (Altman, 1991).

Lack of information about the patients' symptoms and the duration of the depression may be considered a limitation. However the depression was serious enough to require hospitalization. There were more women (60%) than men (40%) who responded, which has also been found in similar study contexts (Van Wijngaarden et al., 2004, Zendjidjian et al., 2012). Nearly half of the relatives in this thesis represented adult children, while in other similar studies spouses are more often represented (Heru et al., 2004, Van Wijngaarden et al., 2004). Furthermore the sample size was relatively small and was recruited from a single hospital trust in Norway; therefore, generalizability must be interpreted with caution.

Trustworthiness (II, IV)

To secure trustworthiness in this thesis, consideration was given to Lincoln and Guba's (1985, 1986) criteria: *credibility*, *dependability*, *confirmability*, *transferability* and *authenticity*.

A qualitative descriptive design with a phenomenographic approach was found to be suitable because the main purpose in studies II and IV was to describe relatives' different experiences and thereby variation of perceptions of the phenomenon under study (*authenticity*).

In a phenomenographic study, the sample selected must be appropriate and relevant to the phenomenon under investigation (Collier-Reed et al., 2009) and for this reason there were clear inclusion- and exclusion criteria (II, IV). Moreover, to ensure variation in the sample, a strategic selection is preferable (Marton & Booth, 1997). Even though a consecutive sampling was performed in this study, *credibility* was partly ensured through a variation due to background variables. However half of the sample was adult children, which may have reduced the *credibility*. The sample size (n=24) was

found to be sufficient due to requirements for phenomenographic studies (Larsson & Holmström, 2007).

All of the interviews were carried out in the similar way by the same researcher (*dependability, credibility*) in a place chosen by the relatives. Two main questions were asked in the interviews (*dependability*), and follow-up questions were posed in order to elucidate the relatives' various experiences according to the phenomenon (c.f. Marton & Booth, 1997). The goal was to achieve an *authentic* understanding of the relative's various experiences.

The interviews conducted, tape recorded and transcribed by the researcher. The research group read the transcripts and took part in the various steps of the analysis (*authenticity, credibility*). The analysis were discussed within the research group, and accounts of the analysis processes are described in order to establish an "audit trail" (Lincoln & Guba, 1985). Additionally, quotations were used to strengthen the *confirmability* of the findings (II, IV).

The researcher's profession as a mental health nurse with extensive experience from mental health nursing enabled her to obtain rich data from the participants, may have strengthened the *credibility*, even though it may represent a risk concerning the researcher's preconceived beliefs about the phenomenon. Ashworth and Lucas (1998) discussed the importance of epoché, in which the phenomenographic researcher has to set aside prior assumptions about the phenomenon being studied. Therefore, the researcher's own pre-understandings were discussed in the research group (*credibility*).

The relatives were recruited from a single hospital trust in Norway, which must be taken into account when considering the *transferability*. However this study may contribute to relevant knowledge to similar groups of relatives (c.f. Lincoln & Guba, 1985).

Discussion of the findings

The overall aim of this thesis was to investigate and describe everyday life among relatives of inpatients with severe depression and their encounter with the psychiatric specialist health services. The findings show that relatives were strained, and they described how the depression influenced not only their own but also other family members' everyday life. The discussion is therefore carried out with a family perspective inspired by Schene's (1990) framework of family burden (Figure 2). This framework was developed from a literature review and is based on a system-, role- and stress theory perspective. The families are considered within its social context of subsystems, such as the patient and other individual family members, social networks and the community/culture. Schene (1990) distinguishes between *objective burden* as the negative influence of the symptoms and behaviour of the patient within their social context, and the *subjective burden* that refers to the relatives' appraisal of the situation regarded as the psychological consequences for the relatives as a result of the objective ones. Although the framework was developed as early as in 1990, it is still relevant and referred to in more recent studies (Gupta et al., 2015, Koutra et al., 2015, Van Wijngaarden et al., 2004).

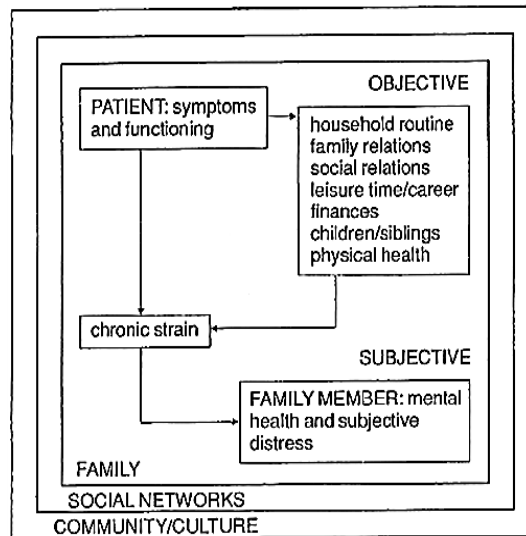


Figure 2. Burden: a theoretical framework. Reprinted with permission from Springer Science+Business Media ©: Schene, A. 1990. Objective and subjective dimensions of family burden. *Social Psychiatry and Psychiatric Epidemiology*, 25(6), 289-297, page 291.

Patient's symptoms and functioning

The *patient: symptoms and functioning* constitute the base for the framework. In this thesis the patient is referred to as the person/next-of-kin suffering from severe depression. Although no data about the patient's symptoms and functioning was collected, due to the requirement from the ethical committee, the depression was severe enough to require hospitalization. Nearly six out of ten relatives were upset by changes in the depressed person (I), which may be understood to be substantial.

Objective burden

The objective aspect of burden concerning the person's illness is of importance. The connection between the severity of the symptoms and the duration of the mental illness is found to be one predictor of burden (Schulze & Rössler, 2005, Van Wijngaarden et al., 2004). Some relatives described that they had experiences of the next-of-kin's depression for many years on recurrent occasions (II). Close to half of the relatives experienced that the *household routines* were changed, and that they felt trapped in their caregiver role (I). This

may be due to having responsibility for their job and caring for other family members, in addition to ensuring that the depressed person was looked after. The relatives had to take on a greater proportion of the shared tasks in everyday life (II). The large span of time between the onset of the depression and the next-of-kin was hospitalized had been a period with great responsibility for household routines for the relatives (IV). Their everyday life had to be adjusted due to the severity of the next-of-kin's depression (II). This corresponds with Stjernswärd and Östman (2008), who found that relatives experienced living in the shadow of depression.

The *family relations (Children/siblings)* were influenced in that nearly half of the relatives experienced that they had neglected their family's needs (I). Difficulties in taking care of the needs of their next-of-kin, other family members and their own needs were described (II). This balancing between different responsibilities is described as a struggle (Syrén, 2010). When the person suffering from depression no longer fulfilled what was expected of him/her, roles changed within the family. Marital relationships were affected in that the partner roles changed, and future life needed to be reconsidered (II). Grown-up children described their experiences as children in hindsight (II), for example how they took care of younger siblings (II). Furthermore, they took a more adult role towards both the ill- and the healthy parent by being supportive and being an interlocutor. Ahlström et al. (2011) reported that children were very sensitive to any changes in the parent's condition, and that they felt left alone even though they had a family.

Concerning the relatives *social relations*, more than half of them reported that they spent less time with friends, and had changed their own plans due to their next-of-kin's condition (I). They did not want to leave their next-of-kin alone because they saw the person suffering or they were afraid that the person might hurt him/herself (II). Nosek (2008) found that some family members of persons suffering from depression experienced the risk of suicide as a constant threat, and that they therefore always had to monitor changes in their next-of-kin's behaviour.

When the situation at home was strained and time consuming, relatives' energy was reduced, which influenced their *leisure time and career* (II). More than half of the relatives reported reduced leisure activities, and some even had to stay home from work or school because of the person's depression (I). It is also reported elsewhere that the relative's professional life was affected, e.g. reduced working hours to be more available for the person suffering from depression (Stjernswärd & Östman, 2008). To differentiate between the family member's own health problem and problems caused by other family members may be difficult.

Concerning the relatives' *finances*, some had to rethink future plans because of lost income in connection with the next-of-kin's depression (II). Despite this, only eight of the 68 relatives reported that they had financial difficulties because of the situation (I), in contrast to four out of ten relatives reporting financial problems related to the mentally ill person in another Norwegian study (Weimand et al., 2010). Nonetheless, the relatives in the above-mentioned study were mostly mothers. The findings in the thesis may be explained by the fact that half of the relatives were adult children who most likely had an economy independent from the ill parent (I).

Some of the relatives experienced that their *physical health* was affected (I). Psychosomatic symptoms such as loss of sleep, feeling exhausted and unwell because of worries about the situation were also described, and some relatives even had to take sick leave (II). Decreased health is found to be associated with an increased burden (Weimand et al., 2010).

Chronic strain

Experiencing that one of your nearest relatives is severely depressed may be understood as a stressor (c.f. Antonovsky, 1987), and being close to a person suffering from recurrent depression was considered as *chronic strain* (II, IV). To experience the next-of-kin showing a lack of emotion and energy for a long time is stressful on a relationship (II). Some feared that their loved one did not want to live

(II), which probably contributed to a higher degree of subjective burden among these relatives.

Subjective burden

The psychological consequences of the next-of-kin's depression contribute to the relatives' experiences of *subjective distress* (c.f. Schene, 1990) characterized by contradictory feelings (II). Some felt gratitude to their next-of-kin, and described it as a matter of course to help (II) earlier described as rewarding (Heru & Ryan, 2004) and contributing to personal growth (Stjernswärd & Östman, 2008). However, feelings as frustration, anger and ambivalence were described (II). Few reported guilt for causing the depression, though some struggled with a feeling of guilt for not helping the depressed person enough (I). The relatives did not communicate their thoughts and feelings towards the next-of-kin, fearing that it could worsen the condition, which was understood as "walking on eggshells" (II). Ahlström (2009) described that suicide problems may be difficult to handle, when nobody in the family dared talking about this as a family matter. This self-adjustment of one's behaviour insofar as being afraid of causing relapse or aggravation of the depression may be a contributor to subjective burden. Relatives' doubts and uncertainties concerning their own perceptions of the person's condition are also reported by others (Tranvåg & Kristoffersen, 2008, Weimand et al., 2013). Most of the relatives were worried about what the future might bring (I), which may contribute to a high degree of burden in terms of always being in a state of readiness even during better periods. A constant assessment of the next-of-kin's behaviour and looking for signs of exacerbation was distressing (II), and may be one explanation of why almost half the relatives experienced difficulty in concentrating (I).

With regard to *mental health*, those who reported the highest burden score reported significantly poorer mental well-being and more mental distress (I). A negative correlation between burden and mental health in relatives is reported by Ildstad et al. (2010) who found a high degree of subjective burden in the spouses of persons suffering from anxiety and depression. The children's mental health may also be at

risk. The healthy parent described how they perceived their children's reactions to the situation as anger towards the ill parent, or that they withdrew from the contact with their depressed mother or father (II). Van Wijngaarden et al. (2004) found that the children showed several psychosomatic symptoms, spent less time with friends and had difficulties concentrating at school. Garber et al. (2011) found a significant positive correlation between parental depression and the child's symptoms of depression. Relatives in this thesis described their own symptoms of depression and anxiety, which for some were serious enough to be on sick leave (II).

Sense of coherence is found to be a resource with an impact on how people deal with stressful life events, and how they mobilize their resources in a health-promoting manner (Antonovsky, 1987). The relatives who showed the strongest sense of coherence also reported less mental distress (I), corresponding to the negative correlation reported by Nilsson et al. (2010). One-third of the relatives (Group C) with the highest burden, also reported a weaker sense of coherence, more mental distress and poorer mental wellbeing (I). This group of relatives may have less resources to handle this demanding situation, and therefore have to be identified by the mental health personnel as needing to be supported.

The importance of distinguishing between distress and burden has previously been discussed (Maurin & Boyd, 1990). The relatives' health may not only mirror the consequences of their next-of-kin's depression, but also that their own mental health difficulties may reduce their ability to cope with the stress associated with their role as a relative (Ennis & Bunting, 2013).

Social networks

Schene (1990) highlights the degree of social support within *social networks* influencing the relatives' experience of both objective and subjective burden. The relatives wanted to be acknowledged by their next-of-kin suffering from depression, as well as from others (II). Social support is revealed as a crucial resource to handle stressful life events (Antonovsky, 1987). The mental health personnel should ask the relatives if they have somebody to give them support when

needed. Relatives who do not have any social network have to be addressed by the personnel in PSHS and be offered support, as a lack of social support from friends or family is found to exacerbate the relatives' difficulties (Highet et al., 2004). A decrease of social support may also be due to those around ceasing to stay in touch (Tranvåg & Kristoffersen, 2008). The symptoms of depression may therefore reinforce this by the person suffering from depression being perceived as dismissive (c.f. Hummelvoll, 2012). This may lead to a social withdrawal of the relatives, in that they give priority to being with- and support their next-of-kin (II), which in turn may become a self-reinforcing negative spiral. Hansen and Buus (2013) described this withdrawal as an attempt to protect oneself and the next-of-kin from stigma and social condemnation, leading to social isolation. Hence depression may not only isolate the person affected, but also their close family.

Community culture

The *community/culture* system comprises among other things the mental health care systems (c.f. Schene, 1990), in this thesis the PSHS, which is influenced by several factors, e.g. availability, the mental health personnel's competence and continuity of care. The findings in this thesis comprise the relatives' perception of their encounter with the PSHS, the treatment and care provided by the mental health personnel and their professional- and empathic skills (III, IV).

With regard to availability, the relatives described it as a struggle to obtain access to help, and that they perceived the depression to be more severe than the mental health personnel did. Even if the person had recurring depression, some perceived it as equally difficult to be hospitalized each time, and that the situation had to be acute before help was given (IV). The relatives may feel left alone with a great responsibility for taking care of their depressed loved one (Hansen & Buus, 2013). Few relatives reported a high number of contacts with the health-care system over the past 12 months (III), which may be due to the severity of the depression and their need for professional support. Relatives described difficulties in making contact, afraid of

being regarded as inconvenient, while some did not know what to ask about (IV). Nordby et al. (2010) found that relatives wanted to be involved from the beginning when their next-of-kin was hospitalized and to receive knowledge gradually, as it can be difficult to receive and remember all the information at one time. In this thesis, the relatives who reported receiving less information in their encounter with the PSHS also reported a significantly higher burden (III). Information sharing, insofar as the relative receives complete and accurate information, is important to be able to participate in the care and decision making (c.f. Walton & Barnsteiner, 2012).

The relatives questioned the mental health personnel's competence and whether their next-of-kin did receive the best possible treatment and care. Some felt unsafe about the risk of the person being able to hurt him/herself at the ward (IV). This fear may be reduced if the mental health personnel request relatives' perceptions of the person's depression and their assessment in order to achieve a mutual understanding of the situation, which is an important premise for good nursing care (c.f. Kim, 2010). Personal qualities such as sensitivity, empathy, cheerfulness and calmness were perceived by relatives as important aspects of competence in mental health personnel (Schröder et al., 2007).

The relatives described the duty of confidentiality as one obstacle for the collaboration between the relatives and PSHS, e.g. to get information even though their next-of-kin wanted them to (IV). The mental health personnel may use confidentiality as an excuse for not involving the relatives (Weimand et al., 2011). It is therefore important that the mental health personnel more actively communicate the meaning of confidentiality with the patient (Schröder et al., 2007). Traditionally, the PSHS focuses on the treatment and care of the patients (Blomqvist & Ziegert, 2011, Weimand et al., 2013). Although nurses' main responsibility is the patient, the Patient Rights Act §3-3 states that the nurses have a responsibility to inform the relatives about the patient's health condition and treatment (Helse- og omsorgsdepartementet, 2001). The ethical guidelines for nurses state that the nurse must show

respect and consideration for the relatives, in addition to safeguarding their right to information (International Council of Nurses, 2012).

The continuity of the mental health personnel to the relatives and their next-of-kin was perceived as crucial. Ensuring that the information was passed on to the next therapist or treating institution and that the same nurse followed throughout the course of treatment was highlighted (IV). Continuity of care is most important in the mental health personnel at the ward, as well as between the different trajectories of care (Ewertzon et al., 2011).

The differences between relatives PR- and SI responses for those recruited via the community specialist health centres may be due to the information received not being in accordance with their needs (III). Similar findings are also described by Ewertzon et al. (2011). This thesis also revealed a difference in the relatives' perception of the received information and support (PR) between hospital wards and wards in the community specialist health centres, in which the latter exhibited lower scores (III). One explanation for this may be a lack of continuity in the mental health personnel, especially in relation to psychiatrist and psychologist in some community specialist health centres, which are characterized by many temporary employees (c.f. Helsetilsynet, 2010, Pedersen & Bremnes, 2011). Even though mental health personnel offered the relative information, it is still the individual relative's perception of the received relevant information that is of importance (Ewertzon et al., 2011). A lack of sensitivity towards the individual relative's experiences may explain why some perceived that the doctors did not settle into how they experienced their situation (III). A good relationship presupposes that the mental health personnel actively assess whether the help and support is experienced as helpful.

Today, there is an agreement in that how the relatives engage and understand the situation affects the patients' health and recovery, and that there is a mutual interdependence in this relationship (Dixon et al., 2001, Jönsson et al., 2011). Psychoeducation provided to the family is found to be effective in the prevention of a relapse in adult

persons with major depression, which also positively affects the relationships in the family (Shimazu et al., 2011).

The findings (I-IV) indicate the importance of giving support to both the patient and the close relatives as a unit (c.f. Rusner et al., 2013). The person- and family-centred care perspective (Barnsteiner, 2014) emphasizes dignity and respect as central concepts. Persons of importance to the patient are included, and their perspectives and knowledge are acknowledged in the planning and delivery of the care for their next-of-kin (c.f. Walton & Barnsteiner, 2012). To see the patient in a larger context should be given more attention in mental health nursing when encountering the relatives of persons suffering from severe and long-term mental illness. This may be in accordance with a holistic view that enables the mental health nurse to understand the family as a whole in the context in which they live (Hummelvoll, 2012, Travelbee, 1971). The mental health nurse's knowledge about what characterizes depression and how this influences the family is important in providing good care (c.f. Travelbee, 1971).

Reflections on the family burden framework

The theoretical framework on family burden (Schene, 1990) has contributed to deepen the reflections of the findings. The framework describes the family as a system (Figure 2), and illuminates the very complex situation for the relatives of a person suffering from severe depression. The relatives' everyday life is influenced by the severity of the next-of-kin's symptoms, burden, health and coping skills, responsibilities for other family members and support from the PSHS (I-IV). Nonetheless, the interaction between the relatives and the patient is not illustrated in the framework, which shows the influence of the patient symptoms and functions toward the relatives and not the other way around. The way in which the relatives react towards the next-of-kin's depression shown in study II will unavoidably be communicated to the next-of-kin (c.f. Hummelvoll, 2012).

Concerning objective and subjective burden (Schene, 1990), contradictory findings in the literature are found regarding the

experience of burden. Some highlight that it is the severity and duration of the illness, and not the diagnosis, that affect the relatives' experience (Hadry et al., 2011). Other studies found that burden is more infrequent in depression than in bipolar disorders (Heru et al., 2004) or schizophrenia (Chakrabarti et al., 1995), whereas others find that the consequences for the relatives of persons suffering from depression and schizophrenia are very similar, but affect different areas of the relatives' everyday life (Van Wijngaarden et al., 2009). The term burden may be considered as value laden putting the blame on the person suffering from a mental disorder. However, the findings in the thesis show that there are also positive aspects for the relatives when caring for their depressed next-of-kin (II). This is not focused in the framework due to a lack of research concerning the positive aspects of caring (Schene, 1990). Even so, the positive aspects of caring for a next-of-kin have recently been reported (Johansson et al., 2013, Weimand et al., 2013).

Conclusions and implications for practice

Everyday life of relatives of inpatients suffering from severe depression is highly affected and that they do not receive the information and support they need from psychiatric specialist health services.

- Relatives of persons suffering from severe depression describe experiences of burden to a various degree with subjective burden more frequently than objective burden.
- Relatives with higher reported burden report poorer health and weaker sense of coherence than those with lower level of burden.
- Everyday life is affected in that relatives take great responsibility for their next-of-kin balancing between their own and other family members' needs.
- Relatives experience ambivalent feelings towards their next-of-kin comprising irritation, anger, guilt and gratitude.
- Relatives describe a long time of struggles from onset of depression to hospitalization.
- In the encounter with PSHS relatives do not necessarily receive the information and support they need.
- Relatives perceiving less received information and support report higher burden.
- Relatives are uncertain as to whether their next-of-kin receive high quality care due to lack of continuity and varying competence among the mental health personnel.

- The mental health personnel should initiate collaboration with- and support to the relatives and recognize their knowledge and experiences in the planning of the treatment and care of their next-of-kin.
- The mental health personnel have to take into account that relatives are a heterogeneous group with various needs that must be acknowledged.
- A person- and family-centred care should be implemented, to address the relative's needs and to emphasise the reciprocal relationship between the relative and the next-of-kin.

Future research

- To study the relationship between the relatives' burden and health .
- To investigate predictors for relatives' burden by means of multivariate analyses.
- To study attitudes among mental health personnel towards collaboration with relatives.
- To implement and evaluate an intervention with focus on person and family-centred care.

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Everyday life of relatives of persons suffering from severe depression

Depression is one of ten global diseases entailing the greatest loss of life quality and years of life, which also gives consequences for the relatives. The overall aim of this thesis was to investigate and describe everyday life among relatives of inpatients with severe depression and their encounter with the psychiatric specialist health services (PSHS). The relatives experienced objective and subjective burden, and their own health was affected. Everyday life needed to be adjusted in line with the severity of the next-of-kin's depression. When the relatives encountered the PSHS a long time of worries and struggles had passed from the onset of the depression until the next-of-kin was hospitalized. To be acknowledged as a resource, invited to collaborate and to share their knowledge was of great importance to the relatives. Additionally, to receive information concerning the treatment and care was crucial. The mental health nurses are in a unique position to support the relatives.

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