

Major Depression and Family Life

- The family's way of living with a long-term illness

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ABSTRACT

The overall aim was to explore the family's experiences of major depression and the meaning of the illness for family life, for the ill person, the partner and the children.

This thesis has a life-world perspective and is a qualitative explorative study using narrative interviews with families with parents who were identified as having major depression MD (Paper I-IV). A case study with a single family (n=3) was performed with a focus on describing what happens and how to manage the illness in a family (I). Group interviews with 7 families (n=18) were conducted to describe the ways of living with MD in families (II). Further, parents (n=8), who were identified as suffering from major depression, representing 8 families were interviewed to elucidate the meaning of depression in family life from the viewpoint of the ill parent (III). Interviews were also conducted with children and young adults (n=8), aged from 6 to 26 years, representing 6 families to elucidate the meaning of a parent's major depression in family life from the children's perspective (IV). The interview texts were analysed using qualitative methods; thematic content analysis (I-II) and phenomenological hermeneutic analysis (III-IV).

The thesis shows that family members had different views and ways of interpreting and managing the family's situation when the mother was suffering from major depression (I). The families faced demanding conditions in the presence of illness which they tried to manage together. The families' situation (fatigue, loss of energy and being burdened with guilt) seemed to bring these families into stressful life situations (II). Depressed parents' suffering and dignity were revealed as being simultaneously present and complicating family life. Dignity has to be repeatedly restored for oneself and the family, and the family's dignity has to be restored in front of other outside the family circle (III). Children's sense of responsibility and loneliness were elucidated. The children's responsibility includes their striving for reciprocity, and in their loneliness is the children's yearning for reciprocity. Children compensate with a sense of responsibility for an ill parent in family life and for their lack of health. Children's family life shifts between responsibility and loneliness as they wait for reciprocity in family life to return to normal (IV).

This thesis shows how a study using qualitative methods makes it possible for family members together and individually to talk about major depression as illness that is an intruder in their family life. The thesis elucidates how the depression complicates and involves the family member's life as well as the ill person's family life. All family members have their own life-world and try to balance everyday life from an individual perspective, which overshadows that managing the illness is a concern for the whole family.

Keywords: children, content analysis, everyday life-world, family, family life, phenomenological hermeneutics, major depression, parents

ORIGINAL PAPERS

This thesis is based on the following papers:

- I. Hedman Ahlström, B. Skärsäter, I. & Danielson, E. (2007). Major depression in a family: What happens and how to manage - A case study. *Issues in Mental Health Nursing*, 28(7) 691-706.
- II. Hedman Ahlström, B. Skärsäter, I. & Danielson, E. (2009). Living with major depression: Experiences from families' perspectives. *Scandinavian Journal of Caring Sciences*. (In Press)
- III. Hedman Ahlström, B. Skärsäter, I. & Danielson, E. (2009). The meaning of major depression in family life: The viewpoint of the ill parent. (Re-submitted)
- IV. Hedman Ahlström, B. Skärsäter, I. & Danielson, E. Children's view of a parent's major depression in the family. (Submitted)

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INTRODUCTION

This thesis investigates family life in families with children, living with an adult family member suffering from major depression (MD), according to Diagnostic and Statistical Manual of Mental Disorders (DSM-IV); (American Psychiatric Association 1994). It is a study in the context of the family's life-world, and should be related to mental health within nursing science. As will be described further on, many persons will experience a depression at some time during their life, which will give rise to challenges for the family as regards their way of living. This situation, with MD in the family, may occur repeatedly over the course of several years, thus becoming a long-term illness that involves both the adults and the children (Weissman *et al.* 2005).

Family function is lowered irrespective of women's or men's MD (Herr, Hammen & Brennan 2007). However, the families have to continue their everyday life in the home and at work which is, or can be, demanding (Judd *et al.* 2008) and accordingly they have to find new strategies to manage their situation (Badger 1996, Skärsäter & Willman 2006). As regards the children in these families, a parent's MD has been regarded as making childhood, as well as adolescence, more vulnerable periods of risk of mental ill-health and depression (Beardslee, Versage & Gladstone 1998, Klein *et al.* 2005) and causing future problems related to psychopathology in adulthood (Peisah *et al.* 2005). For instance, children are affected by loss of appetite, behavioural problems and problems sleeping, playing and paying attention in school (van Wijngaarden, Schene & Koeter 2004). However, there are few people from the families' network or health care professionals who support families in this situation (Skärsäter *et al.* 2003a, Skärsäter *et al.* 2003b). In the studies by Skärsäter *et al.* (2003a,b) of men and women with MD, it appeared that the family was important for the ill persons who wanted to be looked upon as being a part of their family, and they also wanted better support for the family. Knowledge of how MD impacts on parents, children and the family's situation has mainly medical and psychological perspectives. Few studies within nursing science concerning the family's situation focus on living with the illness MD. Further, hardly any studies have been performed with the aim of describing the family's life-world. Family life involves relations and activities on a family as well as an individual basis and families seem to manage life on the assumption that there is some mutual level of understanding. However, a long-term such illness as MD may severely disrupt the family's harmony and a need for care may arise. A person with MD is mainly treated, often for several years, by a general practitioner in primary care (Silferhielm & Kamis-Gould 2000). In primary care, there is little access to health care professionals with specialist knowledge of mental health care and psychiatry and, furthermore, especially at the family level. Greater knowledge in nursing science from the perspectives of the family's own life-world could contribute to a better understanding of the circumstances in which the families lead their everyday life with MD in their specific situation, thus helping health care professionals to care for the families.

BACKGROUND

Major depression

The World Health Organisation (WHO 2001) concluded that MD is a leading cause of disability worldwide, accounting for almost 12% of all disability and affecting adults, the elderly, and children. The cost of depression in Sweden doubled between 1997 and 2005 to €3,5 billion. Included were direct costs; inpatient and outpatient care and drugs, as well as indirect costs; sick leave, early retirement and mortality (Sobocki *et al.* 2007). In the American replication study of The National Comorbidity Survey (NCS), the lifetime prevalence of an episode of MD according to DSM-IV, was 16,6% among persons aged from 18 years and older (Kessler *et al.* 2005). The results of the studies show a female preponderance. The cumulative probability drawn from the Swedish Lundby cohort (Rorsman *et al.* 1990) is 45% in women suffering from depression once or more during their lifetime and 27% for men. It is known that both the environment and genes affect people suffering from MD, and that these factors also have an impact on the disease (Sullivan, Neale & Kendler 2000, Li *et al.* 2008). When dealing with genetic influences, depression is primarily viewed as being a familial disorder (Sullivan *et al.* 2000), which affects families for generations (Weissman *et al.* 2005). Differences concerning symptom profile in men and women showed that women are younger at the onset of MD, suffer more frequent episodes and have more depressive symptoms as well as more atypical symptoms during their “worst ever” episode of MD (Smith *et al.* 2008). MD is linked to the adverse events in an individual’s life, including home, family and work (Hirschfeld *et al.* 2000; Kornstein *et al.* 2000; Judd *et al.* 2008).

The criteria for diagnosing a Major Depressive Episode, modified from DSM-IV, are: depressed mood, low or no interest in pleasure, loss of weight, not dieting or every day changes in appetite, sleep disturbances, psychomotor agitation or retardation, fatigue or loss of energy, feeling worthless or loaded with guilt, cognitive and concentration disabilities, and recurrent thoughts of death. Five or more of these symptoms have to be present in the same fortnight (2-week period). “Depressed mood” or “loss of interest or pleasure” has to be present as one of the five symptoms. The person’s level of function has to be lowered (American Psychiatric Association 1994).

Treatment for a person with MD is provided predominantly in outpatient clinics, such as care centres in primary health care and psychiatric outpatient clinics (Silferhielm & Kamis-Gould 2000). Some psychiatric clinics offer services at “affective units”, which specialize in affective disorders. A treatment usually recommended is anti depressant medication. If there are enough resources, preferably a combination with psychological therapy such as cognitive therapy is offered, provided by psychologists and registered mental health nurses and psychiatrists. Mental health nurses also provide support with a person-centred counselling approach (SBU 2004). If MD becomes more severe, treatment in psychiatric inpatient wards may be available.

Family

The term family as used in this thesis is based on the concept analysis by Stewart (1991) in which the family is a system or unit. Its members may or may not be related and/or not live together. The members unit may or may not contain children, but there is commitment and attachment which include future obligation among its members. The caregiving function in the unit consists of protection, nourishment, and socialization of its members. Using Stuart's (1991) broad definition, it is possible to include modern family structures such as homosexual families and families from culturally diverse family structures. However, when the data collection was carried out, a way of defining the family was used in which the depressed persons were invited to define who their family members were, also described by *e.g.* Benzein, Hagberg and Saveman (2008).

Research on families is extremely varied. Many theories have been used, and in nursing studies have for instance been related to system theory (Fowler 2006, Knauth 2003), role theory (Schumacher *et al.* 2008), attachment theory (O'Connell 2008) and stress theory (Saunders 1999) and life world perspective (Björk, Wiebe & Hallström 2005). In this thesis, a theoretical perspective of the everyday life-world according to Schütz (1999), which will be described further, was chosen to elucidate the families' own perspective of their family life. This differs from other studies in nursing from a professional perspective.

This study has a family's perspective, using a combination of the individual family members' views of their family as well as the family as a unit and their joint views of their family, to acquire knowledge. Family life, in this thesis, comprises activities and interactions between the family members within the family, as well as between the family and the community. However, in this thesis, the focus is on family life as regards what the family defines as "their family life".

The parent's major depression and the children

Family life

Parents' MD and how it impacts on the family's and children's lives has been the subject of considerable interest, and has been studied mainly from medical and psychological perspectives. Some older family-related studies focusing on depression in a psychiatric context should be mentioned as they seem to be relevant and are referred to in later studies of the family and MD. These studies are dominated by quantitative methods. Keitner *et al.* (1986) investigated family functioning during an acute episode of depression. Family functioning was lowered with respect to communication, problem solving and affective reaction. Hops *et al.* (1987) studied depressed women's interactions with their family and showed that the mothers' sadness seemed to hold back families' aggressiveness and vice versa. Jacob *et al.* (1987) assessed the family burden and family attitudes in significant others towards a person suffering from recurrent depression. This situation was a huge burden due to the depressed

person's changed behaviour and feelings of worthlessness as well as worries about how to cope in everyday life. Keitner *et al.* (1995) compared well-functioning families with poor-functioning families when they studied the role of the family in recovery. Families who considered themselves as well-functioning at the onset of MD were considered to be more likely to regain health within a year.

More recent studies have also been performed from medical and psychological perspectives. Their focus is on the ill parents with MD and children aged from 2 to 16 years. The data have been obtained from parents' reports on the children and in several studies of children and adolescents as well as their parents with larger samples. Data have been collected via self-report questionnaires and interview questionnaires as well as from databases such as larger surveys and health care registers. The studies have focused on both parents and children, and how the children react, behave and respond to their ill parents and to aspects of what is happening in the family due to MD as well as its consequences. However, there is a lack of studies exclusively from the children's perspective and the studies neither highlight the family's situation as a whole nor how the family members manage their family life as a result of MD. Rogosch, Cicchetti and Toth (2004) investigated the emotional climate in families with small children and a mother suffering from MD. The study showed more expressed emotion and critique regarding the children, the spouse and themselves compared to families without a history of MD. A meta-analysis by Kane and Garber (2004) showed that fathers' MD are significantly related to children's internalizing and externalizing of psychopathology and to conflicts between fathers and children. Bronte-Tinkew *et al.* (2007) showed that fathers' symptoms of MD differed concerning marital, employment and educational status and were negatively associated to their involvement in small children but positively associated with fathers' bad temper and stress concerning parenting.

Adolescents of 15 years of age participated in a study by Brennan *et al.* (2002) on maternal depression as well as paternal depression, which showed they had an additive effect on adolescents' externalization of disorders and depression. Family stress and fathers' expressed emotions seemed to be a mediating factor. Sarigiani, Heath and Camarena (2003) investigated adolescents' experiences on a daily basis of parents' depressed mood. Adolescents whose parent suffered from recurrent depression reported lower mood and experienced more family conflicts than did other adolescents. Boys spent more time together with the family than girls, who additionally reported feeling more depressed when being with their families compared to adolescents in families without parental mood problems (Sarigiani *et al.* 2003).

Regarding children coping with their parent's MD, Jaser *et al.* (2005) investigated this in adolescents. Girls used more disengagement coping, *i.e.* they tried to avoid stress and its emotional responses. Boys reported that they used more involuntary coping, which appeared as automatic responses to stress,

such as engagement responses in the form of emotions and intrusive thoughts. In other respects, they coped similarly. However, parents and adolescents had different views of how adolescents reacted to stress and about their mental health. Another study by Jaser *et al.* (2007) concerning coping with stress caused by friends and family with a parent with MD or dysthymia, showed that adolescents have fewer symptoms of anxiety, depression and aggression when they use secondary control coping strategies, *e.g.* distraction, positive thinking and acceptance, in response to family stress. Moreover, they had few symptoms when they used primary control coping such as problem-solving and expressing emotions for stress related to friends. However, secondary control coping was the strategy adolescents used the most in both situations. Seeing that these studies to some degree described what happened in the family in close conjunction with MD, other studies have focused on the risks of parental MD and future consequences, especially for children.

Children of parents with MD are more at risk of developing mental illness (Beardslee *et al.* 1998) such as depression, substance abuse and anxiety disorders and this is manifested by early stages of depression (Lieb *et al.* 2002). Children also have lower perceived social competence and are more likely to attempt to commit suicide (Lewinsohn, Olino & Klein 2005). It does not make any difference whether it is the mother or the father who suffers from depression (Klein *et al.* 2005). Regarding families' functioning and children's psychosocial functioning, children and adolescents at high risk of a major depressive disorder, *i.e.* having a parent or relative with MD, were compared with those with acute major depressive disorders with healthy adolescents as a control group (Birmaher *et al.* 2004). Interestingly, adolescents at high risk and the healthy controls had similar psychosocial functioning. Other studies have focused on predictions of symptoms in children due to their parent's MD or related illnesses, *e.g.* Bayer, Sanson and Hemphill (2006) described problematic parenting practices and Meadows, McLanahan and Brooks-Gunn (2007) pointed to anxiety, depression and attention problems in the children.

Adult children have also been of interest for studies related to parents' MD. Peisah *et al.* (2005) investigated factors associated with psychiatric disorders in adult children of parents with depression admitted to hospital 25 years earlier. Being young as a child when a parent was admitted for care was a predictor of psychological morbidity in adulthood, this was also the case when children perceived the depressed parents as controlling. Further, the length of exposure to parental depression had a more negative impact than the severity of parental depression or parents being admitted to hospital. Baik and Bowers (2006) studied adult children of mothers with MD qualitatively with the aim of understanding children's experiences of living with their mothers and how the children disclosed their experiences. Self-disclosing as discovery occurred when the children realised that their parent was different from other parents. First disclosing was the time they told others about experiences related to the mother, and selective disclosing was when children, deliberately or not, revealed their experiences to other people. What they disclosed changed as

time passed. However, the study shows that children experienced a difficult and complicated childhood.

Family care giving

Family care giving in depression caused burdens and relational strain as well as worries about treatment, health and safety. The caregivers felt distress, which was a reason for needing help for their own sake (van Wijngaarden *et al.* 2004). The care givers also reported that children were affected by the situation with loss of appetite, difficulties in behaving, sleeping, playing, and paying attention in school, and according to van Wijngaarden *et al.* (2004), depression had most consequences for children of patients in the non-acute phase. Karp and Tanarugsachock (2000) describe how care givers of parents, children, siblings and spouses experienced emotional anomie while disbelieving their own interpretation of the situation. Having a diagnosis established gave hope, but realizing that the situation could last for a long time and be impossible to control, helped care givers abandon their responsibility without guilt. Highet, Thomson and McNair (2004) conducted a qualitative investigation of family care givers' experiences of the onset of MD and its progression in spouses and children. Care givers identified signs and symptoms of MD, however, mostly in hindsight as they had psychological barriers that prevented them from interpreting the signs as a psychiatric illness such as depression.

Family prevention and treatment

Some studies report on the development of family treatment and prevention interventions. Treatment interventions in families with parental MD and with child-focused perspectives have been studied in a review by Herring and Kaslow (2002). The interventions structured on the basis of development stages comprising infancy to adolescence, in accordance with attachment theory, took both parents depression as well as children's depression into consideration. Herring and Kaslow (2002) concluded that depressive symptoms are alleviated by strengthening attachment bonds among family members. With the intention of developing a family-based depression prevention program, a qualitative study of mothers was carried out by Boyd, Diamond and Bourjolly (2006). Important issues that emerged from this study were related to depression symptoms, general legacy, parenting difficulties and child problems, social support and stressful life events. Beardslee *et al.* (2007) described family interventions, although in a randomized trial concerning prevention for parental depression. Both a lecture intervention only for parents as well as a clinician-based family intervention, where both children aged 8 to 15 years and their parents participated, increased children's and parent's family function, which was retained for several years.

The situation with families living with a person with MD can also be found in studies investigating other mental illnesses. Nursing as well as psychology and sociology perspectives were applied in those studies. The family's situation has been studied without taking into account the differences between illnesses such as schizophrenia, bipolar disorders or MD (Garley *et al.* 1997,

Karp & Tanarugsachock 2000, Handley *et al.* 2001, Muhlbauer 2002, Rose, Malinsson & Walton-Moss 2002, Walton-Moss, Gerson & Rose 2005,). These studies are dominated by qualitative methods, and there are several studies that show processes or phases families go through, and depression is represented by only a small proportion of the participants.

Depression in the family from a nursing science perspective has not been sufficiently focused on, and the concepts concerning depression are only vaguely defined (Badger 1996, Alexander 2001). Few nursing studies revealing the family's situation focus specifically on MD in particular (Skärsäter *et al.* 2003a,b, Skärsäter 2006). Bagder (1996) found in a qualitative study that families living with a depressed member went through a psychosocial process. They had to perceive what had happened in the family and manage a new way of interaction in the family, as well as a new way of relating to the ill person. The family also developed protective and coercive strategies, which arose from the need not to making the situation worse and to speed up the process of recovery. In another a qualitative study, Alexander (2001) showed that men with depression had no confidence in those close to them, not even their spouses. Another qualitative study of men with MD (Skärsäter *et al.* 2003b) showed also that they needed support from other people, for example, from the family or the health care system. A qualitative study of women with MD also showed that support from, and interaction with other people were vital for regaining control over daily life routines, and helped to ease the strain for the woman and her family (Skärsäter *et al.* 2003a). In a quantitative study by Skärsäter (2006), it was found that parenthood was an issue of concern for parents with MD. Additionally, parents were still vulnerable one year after treatment for an initial episode of MD, which led to tensions within the family.

Furthermore, Rose *et al.* (2002) described the basic social process of "pursuing normalcy" as the families striving to live in a way they would have done if not mental illness had occurred. It involved confronting the ambiguity of diagnosis, seeking control over illness and adopting a stance of possibilities and realities. Muhlbauer (2002) investigated the process of changes and needs and described six phases that families went through, which were metaphorically described as "navigating the storm of mental illness". Walton-Moss *et al.* (2005) re-examined data from the study by Rose *et al.* (2002) and showed that the quality of life for families was characterised as "hanging on", "being stable" and "doing well". This was interpreted in order to help professionals to support and intervene in families. Garley *et al.* (1997) studied children's views of a parent's mental illness. Children learnt the signs of the parent's illness and tried to prevent social consequences. The illness had an impact on schoolwork and some children were their parent's close friend. The children need information to understand the situation, manage the parent's illness and avoid unpleasant feelings. Handley *et al.* (2001) studied parents and children as a part of a study about the needs of children with mentally ill parents, and the findings were similar to Garley *et al.* (1997). Further, Östman (2008) investigated similar child life situations; a family with a parent suffering from

mental illness. This study showed that children needed conversations, but they also experienced fear, loneliness, responsibility, maturity and stigma.

Although these studies, taking as their starting point the concept of “mental illness” when describing families’ situation, are well performed and the results are interesting, it might be difficult for nurses and other health care professionals to identify knowledge in order to develop strategies for families and persons with specific diagnoses. Östman, Wallsten and Kjellin (2005) performed a qualitative study of whether the differences in the diagnosis of mental illness were important for the experiences of family burden and relatives’ participation in care. Mental illnesses in inpatients were divided into the subgroups psychoses, affective disorders and other diagnoses. Relatives of a person with an affective disorder more often had to deny themselves time off and more often reported that they were sufficiently in the care of the person. Whatever the diagnosis, relatives reported burdens almost in the same way (Östman, *et al.* 2005). However, in a 1-year follow-up study by Heru and Ryan (2004), care givers to relatives with bipolar disorders reported decreased strain and burden, but care givers of relatives with MD reported impairment in family functioning at the base line as well as one year after discharge from hospital. These families did not report any significant improvement. This indicates that the subgroup “mood disorder” as well as “affective disorder” is also too broad a concept as differences related to diagnoses of how the families experienced their situation were noticeable.

Reflecting on the reviewed literature, the usage of the word ‘child’ in research studies seems to be accepted when it appears in relation to ‘parents’, irrespective of the age of children who can be small children (Bayer *et al.* 2006) as well as adult children (Peisah *et al.* 2005). The classification in age-groups as well as its designations as children or adolescents also varies. In studies where children and adolescents are included, the age limit is 16 years, while in studies where adults participate, they are included from 18 years and older. This leaves a gap of 1 to 2 years and studies of this age group seem to be missing. An exception is Östman (2008) in which the adolescents up to 18 years old participated.

RATIONALE

There is a large body of knowledge mainly in medical and psychological science about diverse aspects of MD related to the family. As shown in the literature review, most studies focusing on the family's situation related to MD have quantitative approaches. They have focused on parts of family life and not the whole situation. Few studies from solely the children's own perspective have been found. Furthermore, parents' MD and its influences on the children have also been thoroughly studied quantitatively and data have been obtained from both parents and children of different ages. Hardly any studies have been performed on the topic of the family's life-world. Moreover, few studies based on qualitative approaches within nursing science, and revealing the family's situation, focus living with the illness MD. Few of these studies include the depressed family member or children under the age of eighteen. Further, most of the studies rely on single informants. There is a gap in nursing science concerning knowledge about families' life-world specifically related to MD. Accordingly, it was considered appropriate to study the family unit, including children, when they live with MD, and thus acquire knowledge from the family's own perspective. The scientific question was: What is the meaning of MD for family life, for the ill person, the partner and the children?

THEORETICAL PERSPECTIVE

A life-world perspective is used in this thesis. The life-world as a philosophical concept was developed by the philosopher Edmund Husserl (1859-1938), and is also known as the “pre-scientific world of experience” (Zahavi 2003 p. 125). A person’s life-world consists of subjective experiences of what he/she is aware of, such as what is “actual, certain, supposed, valuable, beautiful, good” (Husserl 1989 p. 384). These aspects of a life-world are also those that motivate a person’s to live his/her life. Husserl (1989 pp. 384-385) described the immediate experience of another person as an experience of one’s own perceptibility. Nevertheless, the other person, or subject as Husserl puts it, is a subject of motivation to, for instance, communicate and empathise. A life-world is the life a person is living; the natural life, the person’s lived experience. The life-world can be studied scientifically when it is taken as it is and when questions are posed about what belongs to the person’s life-world (Husserl 1989 pp. 384-385). A personal life is, in addition to experiencing living as an individual (an I) and as in togetherness (a we), experiences of living in communities within another level of a community, like, for instance, a family (Husserl 2002/1954 p. 86).

The philosopher Alfred Schütz (1899-1959), has further developed the concept of life-world into the concept of ‘everyday life-world’ (Schütz 1999/1945). The everyday life-world is a description of the inter-subjective world in which a person lives and acts. A person’s everyday life-world is experienced as the natural and real world he or she has been born into and has learned to live in with the help of, for instance, parents’ interpretations of the everyday world, the so called ‘knowledge at hand’. The everyday life-world is possible to change and control. Accordingly, it is both the place a person acts in, as well as the subject of the actions that are performed in interactions with other people. Schütz (1999/1945) uses the word ‘performance’, which is a meaningful experience of spontaneity, also spontaneously gained, which can be open, as an action, or hidden, as a reflection. Further, he uses the expression ‘wide awake’, which is an active state emanating from excitement of life, and is described as the person’s entire attentiveness to life and its demands. When a person performs an action ‘in the living now’, he or she deliberately wants to make a change. The process of this action places the person in relation to time; the time spent in planning the action in advance and the time afterwards spent in reflection on its remembrance. A person is responsible for his or her actions, legally and morally, because of the changes he or she makes. However, according to Schütz, this responsibility does not include a person’s thoughts. Also social relations are the target of the changing actions, as the intention of an action may be to get the other person to react in response. A joint everyday life-world is based on ‘face to face relations’, which result in a joint ‘living now’ (Schütz 1999/1945) The life-world perspective in this thesis is regarded as the family’s joint experiences as well as the family members’ individual experiences of and in their everyday life-world in which social relations and actions take place, thus forming their family life.

AIMS

The overall aim was to explore the family's experiences of MD and the meaning of MD for family life, for the ill person, the partner and the children. The overall aim was investigated in four studies presented in papers **I-IV**:

Paper **I**. The aim was to describe what happens, and how to manage MD in a family.

Paper **II**. The aim was to describe the ways of living with MD in families.

Paper **III**. The aim was to elucidate the meaning of MD in family life from the viewpoint of the ill parent.

Paper **IV**. The aim was to elucidate the meaning of parents' MD in family life from the children's perspective.

METHODOLOGY

The decision to employ a qualitative design was a consequence of the intention of this thesis to study the subjective meaning of individuals, which refers to the tradition of interpretation (Patton 2002 p. 115); accordingly, hermeneutics is used in all four studies. It is hermeneutic in the sense that text from interviews was interpreted in the context of family life. Furthermore, in paper **III** and **IV** the philosophical foundation has been derived from the French philosopher Paul Ricoeur; the spoken word expressed in narratives, transcribed and textually analysed, makes it possible to explain the text and also to attain understanding. Explanation is possible by means of a structural analysis of the text. Understanding is obtained through an interpretation guided by the structure of the text and what the content indicates (Ricoeur 1976). These two components, explanation and understanding, are regarded as dialectical in the sense that they follow on behind each other and they are both prerequisites of interpretation. The idea is that the text is separated from the narrating person. The content of the text is analysed, not the person, and the content is thus no longer related to the individual. The reader appropriates the text. By appropriation, the text and its content are liberated by the reader and what earlier was unknown the reader now makes his own. In other words, the reader acquires knowledge (Ricoeur 1976).

According to hermeneutics, it is important to give information about both the perspective from which the researched problems are viewed as well as from which standpoints the researcher approaches these problems (Patton 2002 p. 115). Consequently, a description of the pre understanding is necessary. As a professional, I am a registered mental health nurse and have cared for patients suffering from MD. As a lecturer in health care sciences I have theoretically taught those who intend to be nurses and registered mental health nurses about MD. Further, in connection with nursing students' practical training and work-integrated learning, I have asked nurses in the psychiatric trainee wards about the extent to which families and children are invited to talk about their situation. In most places, family members were not offered such a possibility explicitly, unless they took the initiative themselves and asked for a meeting. This meant that family members, in a vulnerable situation also had to acquire specific knowledge about unspoken health care routines and rules. Children were not at all intended to be receivers of information.

A fundamental idea behind this thesis was that there are several levels within a family, of their experiences and understanding of their family life. One level might be a family's mutual experiences and understandings, which are also the level at which they communicate with each other; a family level. Another level is the family members' individual experiences and understandings, which they sometimes communicate to their family although they may also be kept private. To make it possible to study both levels, it was decided to collect data at the family level by means of group interviews with families, and data at the level of family members by means of individual interviews.

Accordingly, two qualitative methods for analysis, with their differences regarding the ability to reach breadth and depth were planned. The concept analysis of family by Stuart (1991) were employed in this thesis to establish the criteria for inclusion and exclusion of participants.

To collect data in all the four studies, a narrative research interview (Mishler 1986) was selected as a convenient method to approach the families in their specific situation as regards MD. Two methods for analysing data were used. Content analysis (Baxter 1991) was chosen for study **I** and **II**, and a phenomenological hermeneutic method of interpretation (Lindseth & Norberg 2004) was chosen for the analysis in study **III** and **IV**. These methods will be described further on in this thesis. Other methods were considered, such as Grounded Theory, which has been used in family-related research (*cf.* Badger 1996, Rose 2002), and in caregiving research (Karp 2000). This method was excluded because of its emphasis on social processes, which was not the intention of this study. Quantitative methods with, for instance, questionnaires and self-rating scales were not considered appropriate for the purpose of this study as it focuses on a deeper understanding of experiences and meanings.

METHODS

By way of introduction, an overview of the four papers presented in this thesis is shown in Table 1. This is followed by the descriptions of the methods employed in the thesis.

Table 1. An overview of paper I-IV showing aims, participants, data collection and data analyses

Papers	Aims	Participants	Data collection	Data analyses
Paper I	To describe what happens, and how to manage MD in a family	A family unit, including the member with MD and the children Participants 3	Narrative interviews a group interview and individual interviews (a total of 4 interviews)	Case study Qualitative content analyses
Paper II	To describe the ways of living with MD in families	The family unit, including the member with MD, the partner and the children Family units 7 Participants 18	Narrative interviews a group interview (a total of 7 interviews)	Qualitative content analysis
Paper III	To elucidate the meaning of MD in family life from the viewpoint of the ill parent	The family members, ill parents, who fulfilled the criteria for MD Participants 8 representing 8 family units	Narrative interviews individual interviews (a total of 8 interviews)	Phenomenological hermeneutic method
Paper IV	To elucidate the meaning of parents' MD in family life from the children's perspective	The children living in a family with a parent suffering from MD Participants 8 representing 6 family units	Narrative interviews and drawing a picture individual interviews (a total of 8 interviews)	Phenomenological hermeneutic method

Narrative interview

Narrative interviews are used in paper **I-IV** and make it possible to access other people's inner thoughts and perspectives. The underlying assumption is that inner meanings may be available and are explicitly related in stories (Patton 2002 pp. 340-341). In a narrative interview, the interviewee is asked to narrate candidly, in response to an open question, and is also given the opportunity to formulate and reformulate his/her story. The meaning is constructed in interaction between the interviewee and the interviewer (Mishler 1986 pp. 35-65, Riessman 1993 pp. 1-24). This allows the interviewer to relate him/herself to the content of questions and to the interview situation as a "speech event", rather than relating to the interview as a situation where the questions represent variables, which the answers should fit (Mishler 1986). When interviewing children, one approach is to ask them to tell a story. Children almost always have something to relate, and if the child is given enough time the interviewer may find him/herself gaining access to the child's thoughts (Doverborg & Pramling Samuelsson 2000 pp. 9, 32, Kortessluoma Hentinen & Nikkonen 2003).

Settings and participants

This study was conducted in the south west of Sweden in 2004 and 2005. The meetings with the families took place in a psychiatric outpatient clinic and in the families' homes. Criterion sampling was used to include and exclude participants. The selection was also consecutive (Patton 2002).

Families who were included had an adult member who had experienced an episode, lasting at least four months, or recurrent episodes of MD diagnosed by a board-certified psychiatrist according to DSM-IV, a partner (although not necessarily), and children living at home or who had recently moved out (less than a year previously). There were no limitations regarding language, as long as the family members understood and could express themselves in Swedish. The experiences should come from family life experienced in Sweden over a period of at least two years. The criteria for inclusion were broadened during the data collection since also older children, not still living at home, wanted to participate and contribute to this study.

Exclusion criteria were: psychiatric disorders coexisting with MD according to DSM-IV, Axis I or II diagnosis (American Psychiatric Association 1994), family members who were not available for interviews and children younger than four years. The person with MD could also exclude other family members. One participant excluded a partner and some other participants excluded children, as they did not want them to participate for the sake of the child.

Fifty patients were identified from the care register and received an information letter. Seven families were included in this way in addition to the two families with the help of health care professionals. The families were mainly single-parent families with a mother as the head of the family. This reflects

the preponderance of women suffering MD (Rorsman *et al.* 1990, Kornstein 2000) as well as the greater risk of women contracting MD as described by Hirschfeld (2000) and Hammen (2003).

A total of 21 persons participated in the study; 18 participants in the group interview with the family, 2 persons with MD (belonging to families 2 and 8) who participated without their families and an adult son (belonging to family 5) who did not participate in the group interview. Family 9 left the study on my decision because of their family situation. An overview of the number of family members in each family and how some of them participated in the data collection is shown in Table 2.

Table 2. An overview of the number of family members in each family and their participation in data collection

The whole family	The group interview with the family	Interview with the depressed person	Interview with the partner	Interview with the children
Family 1 Mother, Daughter, Son	Mother Daughter	Mother		Daughter
Family 2 Mother, Daughter, Daughter, Son, Son, Son		Mother		
Family 3 Mother, Father, Son, Daughter	Mother Father Daughter	Mother	Father	Daughter
Family 4 Father, Mother, Son, Son	Mother Father Son Son	Father	Mother	Son
Family 5 Mother, Daughter, Son, Son	Mother Daughter	Mother		Daughter Son
Family 6 Mother, Daughter, Daughter, Son	Mother Daughter	Mother		Daughter
Family 7 Mother, Son, Son, Daughter	Mother Son Daughter	Mother		Son Daughter
Family 8 Mother, Son, Daughter		Mother		
Family 9 Mother, Son, Son, Son, Daughter	Mother Son			
Number of participants	18	8	2	8

In paper I, a family consisting of 3 family members participated and the family was regarded as a case. The family members were a mother with MD, 46 years of age, university educated and unemployed; a daughter, 11 years old and attending a compulsory school; and a son, 19 years old, attending an upper secondary school who had just moved to his own apartment. A third child, a teenage boy, did not participate in the study. Comments relating to him have therefore been omitted. This family was chosen because it fit well in with the inclusion criteria for this thesis and gave rich data in all the interviews.

In paper II, 7 families, in all 18 persons, participated; five single-parent families with the mother suffering from MD and two families with a partner where the mother in one family and the father in the other family suffered from MD. There were 9 adults (7 female, 2 male) between 35 and 52 years of age (median 46 years). Likewise, 9 children (5 female, 4 male) aged 5 to 26 years (median 16 years) participated. Four persons with MD were not working due to unemployment or being on sick leave while the other three were working. One partner was on fulltime sick leave, also suffering from MD, while the other worked. All the children participating were studying at schools at different levels.

In paper III, 8 parents who suffered from MD, 7 female, 1 male, aged 38 to 50 years participated (median 46). Three of the parents were employed, four parents were partly or fully on sick leave, and one was studying.

In paper IV, 8 children, representing 6 families, of parents suffering from MD participated. The children, 1 young boy, 1 young girl, 2 female youths and 4 young adults, were aged from 6 to 26 years (median 17.5) and attended schools at different levels.

The age differences in the participating children in this thesis, from 5 to 26 years, are wide. There was a deviation from inclusion criteria, which were broadened concerning the 2 young adult children aged 26 years. They had not lived with the family in the past year, but one of them had moved in and out of the family since the age of 19. However, regarding the children's participation, the ill parents were, as mentioned earlier, free to define what their family was and these were the children the parents decided to allow to participate.

Data collection

Health care professionals in psychiatric outpatient clinics were informed about the study and asked to mediate the contact with families fulfilling the inclusion criteria. It was planned that as soon as they had identified a patient diagnosed by a psychiatrist as suffering from MD, likewise fulfilling the inclusion criteria, the health care professionals would ask the patient if he or she and the family were willing to participate in the study, and also hand over an information letter. Not until signed informed consent had been given was it

possible for me to contact the depressed person, or a specific family member. This contact was made within a week and by telephone. More information about the study was given and the time and place for a meeting was arranged. This was the procedure used over a period of seven months and which only resulted in contact with two families.

In the autumn of 2005, contact was made with another county council in south west Sweden in order to include more families. The strategy was the same as described above although we did not succeed in including families from this region. Accordingly, another procedure was designed to be used at the same time and this procedure appeared to be more successful. Now information about the patients was obtained from the care register by one of the researchers with special access. The name, address and telephone number were noted down for the patients who fulfilled the inclusion criteria. They were initially contacted with an information letter containing a presentation of this study signed by the manager and a researcher, both employed at the psychiatric clinical department. Shortly afterwards, the researcher contacted the person with MD by telephone and verbal information about this study was given. Thereafter the person with MD was asked to participate in the study. If informed consent was obtained and the person gave special permission, the name, address and telephone number were handed over to me. I then tried to reach the person with MD by telephone within a week to decide on a day and place for a meeting with the family and to conduct the first interview.

During the meeting, more information about the study was given and written informed consent from the family members was obtained. The parents gave special written informed consent concerning their children's participation, which was also signed by the children. Demographic data such as sex, age, occupation, forms of living together and family structure were obtained in conjunction with the interviews. The time and place of the individual interviews were decided on, and in the case of the underaged children, these interviews were decided on in consultation with the parents. Some families chose to meet me in their own home and others at the open care psychiatric unit. One under aged child decided on a sailing boat as a convenient place for the individual interview.

Interviews

The narrative interviews were conducted in the form of group interviews with each family (I, II) and individual interviews with family members (I, III, IV). A group interview was conducted in order to capture the family's shared meanings (Åstedt-Kurki, Paavilainen & Lehti 2001) and family units as informants were used to *e.g.* explore family health and wellbeing (Åstedt-Kurki & Hopia 1996) and experiences of hospitalization of a critically ill family member (Eggenberger & Nelms 2008). Individual interviews with the family

members were performed to make it possible to gain a deeper understanding and uncover other dimensions of the family's life-world, than would have been possible during the family group interviews. An interview guide was compiled and used in the different studies containing question areas to talk about in the interviews. How an interview question is asked has an impact on the direction of the interview (Mishler 1986). It was important to keep to the "speech event" approach during the complicated situation of, for instance, group interviews with families including both children and the depressed family member. Accordingly, it was felt necessary to compile an interview guide with simple and open question areas to support the interview. The family members were invited to talk as freely as possible on the themes given. Clarifying questions were asked if necessary and in line with the intention of using narrative interviews.

The data were collected from one family at a time, and the interviews were completed mostly within a month of the first interview with the family. First, a group interview with the whole family was conducted. This was followed by a separate interview with the person with MD and then an interview with the partner by agreement. Children, who agreed to participate and were permitted to do so by the parents, were asked if they could relate or write a story about family life when there is depression in the family. The children were told that they could also draw pictures. Only one participating child who was 6 years old did so in study IV. The interviews with the other older children began with first the main question for study IV, and thereafter the same procedure as with adult family members was used. In total, 25 interviews were conducted and the lengths of the interviews are shown in Table 3.

Table 3. The length of the interviews in hours (h) and minutes (min) conducted with the families

Family	Length of interviews	Length of interviews	Length of interviews	Length of interviews	Total (h & min)
	Family unit (min)	Depressed person (min)	Partner (min)	Children S (son) D (daughter) (min)	
1	87	83		53	3 h 43 min
2		59			59 min
3	84	55	58	30	3 h 47 min
4	43	81	68	21	3 h 33 min
5	71	64		S/53 D/77	4 h 25 min
6	68	68		60	3 h 16 min
7*	83	72		S/48 D/39	4 h 2 min
8		67			67 min
9	83				1 h 23 min
Total (h & min)	8 h 39 min	9 h 9 min	2 h 6 min	6 h 21 min	26 h 15 min

* The Case study

During the group interview, special consideration was given to the family members and each member was allowed sufficient time to express her or himself. Special attention was paid to the atmosphere. The interview was performed with respect so that no family member would feel hurt or neglected. The intention was that all the participants would be able to leave the interview with a feeling of dignity. The same applied to each of the separate interviews. The interviews were tape-recorded, and transcribed by a secretary. I listened to the interviews and compared them with the transcripts, which were corrected if necessary before the start of the analysis.

Data analyses

Papers I and II were analysed by using content analysis. In paper III and IV, a phenomenological hermeneutic method of interpretation was used.

Content analysis

Content analysis is a well-known method for descriptive analyses of text, and may be performed quantitatively (Weber 1990, Neuendorf 2002, Krippendorff 2004) as well as qualitatively (Baxter 1991, Krippendorff 2004, Graneheim & Lundman 2004, Elo & Kyngäs 2008). Content analysis was developed as a method for analysing a body of text and has been used to analyse mass communication in order to uncover underlying meanings and to predict events (Krippendorff 2004). However, it may also be used as a technique within a method, such as grounded theory and ethnography. Conceptual components as a body of texts, a research question, a context, an analytical construct and validating evidence are central in content analysis. The research question/questions guide the analysis. The context is emphasized and mentioned as being important, as the result of the analysis is inferences that mirror the context in which the body of text, the data, appeared. The reliability of content analysis is emphasized and the most important form is replicability (Krippendorff 2004 pp. 81-89). Content analysis is performed step by step in order to describe prominent patterns and themes (Patton 2002 pp. 452-471). In content analysis, the text is divided into units, which are then sampled in accordance with the research question. Thereafter, the units are labelled with codes describing the content of each unit. Then, the text is reduced and rewritten in categories and themes (Krippendorff 2004 pp. 81-89).

This method has been used in interview studies of experiences of long-term illness by, for instance, Jerlock, Gaston-Johansson and Danielson (2005), Melin Johansson *et al.* (2008) and Jönsson Dahlqvist *et al.* (2008). The method was used because it makes it possible to grasp what family life related to depression has to contend with in a broad sense. The qualitative thematic content analysis according to Baxter (1991) was used for both of the studies.

Paper I

A case study approach (Yin 2003) was used to study the family as a whole using data from both the family unit as well as the individual members. A

case study, convenient for studying current events in connection with a real life context, preferably answers questions of “how” and “why” (Yin 2003). The *why* question was not appropriate for this study and was accordingly not used. A *what* question was considered to be more scientifically correct. A case, a family in this study, involves several units of analysis. These units (text from the interviews with the family unit, the mother, son and daughter) were regarded as domains as described in qualitative thematic content analysis according to Baxter (1991). Consequently, this case study examined four domains, namely, the meaning of family life and major depression to the family as a unit, the son, the daughter and the mother.

These data were drawn from interviews performed with family 7, as shown in Table 3. The answers from three of the question areas were analysed: what family-life is like at the onset of depression, what an ordinary day is like with depression in the family, and what it is like when depression dissipates. The interview texts were sorted into meaning units corresponding to “what happens” and “how to manage”. The coding process started by first coding all the answers to “what happens” followed by the answers to “how to manage” according to content. Codes with a similar content were grouped together into themes, which were then labelled. A chart was created containing the four domains (the meaning of family life and major depression to the family as a unit, and to the son, the daughter and the mother individually), as was also the case with the question areas concerning the onset of the depression, an ordinary day and when the depression dissipated. This strategy preserved both the family’s collective experiences of family life and those of each individual member. A within-case analysis (Ayres, Kavanaugh & Knalf 2003) was performed and the domains in each theme were subsequently compared and the text with the similar meanings were combined into a single text.

Paper II

Qualitative thematic content analysis according to Baxter (1991) was employed in the analysis of the answers from three question areas drawn from the group interviews with the families: tell me what an ordinary day is like with depression in the family, what happens in everyday life and what happens to the family members. These question areas were regarded as the three domains for analysis. The analysis started by reading the text from all the interviews question by question. The text was then divided into meaning units, which were then condensed. A meaning unit may contain statements by all family members when they talk together about an issue or by an individual family member. Each condensed meaning unit was then coded according to its content. Additionally, codes were marked to make it possible to identify whether they were derived from text narrated by the family member with MD, the children or the partner. Thereafter, all the codes from the three domains were compared and codes with a similar content were grouped together. In addition, the content in each group was interpreted to form themes, which appeared in all the domains in accordance with Baxter (1991). Thereafter, texts with a similar content were combined.

Phenomenological hermeneutic method

A phenomenological hermeneutic method was used since the content of the interviews appeared to make this a convenient method. Phenomenological hermeneutic as a method for analysis and interpretation was developed at the universities in Tromsø and Umeå (*cf.* Lindseth *et al.* 1994, Lindseth & Norberg 2004). This method is used in several studies of patients suffering from long-term illnesses and their relatives, especially in narrations of lived experiences as for instance in Svedlund and Danielson (2004) Edwall *et al.* (2008) and Ringdal, Plos and Bergbom (2008) and is underpinned by the philosophy of Ricoeur (Ricoeur 1976). When using phenomenological hermeneutics, the interpretation alternates between the text as a whole and its parts. The method is performed in three steps: first, a naive reading is carried out in order to acquire a sense of the content and ideas guiding the second step, which is structural analysis. Meaning units, which are parts of the text meaning the same thing, and themes are identified and then organised. The third step is an interpretation of the text as a whole. The interpretation is made through reflection on the other two steps and the scientist's own knowledge (Lindseth & Norberg 2004). Using this method for interpretation makes it possible to elucidate a deeper understanding of the meaning of depression in family life from the ill parents' perspective as well as from the children's viewpoint, unlike when using the method of content analysis, which presents broad descriptions as in paper I and II.

Paper III and IV

In paper III, the phenomenological hermeneutic method of interpretation (Lindseth & Norberg, 2004) was performed on the data from four question areas: what is it like to live with depression in the family, what happens to everyday life when you are suffering from depression, what is family life like when depression arrives, and what it is like when depression dissipates.

In paper IV, the analysis was based on five question areas which were: what is a normal day like when a parent is suffering from depression, what is it like to live with depression in the family, what happens to everyday life when there is depression in the family, what is family life like when depression arrives, and what is it like when depression dissipates.

The stepwise analysis started with the naive reading which resulted in the naive understanding, which, in turn, guided the analysis in the next step. A structural analysis of all the interviews, now regarded as one text, was performed. Meaning units were identified and condensed in everyday language. In paper III, the condensed meaning units were first interpreted and divided into preliminary sub themes and thereafter into sub themes according to meaning. The step involving preliminary sub themes was not used in paper IV where the meaning units were instead directly interpreted into sub themes. The sub themes were reflected on in relation to the text as a whole and their meanings further interpreted into themes. Then, the themes

and sub themes were reflected on and compared to the naïve understanding to make possible a new understanding of the text. In the last step, a comprehensive understanding was arrived at by an interpretation of the text as a whole through reflection on the other steps as well as the authors' own knowledge.

Ethical considerations

Ethical considerations were guided by the World Medical Association Declaration of Helsinki (2000), with special attention paid to relevant issues, which were: protection, vulnerability, confidentiality, informed consent, the procedure for including or excluding people from the study, the procedure for contacting the people for interviews, information letters, how to establish coherent agreements, the possible need of help and support for the interviewed people as a consequence of the interview situation, and the contributions to the study.

Special efforts were made concerning the information about the study. Bills were posted at the psychiatric outpatient clinics entrances and on public notice boards. The written information to the families was specifically tailored for small children, adolescents or adults. Informed consent was obtained in several steps. First written informed consent was obtained, permitting health care professionals to give the patients' name and telephone number to me. After the first telephone contact the specially tailored information in writing for the family members was sent by mail. In conjunction with the interviews, the family members signed the informed consent and parents' signed a special consent form for the children who participated. Before the start of each interview, the questions about the family members participating of their own free will and the right to refrain from participating were discussed with the participants.

The children's participation has been paid special attention. The decision to also invite children to give their view of family life when a parent is suffering from MD was based on the presumption that children as family members are aware of what is happening in their family and are also affected by the family's situation. Consequently, children's contributions during the interviews as well as to the data are regarded as equally important as the adults' contributions. Further, as a precaution, a strategy was prepared for professional support for the family members. The study as a whole has naturally been influenced by ethical considerations, which are also reported in each paper. The Ethical Committee of Science at Lund University has approved the study (LU-68-03) as has The Regional Ethical Appeal Board in Gothenburg (GU 379-04).

FINDINGS

The families' experiences of MD were trying and resulted in the families and children experiencing severe stressful life situations. The children were aware of their parent's MD, were involved in managing everyday life and were emotionally affected by the situation (II). However, the children's experiences and interpretations of MD, and likewise their strategies for managing the situation, may be quite different from those of a parent (I). The ill parents' suffering and dignity were revealed as simultaneously present in family life. The movements between suffering and dignity complicated family life. Dignity was threatened by the awareness that suffering in MD recurrently appears. Dignity repeatedly had to be restored for oneself and the family, and the family's dignity in front of others outside the family circle had to be restored (III). For the children, the meaning of the parents' MD in family life was a sense of responsibility and loneliness. Inherent in the children's responsibility was their striving for reciprocity, and inherent in children's sense of loneliness was their yearning for reciprocity. A parent's MD put the child in the position of the observer, thus experiencing loneliness. Children compensated for ill parents in family life and for their lack of health with a sense of responsibility. Children's family life alternated between responsibility and loneliness as they waited for reciprocity in family life to return to normal when the ill parent, possibly, recovered (IV).

A troublesome family life with MD

The findings showed that uncertainty invaded family life, and from the single family's perspective, MD was like *a stealthy intruder*, which caused the family to lose control of family life, which became unpredictable until depression dissipated (I). From the perspective of the whole families, *uncertainty and instability were affecting everyday life* and temperamental emotions had an influence on the atmosphere. Dimensions of uncertainty concerning the state of their health, their precarious financial situation and the mark depression made on working life occupied the family members (II).

The family members in the single family were drained of their strength, and *moved slowly to helplessness*. The mother was weighed down by her inability to cope and the son by the thought of possibly being one cause of her sadness. The family members followed the mother's mood, which especially influenced the daughter (I). Similar consequences were found in the whole families, as *they were forced to relinquish control of everyday life*, and their loss of energy made them unable to manage the family's everyday life. The children became worried and wanted to help, but were unable to do so. They lost energy as well, and tiredness was a challenge to the whole family (II). Further, from the ill parents' perspective, *being worthless* was revealed as incapacity in thoughts and actions, and the inability to participate in social life. The ill parents were not available to the family as before. Poor self-confidence, a dependency on structure to perform in everyday life and their unwillingness became visible.

The ill parents felt guilt for burdening their family (III). The families' *everyday life became hard* and made demands on everybody in the family with the responsibility shifting between family members. The planning of everyday life failed because of inability and a lack of practical routines. However, some depressed parents managed to take full responsibility when it was necessary, but just routinely, mostly dutifully and without pleasure. Children took over responsibility on their own initiative, and this responsibility could weigh them down (II). The ill parents *were unsatisfied* and did not trust to their own and others capability, and were thus guarded. Their doubts included health care professionals' competence as well as the own experience of the illness. Disappointment with a boring family life and at being misunderstood also became visible (III).

The children *felt discomfort* and were sensitive to their ill parents' mood and to changes in the atmosphere. They did their best not to be disruptive in order to avoid being criticized. However, feelings of being violated in their own family became visible as the children took their ill parents behaviour personally and became self-controlling. The children worried about the ill parent who could become worse or commit suicide. The children also described dreading not being available to their family members when needed. Furthermore, children experienced anxiety physically. However, they did not succeed in communicating to the ill parents that they also felt bad and needed support (IV). The ill parents *felt hopelessly bad* with a general feeling of being changed and extremely tired. They felt seriously ill and were not able to concentrate on family life and instead turned inwards in sadness. This prevented interaction in the family. However, they were careful in social life to conserve their energy for the family. Similar to the children, the ill parents' thoughts of suicide were frightening as it was at the back of their minds. It created a dilemma related to themselves, the burdened family and the need for help regarding the question of lying about being suicidal in conjunction with seeking professional psychiatric help (III).

The family units *lived on the edge of the community* when they at times lived in seclusion. Uncommunicative behaviour in everyday life was common. Even if the ill parents had feelings of meaninglessness, the needs of the children made it easier to participate in family activities. The parents thought, incorrectly, that children did not notice their introvert behaviour. The ill parents avoided social life and friends were chosen carefully (II). From the children's perspective, they *were out of it* and unable to interact in family life. They were excluded by their parents as well as children both avoided and excluded themselves off the influence of MD. As their relation to the ill parent changed, children became silent as did their family life. Accordingly, they were not acknowledged which they needed in order to understand family life and to acquire useful knowledge for personal strategies to manage their own family life. The opportunities for togetherness became fewer and children were left with little response (IV).

A barely acceptable family life in the shadow of MD

The single family members tried to help each other to lead a normal life during the parent's MD and in this way *they saved the situation*. The son made efforts to make matters easier and the daughter as well as the son gave up other plans. The mother tried to keep up her appearances but wanted the children to be more responsible although the son thought they were doing the best they could. But the family was in need of help (I). As regards the children's view, they *were attentive* in their thoughts and senses to collect relevant information about their ill parent's mood. They looked for clues such as *e.g.* tiredness and stressful behaviour. However, they also noticed when the parent regained energy. Family life became unpleasant and unsafe when the children unintentionally overheard their parents' discussions thus becoming aware of serious family conflicts and the ill parent's thoughts of suicide. To gain some control over the situation, the children listened carefully to their parent's voice to determine his or her mood, in addition to which they needed to watch over the ill parent both openly and unobtrusively. Also siblings' mental health was the subject of the children's attention together with their worries (IV). Further, in the single family it was a question of *protecting oneself and others* as the family members watched over each other. The mother's way doing this was to cancel her activities, the son spent the weekends with his friends to avoid being a source of irritation and the daughter withdrew to her room or was silent, which was a good way of protecting herself, especially from arguments. However, the school was a breathing space for them (I). From the perspective of the ill parents, *they were active* and participated in social life to a lesser degree and on their own terms. Further, they managed to maintain a constructive attitude and were a driving force in easing the family's stressful situation, and the ill parents' willingness became visible. Ill parents also communicated to help the family to understand MD (III).

The family units' view was that *despite everything a way out could be found*. The families as well as their members had their own ways of coping and finding satisfaction. Doing something together outside the home was the same as having a good time. The parent's depression did not prevent some of the children from inviting friends to home. Some children were able to turn the parent's MD off when they were at school. And children were a reason for parents living and struggling through depression (II). The ill parents also struggled to *maintain parenthood* with both sensitivity and respect towards the children. The parents tried to uphold family rules and in this way were consistent parents. The ill parent's understanding of the children's reactions to MD became visible, likewise that they were protective and thought children were the most important. And the parents showed interest in their children's life (III). The children *were considerate*, while taking responsibility for the family's everyday life, and as a result they took the family out of acute situations. However, the children were burdened as their helpfulness intruded on their schoolwork and recreational time. Children's loyalty became visible when they gave priority to the ill parents' needs. Children also accepted family life "freezing" due to MD. Further, they took responsibility for their behaviour and scaled down

their activities and demands on the ill parent. The bonds between the children, the parents and the family remained strong as the children felt obliged to maintain contact with the ill parent. Their feelings of responsibility, which follow the children into adulthood, became visible. Additionally, children acknowledged their parents' efforts to show love and affection (IV).

Conveying things that are beyond words was the efforts of the single family to make their situation understandable to themselves and to others. The daughter thought it was difficult, but had herself told the school nurse. The son did not ask his mother why she was sad. Just a few of the children's friends knew. The mother adjusted her version depending on whom she speaking to as she felt that other people generally made light of her situation. Moreover, *the dispersal of shadows* was a way of describing what invigorated the single family. The mother made arrangements so the family could experience joy and not just sadness. According to the son, the mother's recovery affected in the family's health, and the daughter experienced fewer arguments. The mother had learnt about how depression recurrently 'punctured' her life and how it affected her (I). Similarly, the ill parents *were satisfied*, which was based on the belief in the honesty in the family and the awareness of belonging together with the family. The family ties protected the parent from suicide. Ill parents had hope for a future after the depression and were able to feel that they were improving mentally as self-knowledge expanded and their tools for preventing depression increased. Being observed in this situation by others was a way of being acknowledged (III).

DISCUSSION

The everyday life-world, expressed by Schütz (1999) in his philosophical works will contribute to elucidating further the meaning of MD in family life in the following discussion.

MD changes the family's everyday life-world

The findings in this thesis show that the family's everyday life is affected by uncertainty when a parent suffers from MD. The uncertainty contributed to serious changes in the family's life both momentarily at the onset of MD but also in a longer perspective. Badger (1996) described the changes the family members, except the person with MD, go through as the psychosocial process of managing the uncertainty as well as the demands of family life. However, findings in this thesis show that uncertainty is a feeling the whole family experiences in their everyday life-world. Here, the concept analysis by Penrod (2001), who describe uncertainty as a dynamic state of inability to predict consequences, which, in turn, lead to feelings of discomfort, is useful for understanding the strain this brings about in the family. From a longer perspective, this gives a view of stressful family everyday life experiences when the family members do not know how to act as regards the whole family or the individuals. Schütz (1945) writes that actions place a person in relation to time in the process of planning and accomplishing an action. However, if the planning process of creating managing strategies for MD is influenced by uncertainty, a kind of vacuum in time appears early on where family life "freezes", which was shown in this thesis and is especially evident in the children's everyday life-world. Children's relations to time consisted of the time spent waiting and thus experiencing loneliness. How the children in their loneliness waited for signs as well as answers to their questions in a situation where there was decreased reciprocity was elucidated. Mordoch and Hall (2008) argue that if children have knowledge about their parent's mental illness, they will be better prepared to determine how to adjust their behaviour and actions to the situation.

In this thesis, the findings showed that children became observers of, as well as confused by, the changes in ill parents' mood and behaviour, which indicates that the children were unable to interpret the course of events in the family. According to Schütz (1932), an observer's interpretation may be made indirectly and he describes three possible ways of interpreting the other person's actions. First, the actions may be understood and interpreted based on the observer's own similar experiences. Second, if there are no such similar experiences, the interpretation may be made based on knowledge about how the other person usually acts. Thirdly, if the situation is new or if the person's experiences are insufficient, he or she has to interpret the whole process of actions to the best of their knowledge. When a parent falls ill with MD, children probably interpret the new situation in accordance with the third step, and this may repeat itself several times depending on the child's age and ability to

relate to earlier experiences. However, this is a critical period when the child is vulnerable and at risk of *e.g.* internalizing symptoms and guilt (Beardslee 1998) and there is a large body of scientific literature highlighting the risk of children of falling ill as a result of parental MD (*cf.* Brennan *et al.* 2002, Kane & Garber 2004, Sarigiani *et al.* 2003). It is when a parent has been given the diagnosis MD, that the family should be invited to talk about what family life is like with a parent suffering from MD. The children in particular should be helped to acquire knowledge so that they can recognize the ill parent's acts thus be able to interpret them. Otherwise it is possible that in their loneliness, children's interpretations of the situation could lead to, for instance, guilt (Beardslee 1998). However, preventive family intervention is directed at both parents and children. One of its benefits is that it helps the family to communicate about depression, and participating in the intervention increased family function for some years (Beardslee *et al.* 2007). An increased offering of interventions also from other perspectives and an adjustment to the families' needs in a flexible organization could make it easier for families to participate.

The findings showed that the family members were extra burdened by family everyday life because MD changed the circumstances and the interplay in family life. The ill parent's tiredness and loss of energy, also affected children's everyday life. Also here, the prolonged perspective of MD and the relation to time is noteworthy and in line with van Wijngaarden *et al.* (2004). However, they noted, from the family care giver's perspective, that the children were affected by the situation with physical and mental problems, which influenced their behaviour and their results in school. However, what should be regarded most seriously was that depression had most consequences for the children of parents in the non-acute phase (Wijngaarden *et al.* 2004). According to Peisah *et al.* (2005), the length of exposure to a parent's MD was an important factor in children's ill-health, which was the situation for the children in this thesis with parents suffering from a long-term illness.

Findings pointed to a complex state of ill-health in the families, with the ill parent experiencing a general feeling of being changed, tired as mentioned before, sad and incapable. The ill parents were suffering, and findings show that ill parents did not become reconciled with their suffering but in a broader sense with the situation in family life that MD brings about. Restoring of dignity cannot be regarded as an ending of the suffering (*cf.* Wiklund 2000) but as an ongoing process that is constantly interrupted by new episodes of MD. The alleviation of the suffering was temporary as the suffering started again. In the case of the children, their ill health was related to their sensitivity to the parent's mood. For example, they felt violated by their parents' behaviour, which, in turn, the parents felt unable to control due to MD. Furthermore, there was an atmosphere in the families of silent worry about death, in the shape of the possibility that the parent might commit suicide. There are different dimensions of the worry about suicide. The parents fear that MD is pushing them towards being suicidal, and the children fear that their parent

was already considering to committing suicide because they understand that the parent feels awfully depressed, and children fear it could happen at any-time. Moreover, nobody in the family dared to mention it as a family matter. This is reminiscent of the silent process in persons who turn suicide over in their minds, as described by Talseth, Gilje and Norberg (2003) in an attempt to elucidate the struggle for consolation in suicidal patients. They describe an inner and an outer dialogue, where the inner dialogue is a painful experience of despair with relationships as well as with life. Simultaneously, there is a longing for closeness to others. However, this need for others is difficult to communicate, and therefore not available to the children described in this thesis. Furthermore, the children's knowledge at hand (Schütz 1945) seemed insufficient and children had no access to strategies for managing such a serious situation. The findings also highlight the extension of the problems of suicidal thoughts into a family matter. As the prerequisite for receiving professional care in a tense situation was to be suicidal, an ethical dilemma arose in ill parents concerning whether to disclose suicidal thoughts or not because the consequences for the family were impossible to predict. According to Schütz (1945), it is possible to control the everyday life-world. However, the nature of the suicide problems is such that they are difficult for a family to master, and both the ill parents and the children suffer.

Face-to-face relations in the family's everyday life-world

The family members' joint everyday life-world, which Schütz (1945) states is founded on face-to-face interactions with others, is interrupted when family members stop talking to each other. The ill parent withdraws, due to MD, from family life and is not able to communicate the children, and the children become quiet, not knowing how and what to communicate and the family as a unit temporarily withdraws from social relations. It becomes a chain of broken social connections. Moreover, the situation of MD in the family was difficult to describe.

However, there are several reasons for the prevention in interaction, *e.g.* ill parents feelings of meaninglessness and their belief that children were unaffected by the parent's withdrawal. The children felt that they were unable to interact in family life as a result of being excluded by their parents in several essentials respects regarding their family life. Being "unhappily disconnected" was the meaning of loneliness described by Kristensen (1995) when children aged eight to ten years were investigated on the topic. An interrupted face-to face relation could mean loneliness in the form of an unhappily disconnection even for adolescent family members and adults. Depressed parents, for instance, described by Pihkala and Johansson (2008), were aware of the silence in the family and both feared and longed to begin the dialogue with their children, and the broken communication was one reason for participating in family intervention. However, in this thesis, children deliberately distanced themselves, as also described by Mordoch and Hall (2008), from their family life with MD as the children were in great need of peace in mind and enjoyment.

Mastering in the family's everyday life-world

In this thesis, the families strived to manage their family life both on an individual basis and with contributions from family members in different group constellations. They made efforts to help each other to get back to an acceptable level of family life. When a person performs an action "in the living now" (Schütz 1945), the intention is to deliberately make a change. Accordingly, the family members acted in everyday life to partly compensate for each other as a strategy for not making the situation worse and partly to compensate for the ill parent's inadequate contribution to family life. This is in line with Skärsäter *et al.* (2003a,b) who described how family members temporarily took over tasks the ill family members otherwise performed. However, in the present thesis it was mainly the children who did this. Their attention was focused on collecting information and knowledge that could explain the ill parent's mood and promote the family's situation. A similar description can be found in studies by Garley *et al.* (1997), Handley (2001) and Östman (2008) where the children's need for information to manage was highlighted. In Schütz's words (1945), the children were "wide awake", which he describes as an active state emanating from excitement of life. Children used their attentiveness to predict the ill parent's state of mood, which gave them a feeling of controlling the situation.

The children took responsibility for their ill parent when they realized the parent could not do it properly him/herself, and they also took responsibility for their brothers and sisters as well as themselves. Probably, the children in these families were born into a life world where they learned from parents and relatives to take care of a vulnerable and ill person, which is in their "knowledge at hand" (Schütz 1945). Because of this, the children think it is a matter of course to take responsibility. However, children have difficulties finding a realistic level and misjudge the situation because of their lack of knowledge and inability to act. In this thesis, the children were burdened with too much responsibility and were left alone in situations where there actually should be adults who take charge (Mordoch & Hall 2008), such as when they perceive that their ill parent is suicidal. In this thesis, the findings also indicate that the ill parents were capable and responsible when they needed to be in order to preserve the family's interests. This involved ill parents' dignity, which at the same time was present in their family life, as described earlier.

The ill parents struggled to maintain parenthood, which on the one hand can be viewed as a part of their responsibility, and on the other as a way of upholding relations with their children. They did their best to uphold family rules, which were important as the guiding principles for their family life. However, the parents also felt frustrated at not being a good enough parent. Nevertheless, parenthood involves both children and their parents and takes place in the family's "joint now", in accordance with Schütz (1945), as a family matter. In addition to Pihkala and Johansson (2008), the importance of parenthood was shown by Skärsäter (2006) who described the concerns for and worries about the children. Further, the findings showed that as the pressure

in family life eased, the family regained health to a certain degree (*cf.* Åstedt-Kurki, Hopia & Viori 1999), as MD and its consequences were taboo, and the worries that the parent might fall ill with MD again were present. In this situation, for instance, an intervention like the health promoting conversations with families performed by nurses (Benzein *et al.* 2008) could make it easier for families to find and acknowledge their own strengths and ways to attain better family health.

Findings from phenomenological hermeneutical interpretations of lived experiences can be used to influence such experience and gain a different insight, which would perhaps make it easier to understand the situation and to change behaviour (Lindseth & Norberg 2004). The connection of findings in paper III and IV to the theoretical context of the concepts suffering, dignity, loneliness, and responsibility do not seem to be normal concepts used in studies related to mental health and psychiatry, which became evident when literature regarding these concepts was reviewed. Accordingly, it could be beneficial to highlight these concepts and, so to say, re-introduce them into the context of mental health as tools for reflection by health care professionals when they support families. Moreover, the concepts can be the subject of a dialogue with the family about family life, which could be used especially in nursing.

Reflecting on and regarding important findings through the lens of Schütz (1999), and to some degree interpreting it even further, this theoretical framework has enriched and strengthened a deeper understanding of the findings as a whole. This highlights the philosophical works by Schütz (1999), where he contributes tools for interpretation of the everyday life-world that could help guide the work of health care professionals with families' mental health. Schütz (1999) emphasises the interpretation of the everyday life-world which is in line with the phenomenological hermeneutics used in this thesis.

Methodological considerations

This study was performed qualitatively, with a foundation in hermeneutics and a life-world perspective on family life. The design was intended to capture different levels of family life related to MD through interviews with both the family as a unit and with the individual family members, and with two different methods of analysis. In this way, it was possible to show the complexity and the suffering MD caused in the families' everyday lives. However, the design of this thesis was perhaps too demanding, as the initial decision to participate rested solely on the family member, the ill parent suffering from MD. Thereafter, the ill parent had to ask the family if they also were willing to participate. This requires courage and strength which perhaps some of the prospective participants did not have at that time. The few participants recruited to this study can to some degree be due to the design. It may also be related to mental health problems. Sanford *et al.* (2003) described a dropout from a sample of 66 persons to 25 in a pilot study of a parent-education group for families living with depression due to the severity of depression. Handley *et al.* (2001) distributed questionnaires to 166 mentally ill parents, which were

completed by only 25% of the parents. This was explained by the stigma, secrecy and fear surrounding mental illness. Heru and Ryan (2004) recruited 39 care givers of relatives with mood disorder and 42% had dropped out after one year. However, the families who participated in this thesis contributed rich interview data. It is, of course, possible to interview family members from different families about their varying family life, but it was important to ensure that the participants were members of the same family in order to satisfy the goal of capturing each family's situation as a whole. Data from one of the families was used in all the studies due to the decision to perform a case study with permission from the family and with material from interviews which had already been conducted. However, it was not felt that this would have a negative influence on the other studies since the family's contributions were then included as part of the larger body of data for these studies.

Being an outsider in the sense of not being employed at the psychiatric out-patient clinic, and having been given the opportunity to be a guest in others' professional domains as well as having been permitted to perform research was a privilege, although with some obstacles. Being part of the clinical staff might make it easier to ask for participation in a study. It would probably be easier to have a closer relation to the health care professionals at a psychiatric clinic, and thus have the opportunity to remind them about the study. Including health care professionals at the early stages of drawing up the study design could be a way to encourage their participation.

The process of including families was certainly complicated and brings up the question of how to make the problems of vulnerable individuals visible and investigate them in research. Finding patients and mediating contacts with a researcher may be time consuming for health care professionals and leads to dilemmas such as the ethical cost and gain for the patients. This is perhaps not sufficiently discussed among health care professionals. For instance, Walter, Cleary and Rey (1998) found that the attitude of mental health personnel towards rating outcomes was that it took too much of their time and even though they knew it meant better care, the majority were not in favour of rating outcome routinely. In the case of this thesis, the strategy of including directly through health care professionals was changed as we realized that a very small number of participants had been recruited. However, identifying the ill parents via a health care register followed by an information letter and thereafter by a personal contact resulted in more families being included. Perhaps this is a method that preserves the rights and dignity of vulnerable individuals; asking them directly for their participation is a way of letting them form an opinion of the value of the study themselves.

The participating families were mainly single-mother families, which reflects the preponderance of women suffering from MD, is to some degree the strength of this thesis. On the other hand, only two men participated, one father was included as the identified family member suffering from MD, and one of the partners was a man. This is a limitation of this thesis as well as the fact that entire families did not participate as family members were excluded

for several family reasons. However, the children's participation strengthens this study of families. The children had opportunities to directly give their view instead of by proxy via adults as in, for instance, Birmaher *et al.* (2004). The minimum age for a child to be included was four years. According to Kortessluoma, Hentinen and Nikkonen (2003), it is possible to carry out qualitative interviews with children 4 years and older, but with children under the age of four other approaches are needed. However, a child of that age did not appear as a participant. But considering the topic of this study, it may be better to set the limit at six years of age or that the child should have attended school, thus having the opportunity to broaden their experiences of family life and be more developed (Kortessluoma *et al.* 2003).

The age differences in the participating children in this thesis can be criticized as too wide and therefore a limitation. However, from a family perspective, it could be regarded as strength of this thesis to not exclude family members because of age, as family structures are specific to each family (Benzein *et al.* 2008). There were, of course, differences between what children expressed about family life due to age, maturity and life experiences. However, the aim of this study was not to compare data from family members from different age groups but to investigate a phenomenon such as the meaning of MD in family life. Each participant contributed from their own experiences of family life, which was both a scientific and an ethical standpoint. The young adults contributed data concerning being an adolescent child of an ill parent who suffered from MD, and also with data concerning the deep devotion to family which follows them into adulthood.

As regards the collection of data with a focus on experiences, the narrative interviews were a convenient way of interviewing when the participants had different levels of life experiences and maturity and when the differences in abstract thinking ability were wide. As mentioned earlier, the interviews were rich in data as the participants had the opportunity to narrate freely. The richness and the nature of the data made it possible to perform the analysis on a level required for both phenomenological hermeneutics and thematic content analysis. Furthermore, the narrative interviews contributed to balancing power relations both in the relation to me as an adult and researcher and to participating parents, brothers and sisters. Power relations, informed consent and confidentiality (Kirk 2007), were some of the ethical issues relating to research with children as participants, which were seriously considered throughout the whole work on this thesis.

In this thesis, content analysis was the choice for papers I and II, which explored the family's situation from the view of the family units. In content analysis, according to Krippendorff (2004) and Baxter (1991), there is an interpretive stage. Therefore, the choice of this type of content analysis was made to fit in well with the phenomenological hermeneutic method of interpretation and its philosophical foundation. A broad illustration of the challenges these families have to cope with was made via the interpretive element in this analysis of papers I and II. The single case study of a family unit contributed to this

thesis with detailed descriptions of experiences of MD in family life. Performing the analysis in several domains in line with Baxter (1991) made it possible to show the different life-worlds the family members experienced as well as what the family members experienced jointly. The content analysis involved interpretation of meaning to a certain level; the labels of the themes are the interpreted meanings of its content. In the other study of family units, data from several family units were also analyzed using content analysis (Baxter 1991). The findings in paper **II** could be criticized as to whether they are the individual's perspectives or the family's. However, the themes must be regarded as describing a family level as they were interpreted from the codes of all family members, which was a different approach to *e.g.* Eggenberger and Nelms (2007) who interpreted the family level at the start of the analytical process.

Hermeneutics contributed to deeper knowledge in papers **III** and **IV** through the use of the phenomenological-hermeneutic method of interpretation (Lindseth & Norberg 2004). Papers **III** and **IV** were expected to add to the knowledge about MD and family life with a deeper understanding from the individual's perspective on the family situation. The views of the ill parents and the children were studied, thus capturing the family's situation while living with MD. The methods complement each other as regards the potential for breadth and depth. The interpretations of findings in paper **III** may, however, be criticized for return to the starting point, the patient; the suffering individual. Nevertheless, the expectations when receiving treatment for MD are that the suffering should come to an end. Even if the episode of MD abates, MD stays in the families in the shape of worries and fears, which constitute prolonged family suffering related to MD.

Quality aspects of the thesis were continually reflected upon in the light of trustworthiness. The presentation of the pre understanding is reported in this thesis, contributes to making visible the context in which the interpretations in this study were made. This makes it possible for the reader to form an opinion about some aspects of the trustworthiness of the findings. Trustworthiness was, for example, established as all interviews were conducted, listened through and corrected if needed by the same person who carried out the analysis (Rose & Webb, 1998). Further, in all the papers the analyses moved between the parts of the text and the whole text, which is a way of reflecting and perform analysis in accordance with hermeneutics. The three authors of the papers in this thesis carefully read and reread the transcribed texts as well as the analysis, and discussed the analytical processes, which were then revised. Finally, findings were scrutinized and discussed. This was also the process used to enhance intellectual rigor (Patton 2002 p. 570). Furthermore, inherent in the analytical process in the phenomenological-hermeneutic method of interpretation in papers **III** and **IV**, there is a strategy for ensuring trustworthiness as the three steps of the analysis were compared to each other and thereafter corrected as a way of validation (Lindseth & Norberg 2004). However, the interpretive process in analysing is also a process of balancing the interpretations so that they elucidate the meaning in a truthful

way, and in the best possible way not overinterpreting the data, which is the responsibility of the researcher.

Generalizing findings from a qualitative study like this is not possible. However, transferring the findings (Leininger, 1994, Patton 2002 p. 581-588) to other families in the same situation living with an adult family member with MD is possible, which hopefully will bring about a deeper understanding of the family's everyday life-world and make their situation more visible, which was the intention of this thesis.

CONCLUSIONS

This thesis shows how the whole family's everyday life-world is changed and complicated by a parent's MD. The family's everyday life is affected by uncertainty both at the onset of MD but also in a long-term perspective, and uncertainty is a feeling the whole family experiences in their everyday life-world. The ill parent's suffering from tiredness is a state of exhaustion that also involve in the children's everyday life. Family members become extra burdened by changes in the family's everyday life related to MD. Relations in the family, between parents and children, become complicated as reciprocity declines, thus preventing a constructive interplay in the family. The ill parent withdraws due to MD from family life and is unable to explain why he or she does so. The children become quiet and lonely, neither recognising their family life nor knowing how and what to communicate. The family as a unit temporarily withdraws from social relations as well. Furthermore, this thesis shows the devotion of family members, parents and children to each other and the family, and the family's efforts to master their own everyday life-world, on an individual as well as a family basis, in order to bring family life as well as the family's dignity back to an acceptable level. Children take responsibility for their ill parent and for their sisters and brothers as well as themselves when they realize that the parent cannot manage. However, their heaviest responsibility is that of seeing to it that the parent stays alive. The meaning of MD for the ill parents was elucidated as suffering and dignity that are simultaneously present in family life. Dignity is threatened by the awareness that suffering from MD recurrently appears. The meaning of parents' MD for the children was described as sense of responsibility and a sense of loneliness. Inherent in the children's responsibility is their striving for reciprocity, and inherent in their sense of loneliness is their yearning for reciprocity. Even though depression dissipates for periods of time, the families do not seem entirely liberated from MD as their worry remains. This means that the families' life-world involves prolonged suffering related to MD.

This thesis shows how a study using qualitative methods makes it possible for family members, together and individually, to talk about MD as illness as an intruder in their family life. The thesis elucidates how MD complicates and involves the family members' life as well as their family life. All family members have their own life-world and try to balance everyday life from an individual perspective, which is that managing the illness is the concern of the whole family.

IMPLICATIONS

The thesis shows that it is important to involve the family in conjunction with the onset of MD for the sake of both the ill parent and the children. There ought to be a well-defined lowest level for when, how and by whom support of the ill patient's family should be provided, thus enhancing and preserving the quality of care. Interventions in mental health care could be characterized by offering more interventions from several perspectives and an adjustment to the families' needs by a flexible organization, which could make it easier for families to participate. This would also facilitate access to mental health care in primary care where the ill parent probably seeks care and is treated for MD. Furthermore, the family could be in need of support from multiprofessional teams. Registered mental health nurses are in a special position to meet the families' needs and to guide and support families and their members. They could be a key person for the family and especially the children to contact. This will also make demands on health and medical care education to be specially focused on the family's situation. Interventions in the form of teaching children at school about mental health and mental ill-health problems are of the greatest importance when it comes to changing attitudes and breaking the silence surrounding mental ill health. Targeting young peoples' meeting places with information about depression, for instance, on the Internet is very important. Supporting the families in their everyday life-world and communicating with the family members from their perspective requires an open mind and creativity on the part of health care professionals. There is a need for a changed view in the health care sector that favours new structures and methods concerning how to provide care that corresponds to the needs of the family.

FUTURE RESEARCH

Future research could investigate how to organize existing health care organisations and psychiatric services so that they can develop and implement mental health care interventions aimed at supporting family members suffering from MD, as well as evaluating its consequences for the whole family – both the parents and the children.

SWEDISH SUMMERY

Depression och familjeliv - Familjens sätt att leva med en långvarig sjukdom

I många familjer finns en vuxen familjemedlem med en depression som kan återkomma i episoder under flera år och bli en långvarig sjukdom. På flera sätt involveras både barn och vuxna familjemedlemmar, oavsett vem av föräldrarna som insjuknar. Vardagslivet hemma och på arbetet blir påfrestande och familjen kan behöva hitta nya strategier för att hantera situationen. Flera studier har visat att en förälders depression påverkar familjen och relationen till partnern på ett negativt sätt, vilket ger spänningar inom familjen. Barn och tonåringar berörs av föräldrarnas depression, vilket kan påverka deras hälsa negativt. Som exempel kan nämnas försämrad aptit och sömn, problem med lek, sociala relationer och med uppmärksamhet i skolan. Barnen blir mer sårbara för att utveckla psykisk ohälsa och sjukdom. På längre sikt kan föräldrarnas depression ha betydelse för barnens hälsa även i vuxen ålder. Familjerna saknar stöd från närstående och hälso- och sjukvården.

I denna avhandling undersöktes familjelivet i familjer med barn när en vuxen familjemedlem har en diagnostiserad egentlig depression. Avhandlingsarbetet har gjorts inom ramen för familjernas livsvärld och området psykisk hälsa inom omvårdnadsvetenskap. Övergripande syftet var att beskriva familjens erfarenheter av depression och att klargöra vilken innebörd depressionen har för familjelivet, den sjuke föräldern, dennes partner och barnen. Detta undersöktes i fyra delstudier.

Åtta familjer som representerades av sammanlagt 21 personer deltog. Intervjuer med familjerna genomfördes dels som en gruppintervju med familjen, dels som individuella intervjuer med den sjuke föräldern, dennes partner om det fanns någon och med barnen. Intervjuerna skrevs ut ordagrant och texten analyserades.

Studierna visade att familjerna hamnade i en besvärlig och stressfull familjesituation relaterad till föräldrarnas depression, och att barnen var medvetna om den. De sjuka föräldrarna mådde mycket dåligt med en allmän känsla av att förändras. De var extremt trötta och upplevde sig allvarligt sjuka, vilket förhindrade samspelet i familjen. Föräldrar och barn hade olika upplevelser av situationen och hanterade den olika. För den sjuka föräldern är innebörden av depressionen ett lidande och samtidigt med lidandet försöker de bibehålla en värdighet, vilket komplicerar familjelivet. Värdigheten, den egna liksom familjens, hotas av vetenskapen om att depressionen kan återkomma och därmed också lidandet. Det blir då nödvändigt att den sjuka föräldrarnas värdighet, liksom också familjens värdighet gång på gång återupprättas både för egen del och inför andra utanför familjens. Familjelivet präglades av osäkerhet och förändring, och familjerna dränerades på energi och tappade kontrollen över vardagen. Vardagslivet blev svårt och ansvaret skiftade mellan familjemed-

lemmarna. Innebörden av föräldrarnas depression för barnen var känslan av ansvar liksom känslan av övergivenhet. I barnens känsla av ansvar finns deras strävan efter ömsesidighet och i känslan av övergivenhet finns deras starka längtan efter ömsesidighet. Barnen kände obehag, var känsliga för föräldrarnas sinnesstämning och oroade sig för att föräldern skulle bli sämre och till slut ta sitt liv. Barnen kände ångest men lyckades inte förmedla sitt behov av stöd. När relationen till den sjuka föräldern förändrades tystnade barnen, liksom familjelivet. Barnen var utanför, oförmögna till samspel i familjen. Barnens vardagsliv blev olustigt när de blev medvetna om familjekonflikter och den sjuka föräldrarnas självmordsförsök. Föräldrarna var själva rädda för sina självmordstankar och dess konsekvenser, och var tveksamma att berätta om dem, särskilt i samband med att de sökte vård.

Familjerna försökte hitta en väg ut ur situationen. Barnen försökte bilda sig en uppfattning om hur föräldern mår för att återfå kontroll över situationen. Föräldrarna kämpade för att upprätthålla föräldraskapet med känslighet och respekt för barnen. Barnen var lojala och prioriterade sin sjuka föräldrars behov och bar med sig ansvarskänslan in i vuxenlivet. Familjen ansträngde sig att förstå sin situation och att kommunicera den inom familjen och till andra. När föräldrarnas hälsa förbättrades förändrades också hela familjens hälsa till det bättre. Det fanns hopp om en framtid trots depressionen och föräldrarna kunde se att de skaffat sig redskap för att förebygga depressionen. Att vara sedd i sin speciella situation av andra var ett sätt att bli bekräftad.

En studie som denna med kvalitativa metoder gör det möjligt för familjemedlemmar att tillsammans och individuellt berätta om upplevelsen av depressionen och om sjukdomen som en inkräktare i familjelivet. I avhandlingen klargörs hur depressionen komplicerar och involverar familjemedlemmarnas liv liksom deras familjeliv. Alla familjemedlemmarna har sin egen livsvärld och försöker balansera vardagslivet från sitt individuella perspektiv, vilket överskuggar att hantera sjukdomen är en angelägenhet för hela familjen.

Avhandlingen visar att det är viktigt för både barn och förälder att familjen involveras i samband med att föräldern insjuknar i depressionen. Det är viktigt med en väl definierad nivå av garanterad vård såsom när, hur och av vem familjerna får stöd för att förbättra och bevara kvaliteten i vården till familjerna. Sjuksköterskor inom psykiatrisk vård möter människor med depression i ett tidigt skede och har därmed möjlighet att fokusera vården på familjen för att tillsammans identifiera familjens behov för att underlätta familjens sätt att ta sig igenom episoden. Det behövs ett nytt och förändrat synsätt inom vården för att möta familjer utifrån deras perspektiv och behov av hjälp och stöd.

Forskning kan därför inriktas på hur olika sätt att genomföra vård och stöd till familjer kan utvecklas och införas i den redan befintliga organisationen, samt att utvärdera dess konsekvenser för hela familjen, föräldrarna och barnen.

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