 Mothers’ Everyday Experiences of Having an Adult Child Who Suffers from Long-Term Mental Illness

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This paper aims to describe everyday life experiences of mothers who have an adult child with a long-term mental illness. Sixteen mothers were interviewed. A content analysis resulted in one main theme: My adult child who is struggling with mental illness is always on my mind, and three subthemes: (1) living a life under constant strain, (2) living with an emotional burden, and (3) seeing light in the darkness despite difficulties. Knowledge of mothers’ everyday life experiences is of great importance in order to support them and thereby increase the possibility of these mothers being a source of strength for their child.

The adverse consequences of mental illness for families, known as caregiver burden, have been studied since the early 1950s (Schene, Tessler, & Gamache, 1994). A review of the literature revealed a constant high level of burden on parents who have a son or daughter with serious mental illness (Lowyck et al., 2004; Milliken & Rodney, 2003; Östman, Wallsten, & Kjellin, 2005). Emotional reactions such as feelings of grief (Godress et al., 2005; Milliken, 2001), anguish, constant worry, fear, guilt, and shame have been described (Mohr & Regan-Kubinski, 2001; Peilert, 2001), and such parents have been found to be less satisfied with their quality of life (Foldemo, Gullberg, Ek, & Bogren, 2005). Moreover, they have been identified as at greater risk of poorer health and marital disruption than parents who do not have a child with mental illness (Aschbrenner, Greenberg, & Seltzer, 2009). The burden can be rated as high, but if the parents themselves do not appraise it as too burdensome, it can lead to positive responses and the view that their child’s mental illness enriches their lives (Greenberg, Seltzer, & Judge, 2000; Schwartz & Gidron, 2002). Veltman and co-authors (2002) found that caregiving made relatives stronger and feel less judged by others. Research has indicated that mothers tend to assume the primary caregiving role (Grandon, Jenaro, & Lemos, 2008; Milliken, 2001). In most cases, the mothers adapt their lives to take care of the child, which may lead to psychological distress, a feeling of being disenfranchised, and have a negative impact on their caregiving (Milliken, 2001).

In the previously mentioned studies, the participants were mostly referred to as “parents” despite the fact that the majority were mothers. However, some studies specifically report mothers’ experiences. St-Onge and Lavoie (1997) described mothers’ feelings of confinement and isolation as psychological distress, and Howard (1994) characterized maternal caregiving as a lifelong effort. If the child became violent, usually the mother was the victim. Mothers have described waiting for their children’s involuntary hospitalization as a chaotic and fearful
period (Copeland & Heilemann, 2008). The way in which they deal with such situations has been described as mainly related to the child’s aggressive behavior. Emotional support (Puotiniemi & Kyngäs, 2004) and help with caring (Hanzawa et al., 2008) from other family members and friends have been reported to be important.

Mothering has, from a theoretical perspective, been discussed by the Swedish philosopher Holm (1993). She coined the concept “modrande,” which in English is comparable with “mothering.” The concept is gender neutral and includes the interaction and activities necessary for the child to survive, grow, and develop. Holm described the responsibility as relational; the relationship between the caregiver and child changes in character over time; the small child is dependent on care and, gradually, his or her independence increases and the relationship becomes more symmetrical and similar to friendship between adults. Mothering encompasses an ethical dimension. The asymmetry within the relationship should not be violated. The mother has to be aware that it is sometimes justified to treat the child as an equal and independent individual, while at other times the difference in maturity, capacity, and autonomy requires that she step in and act on behalf of the child. A mother’s identity develops throughout life and she has to face new challenges in line with the child’s development (Holm, 1993). Based on the literature it seems that being a mother of an adult son or daughter with mental illness requires different skills and roles compared to those of mothers whose children are healthy.

Few studies in this field have explicitly described what it means to be a mother or the everyday life experiences of being a mother who has an adult son or daughter suffering from mental illness. Therefore, the aim of the present study is to describe the everyday life experiences of mothers of an adult child with long-term mental illness.

**METHOD**

A qualitative descriptive design using open-ended interviews was selected for the study, which is the first study of a larger project where parents’ experiences of having a son or daughter who suffers from long-term mental illness are covered from different perspectives.

**Participants**

This study took place in Sweden from June to December 2007. The participating mothers were recruited through an advertisement in a local newspaper that requested them to contact the research team. The inclusion criteria were that the participants should be a mother of an adult child (older than 18 years of age) with long-term (greater than two years) mental illness (psychotic, mood, or anxiety disorder without intellectual handicap or substance abuse) and that the mother and child should have contact on a regular basis. Twenty-five interested mothers contacted the first author, several of whom were not aware of their son’s or daughter’s diagnosis and instead provided a detailed description of the symptoms. They were informed that they would receive acknowledgment and feedback if deemed to meet the inclusion criteria. After this first contact, the authors discussed whether the mothers met the inclusion criteria and selected participants. Then, within two weeks, the first author telephoned the mothers in order to inform them of the decision. Fifteen mothers were assessed as eligible for the study and all agreed to participate. Additionally, one participant recruited from an open care psychiatric unit who had taken part in a pilot interview for the present study was included. The participants’ socio-demographic characteristics are presented in Table 1.

The adult children with mental illness comprised 13 daughters and 3 sons, aged between 18 and 49 years (average 29 years). Five suffered from schizophrenia, two from bipolar disorder, one from recurrent depression, and one from obsessive-compulsive disorder. In the remaining cases, the diagnoses were unknown to the mothers; three described mood disorders, two psychotic disorders, and two symptoms and disabilities in line with anxiety disorders. The time-span since the onset of the child’s mental illness ranged from 3 to 20 years (average 7 years). Four of the children lived with their mother or father (or both parents), nine lived on their own without a partner, and three lived with a partner. Four were parents. At the time of the interview, the majority of the children were unemployed, in some cases due to their youth or lack of adaptation to the work environment. Some had been forced to leave their previous employment because of their illness. All had current or previous ongoing contact with psychiatric care. The majority had been admitted to hospital care either voluntarily or involuntarily.

**TABLE 1**

<table>
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Data Collection
Methodologically, an open-ended qualitative interview seemed to be an appropriate data collection method. The participants were encouraged to tell about their experiences in a narrative way (Patton, 2002). The opening question was, “Can you please tell me what everyday life is like for a mother of an adult son/daughter who suffers from mental illness?” Probing questions (e.g., can you explain more? How did you feel?) were asked in order to obtain a deeper understanding. An interview guide was used in order to cover areas of the participants’ everyday lives, such as family and work situations, knowledge of the disease, as well as positive and negative consequences. The participants chose the place for the interviews, which lasted from 52 to 107 minutes and were audiotaped with the exception of one, due to that particular mother’s wish to protect her child’s integrity. In the latter case, the interviewer took notes, which were formulated into a statement immediately afterwards. Eleven interviews took place at an open care psychiatric unit (the first author’s place of work), four in the participants’ homes, and one at the participant’s workplace. Three to six weeks after the interviews, the first author telephoned the participants in order to ask clarifying questions as well as to give the mothers an opportunity to add to their information. In the case of the non-audiotaped interview, the participant confirmed the researcher’s summary.

Data Analysis
The interviews were analyzed by inductive qualitative content analysis, which deals with interpretation and can vary in depth and level of abstraction (Graneheim & Lundman, 2004; Patton, 2002). During the data analysis, the QRS NVivo 7 computer program was utilized as a data analysis tool.

The interviews were first transcribed word for word. Thereafter, the first author verified the transcribed text against the audiotapes. Then the text was read and re-read to gain an overall impression, after which it was divided into meaning units in line with the aim of the study. Each meaning unit was labeled with a code and patterns in the codes were searched for. Codes that expressed related meanings were grouped together into categories. Categories with similar content were sorted into subthemes. The underlying meaning of the findings resulted in a theme. The analysis was performed by means of a dynamic process alternating between the parts and the whole. The authors continuously discussed the analysis process. Quotations from the interviews are used to illustrate the content of the themes.

Ethical Considerations
Several ethical considerations were taken into account. People with mental illness belong to a vulnerable group and their parents can be subject to prejudice and negative attitudes in society (Goodman, 2004). It is important to be aware of this in the interview situation. The main focus of research in this study can also be sensitive and arouse or strengthen feelings of guilt. Therefore, a qualitative open-ended interview approach seemed appropriate, where the mothers were encouraged to narrate about their situation. The participants received oral and written information explaining the aim of the research, that participation was voluntary, that they could withdraw from the study at any time, and that the data would be treated confidentially. Prior to the interview, the participants provided their written informed consent (Swedish Research Council, 2002). The Regional Research Ethics Committee approved the study (No. 071138/Skas 112-07).

FINDINGS
The results consist of the following main theme: “My adult child who is struggling with mental illness is always on my mind.” Central to the mothers’ narratives was how they managed the long-term responsibility for a dependent child as well as their permanent adaptation to the specific circumstances. This led them into highly stressful life situations with a great deal of sorrow and uncertainty. Despite the high level of burden, positive aspects, such as hope for the future, were reported. The emerging subthemes were: (1) living a life under constant strain, (2) living with an emotional burden, and (3) seeing light in the darkness despite difficulties. The main theme, subthemes, and categories are illustrated in Table 2.

Living a Life Under Constant Strain
The subtheme, living a life under constant strain, consisted of two categories: (1) Uncertainty affects daily life and (2) The child is permanently present. Living with a constant awareness of the child’s dependence, as well as uncertainty, vigilance, and being more or less permanently on-call were experienced as a continuous strain emotionally and even physically.

Uncertainty Affects Daily Life
Over a long period, sometimes several years, the mothers described themselves as suspicious that something was wrong with their child. This uncertainty resulted in a great deal of worry...
and they searched for a “normal pattern” in the child’s mental and emotional development. The mothers mentioned depressive symptoms and “burnout” in their children and also that it was sometimes difficult to distinguish between a normal teenager’s emancipation and a pathologic state. Some experienced the fact that the child had been affected by mental illness as shocking, while others spoke about confirmation of something they had suspected for a long time. Denial and fear could hamper acceptance that the child was suffering from mental illness:

> I just understood that something was not the same as with the other children . . . when X became ill I saw it clearly straight away. I became very cold inside, you know, this was what I had feared for a long time. I suddenly understood it . . . she stood on the other side of the dinner table and I looked at her gaze, then I saw. So now it’s like that! Now I know, psychotic . . . When your child becomes ill, the feeling becomes exceptionally strong, it’s almost the worst thing that can happen to you, apart from death . . . you just don’t accept straight away that your child has a serious mental illness, you just don’t! It actually takes a very long time to accept it.

Mothers who did not know the child’s diagnosis described uncertainty in their behavior toward the child. They also had concerns about medical treatment, its side effects, and whether or not life-long treatment was necessary. Awareness of the child’s diagnosis facilitated an understanding of the child’s behavior, and the mothers’ worries often decreased if they were familiar with the symptoms. Some mothers had grandchildren, which meant they also were concerned about their grandchildren’s lives and how they were influenced by having a parent with mental illness. Uncertainty about the future, when the mothers feared they would no longer have sufficient energy, also became apparent:

> What will happen when I can no longer cope? I’m already beginning to feel very very tired. So that’s what’s most noticeable, when you worry a great deal about the future.

The mothers’ lives were periodically chaotic, and the recurrence of difficult negative events and frequent changes in the child’s health resulted in a great deal of vigilance and distress. Sleep and appetite were affected and their own health status deteriorated. Often, the seriousness of the situation resulted in lack of self-care. Some mothers related that after a chaotic episode they felt completely exhausted and had a great need of support and rest. Despite their need for support, several mothers were uncertain about where they could obtain it.

**The Child is Permanently Present**

For the mothers, the child who is struggling with mental illness was constantly present, either physically or emotionally. Several stated that the child was present in their mind when they woke up and just before they fell asleep. They strived to be available at all times and some described this as being on-call, day and night. The child’s dependence was not changed by the fact that he or she was an adult. In order to manage family and working life, some parents worked shifts, or siblings or grandparents stayed with the ill child when necessary. Some mentioned constant distress about the child’s health when they were at work, while others described the workplace as a place for recovery. Several of the mothers wished for an opportunity to stay at home in order to take care of the ill child, regardless of the child’s age. The mothers constantly watched for any sign of deterioration in their child. Furthermore, the fear of repeated destructive acts and that threats of suicide would be put into action could sometimes become overwhelming:

> It feels a bit like having a time bomb, you’re stressed and worried all the time, thinking, “will it happen the next time she gets upset?” She took tablets once, as she felt that she couldn’t cope any more . . . you are on your guard and worry constantly . . . you are so concerned and anxious about her the whole time and you feel depressed, it’s very, very difficult and tough.

Being a mother of an adult child struggling with mental illness was described as more demanding than the infant period. At times they could not leave the child on her or his own, and the mothers reported feelings of being uncomfortable about always having the child present on social occasions. A large part of their social life was centered around the child’s health. Some mentioned how friends had disappeared and had the impression that the mothers were no longer interesting in socializing. Several mothers experienced extreme loneliness as a result of the demanding situation in addition to lack of time for own activities.

The mothers related how they systematically tried to increase the children’s independence. It was sometimes difficult to decide what demands they could place on the child or if they had made the right or wrong decision. To be the child’s only form of security was described with mixed feelings. One mother wished for an “extra nanny,” she explained that her child needed support in everyday life and would only accept support from her. All contact with the child occurred outside the child’s flat, which nobody, not even the mother, was permitted to enter.

**Living with an Emotional Burden**

The subtheme, living with an emotional burden, consisted of three categories: (1) a feeling of constant sorrow, (2) a feeling of being exposed as a mother, and (3) a feeling that the whole family is affected. The mothers described that being a mother of an adult child with mental illness gave rise to many emotions with which they had to manage. They described a constant sorrow that was difficult to handle. Feeling exposed and insufficient as a mother increased the feeling of guilt and the sense of having done something wrong.

**A Feeling of Constant Sorrow**

The mothers talked about their constant sorrow due to the child’s disease-related personality changes and their visions of the future being destroyed, which was difficult to bear. The child was still dependent, while friends of the same age were developing independent lives. The child’s suffering as a result of
mental illness, dejection, and dependency was described as very painful. Sometimes, contacts with social workers and police were unavoidable. One mother related that she tried to contain the situation within the family but finally had no more energy and was forced to contact the social workers. She related that she regarded this as the last resort, but later felt relief due to having relinquished a part of the heavy responsibility. Another mother described traumatic experiences with repeated need of assistance from the police, which became a part of her everyday life:

You can’t force an adult . . . now we will go to the hospital . . . the only option available is to request a police escort . . . as a mother you often feel that that’s a bit too drastic . . . yes, but you get used to it somehow.

The mothers learned to live with a constant sadness, and several described how they became hardened by all the problems. One mother reported how she had received repeated telephone calls from her child who was threatening suicide. The child said “I’m standing high up on a roof and will jump.” The mother assured her child that she loved her but did not approve of what she was going to do and, with determination, hung up. In such situations, major questions arose, such as who has the right to decide over another person’s life:

I don’t want to listen to her when she phones and says now I will do this and that [suicide threat] . . . there have been so many times . . . It has become too common . . . eventually you do not pay much attention to it to protect yourself . . . do you have the right to prevent her indefinitely, if she really wants to die?

Some mothers described telephone terror from the children. Sometimes the calls were accusing and offensive. However, they became a part of everyday life and offered a possibility to evaluate the child’s well-being. Some mothers had lost hope of recovery due to various incidents and deteriorations in the child’s health. Some spoke in terms of having lost their beloved child.

A Feeling of Being Exposed as a Mother

Being questioned and exposed as a mother as well as when others told them what was best for the child was experienced as uncomfortable and sometimes the mothers in our study felt offended. The feeling of being exposed could be increased if the mother was single and, on occasion, led to the mother mistrusting other people. This was more obvious in small villages. The mothers were frequently unanimous in their view that individuals who had not experienced similar problems could understand the mothers’ situation. One mother told how she used her healthy siblings to show what a “normal” family could look like:

I have three healthy children and they look very well compared to X, who looked really poorly during the illness period . . . I had a sort of advertisement board saying, “Here you see a completely normal mother and she has these children, too” . . . It sounds terrible but the whole package looked very normal, it was only one who had a difficult time.

The mothers reflected on the child’s upbringing and wondered if it had played a role in the disease. They spoke about misfortune and blamed themselves for being part of the development of the disease. Some viewed it as a punishment for choices made in their earlier lives:

I felt that I had done something wrong . . . I thought that it was because of something I had done that I got X, because I have to go through this . . . I was the one who was to be punished.

When the child accused the mother of causing the disease, the mothers stated that this exacerbated their feelings of guilt and insufficiency. In trying not to blame themselves, they emphasized the importance of separating their own perspective from that of the child. Knowledge of the disease made it easier to understand that deviant behavior was one of the symptoms. It also became easier to restrict the child, thereby protecting themselves without feeling guilty.

A Feeling That the Whole Family Is Affected

Although the mothers strived for a normal family life, some reported that the whole family was affected and that there were negative attitudes within the family. Some disregarded their own need of support on the grounds that if the whole family applied for care they would be considered as a “madhouse.” Sometimes the mothers mentioned diverging opinions within the family about how best to support the child. They reported that they were accused of being overprotective and, at times, had to justify their actions. Several stated that the fathers distanced themselves from the family situation and that they were not understood by their husbands:

The relationship between us [husband and wife] is tense, there are many worries and concerns, so much so that you lack the strength to be cheerful and become irritated and grumpy more easily . . . He doesn’t understand and finds it odd that I react the way I do . . . It affects us all . . . He doesn’t think that it’s very serious and he can brush things under the carpet and perhaps doesn’t want to talk so much about her problems.

Lack of time for siblings became apparent, and some mothers experienced that they had failed to notice signs that their other children were also developing mental problems. They tried to protect the siblings from unpleasantness but were unable to withhold everything, and sometimes the other children had to witness chaotic encounters, such as contacts with acute psychiatric care and the police. In several cases the mothers described how the siblings had assumed too much responsibility.

Seeing Light in the Darkness Despite Difficulties

The subtheme, seeing light in the darkness despite difficulties, consisted of two categories: (1) a sense of security and hope and (2) a sense of belonging. Despite the great burden, mothers described positive aspects in addition to sorrow and misery. The mothers mentioned trusting that everything would eventually work out for the best. Belonging was experienced as important.
A Sense of Security and Hope

Despite uncertainty about what the future would hold, glimpses of light and hope were described. A good insight into the disease made the mothers feel more secure in their mothering role and they dared to trust their ability to handle the situation. Several emphasized that there is some meaning in everything that happens. Despite a high level of burden, they described happiness in their family lives:

I have a happy life full of love … We laugh and work a lot but we work together … we take care of our children together, thus I’m a very traditional mother … I’m very lucky because my life is super despite X’s illness, but I feel that it isn’t over yet.

Several talked with pride about their child who, despite the difficulties caused by the disease, took responsibility for his or her everyday life as best he or she could. The mothers highlighted the fact that small, usually taken-for-granted, things could provide them with great pleasure, helping them to see light in the darkness. When the child was well, they overlooked the difficulties and hoped that everything was “normal” again. They mentioned the importance of trying to accept the factual situation, living in the present, and accepting that they could not change the past.

A Sense of Belonging

A sense of belonging was described as important. A majority of the mothers reported a lack of knowledge about mental illness in their surroundings. Therefore, several chose to treat their strained everyday lives as a private family matter. To avoid misunderstandings and out of respect for the child’s integrity, the mothers carefully considered whom to trust. Mothers who talked openly about their situation described feelings of strength and acknowledgment and also recognized that others had similar problems. They mentioned openness as a kind of survival strategy. It was also important to provide a positive message and acknowledge the child for the person he or she was:

I don’t want her to be the disease but the great girl she is … such a good person, yes I’ve never met a person in all my life who is so good through and through … and I want other people to be aware of it.

The heavy burden the mothers carried could result in closer contact with other people. Some mothers described having a limited but unchanged social life and emphasized the value of mutual confidence. In cases where the children received support from their surroundings or the health care services, the mothers had greater flexibility to make the most of their free time without feeling worried or guilty. When siblings and the ill child had a good relationship, the mothers’ well-being was improved. Some described their profession and work as a form of belonging and appreciated that their services were required. Several would have liked to come into contact with other parents with similar problems, but did not know where to turn.

DISCUSSION

The main finding in this study was the mothers’ experience of long-term responsibility for a dependent child, here expressed as “My adult child who is struggling with mental illness is always on my mind.” This highlights the limitations and emotional burden in the mothers’ everyday lives but also the light in the darkness. The mothers’ situation can be described as being permanently on-call. They strived to be constantly available when the child needed them. In Sweden, the social security system allows parents to take sick leave with maintained income in order to take care of their children up to the age of 12 if they are unwell, in specific cases up to the age of 16 or, in exceptional cases, the age of 18. This opportunity is no longer offered when the child is regarded as an adult (older than 18 years of age), no matter what their needs are (Försäkringskassan, 2010). This makes the mothers’ situation more difficult. In addition, they experienced difficulties in planning for themselves as well as a great deal of distress and worry, often related to uncertainty over the child’s health. This confirms results from previous research suggesting that parents are at increased risk of poorer health (Ha et al., 2008; Magana, Greenberg, & Seltzer, 2004). Less time and possibilities for taking care of themselves became obvious, which was also found in the study by Ryan (1993). Despite the fact that support was mentioned as important, the majority had no support from the health care system. Several would have liked to come into contact with other parents with similar problems, but did not know where to turn. In our study, only two mothers belonged to a support group while, in the study by Doornbos (2002), all respondents were members of such groups and seemed to be more proactive and have greater expectations of the mental health care system.

Living with an emotional burden was associated with distress and disruption for the whole family. The mothers experienced a high level of sorrow, which is consistent with Eakes’ (1995) findings that grief-related feelings are mainly triggered by the never-ending caregiving responsibilities. Although our intention was not to investigate chronic sorrow, the findings suggest that the mothers suffered from it due to the long-term responsibility for a dependent child and experienced sorrow each time the child’s health deteriorated. Pei lert (2001) and Milliken (2001) depicted the mentally ill child as a stranger isolated in his or her own world, and Ryan (1993) described the loss of the child’s potential to live a “normal life.” Boss (2002) refers to two basic types of ambiguous loss. In the first type, people are physically absent but remain psychologically present. In the second type, people are perceived as physically present but psychologically absent. In our study, Boss’ (2002) second type of ambiguous loss emerged. Sometimes the mothers blamed themselves for the child’s disease, which is in line with Mohr and Regan-Kubinski (2001). In accordance with Jackson and Mannix (2004), the mothers reported feelings of being judged and made to feel guilty by others. In our study, mothers’ everyday lives are accompanied by periodic chaos and unpredictability, often with frequent emotional and behavioral crises. Family
life tends to revolve around the mentally ill adult child and his or her needs. Difficulties mentioned in our study can be compared with other studies that investigated families’ experiences of caring for chronically ill children (e.g., Parker, 1996).

The mothers’ everyday lives seemed to waver between hope and despair. Despite their parental situation, several mothers were reflective and optimistic and able to see light in the darkness. Long-term and repeated painful experiences made the mothers patient and hardened in order to protect themselves, which probably made them stronger. Acceptance and knowledge of the situation seemed to be of great importance. This is comparable with Bowman’s (1997) study, that found that attention to unrealized dreams can be necessary before new aspirations can be created and pursued. Grieving for the old ambitions can be essential for acceptance, healing, and recovery. Ha et al. (2008) recommended that parents of children with mental health problems take a break from caregiving tasks and engage in other activities in order to increase psychological well-being and protect them from acute stress. This agrees with a finding in our study revealing that having the opportunity to share experiences or responsibility with someone else or having time for one’s own activities was a kind of survival strategy. On the other hand, the majority of the mothers in our study reported not having enough time for themselves.

The theme, “My adult child who is struggling with mental illness is always on my mind,” comprised long-term responsibility for a dependent child and the mothers’ attempts to make him or her less dependent. This can be viewed in the light of the Swedish philosopher Holm’s (1993) concept of “mothering,” which aims to make the child independent and gradually abandon the asymmetry of the childhood years. Often, the mothers described it as playing by ear, feeling their way, and trying to find a balance between helping the child to assume increased responsibility and the risk of giving him or her responsibility that he or she was unable to assume. Being the mother of an adult child who suffered from mental illness with a risk of relapse or suicidal behavior led to increased vigilance and worry. Perhaps it would be better for the child if the mother did not have this worry but the child often needed the mother’s vigilance and timely interventions. According to Holm, responsibility is seen as a basic requirement of mothering and encompasses both the here and now as well as retrospective and prospective responsibilities. Retrospective responsibility became visible when the mothers believed that they had failed to notice their child’s needs or the early development of the disease and blamed themselves for not supporting their child in a better way. Holm stated that moral guilt and ethical stress are not unusual in connection with mothering and are likely to be common when having children who suffer from long-term mental illness. Because of the disease, the child’s contacts with others had decreased, which could increase the mother’s responsibility. The prospective responsibility appeared clearly when mothers reflected on the future and who would take over when they no longer have enough energy or become too old (cf. Holm, 1993). This total responsibility was experienced as a heavy burden and the mothers called for support and greater knowledge of the child’s disease. Joining a support group could be one way of easing this burden.

Guba’s (1981) constructs for ensuring the trustworthiness of qualitative research were used in this study. To guarantee credibility, and in order to minimize the imposition of predetermined responses when gathering data, the questions were posed in a truly open-ended fashion (Patton, 2002). Qualitative content analysis seemed an appropriate method, as our intention was to describe this area in a broad way. The first author conducted all the interviews, corrected the transcripts, and carried out the analysis in cooperation with the other authors. Some weeks after the interviews, the first author also telephoned the participants in order to ask clarifying questions as well as to give the mothers an opportunity to add to their information; this increases the confirmability of the study. Despite creative and reflective discussions between the authors and in seminars throughout the analysis process, there might be some content in the categories that seems to be overlapping. Human experiences are often intertwined, and therefore it is not always possible in research to achieve mutually exclusive categories (Graneheim & Lundman, 2004). The interviewer and one of the co-authors were familiar with the research field. Awareness of the researchers’ preconceptions minimizes the risk of reducing the variation in the content, and the levels of abstraction become more distinct. Dependability was achieved by describing the study process in detail, thereby enabling a future researcher to repeat the work, but not necessarily obtain the same results. The NVivo computer program increased the possibility to remain close to the context and alternate between the parts and the whole. To achieve confirmability, quotations were used to illustrate the findings. The results cannot be generalized, but hopefully the insights and meanings will make it possible for clinicians in psychiatric care to understand their own practice in a broader fashion. The reader will have to decide whether or not results are transferable to other contexts (Graneheim & Lundman, 2004).

CONCLUSION AND IMPLICATIONS

The adult child who is struggling with mental illness was always on the mother’s mind. Despite a high level of burden, positive aspects and feelings of trust that everything will eventually be resolved for the best were described. The mothers’ responsibility included both the here and now, as well as retrospective and prospective responsibilities. As these mothers are at risk of poor health, this knowledge is of great importance for health care professionals in order to support mothers and increase the possibility of being a source of strength for their child. Further studies are required with focus on fathers’ experiences in order to broaden our understanding from a family-centered perspective. In situations of long-term mental illness, the whole family could benefit from such a perspective.
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REFERENCES


