Being a parent of an adult son or daughter with severe mental illness receiving professional care: parents' narratives

Anita Pejlert RNT PhD
Department of Caring Sciences, Mid Sweden University, S-851 70 Sundsvall, Sweden and Department of Nursing, Umeå University, S-901 87 Umeå, Sweden

Correspondence
Anita Pejlert
Department of Caring Sciences
Mid Sweden University
S-851 70 Sundsvall
Sweden
E-mail: anita.pejlert@mh.se

Abstract
The aim of this study was to illuminate the meaning of parental care-giving with reference to having an adult son or daughter with severe mental illness living in a care setting. The parents were asked to narrate their relationship to offspring in the past, in the present, and their thoughts and feelings concerning the future. The study was guided by a phenomenological hermeneutic perspective. The meaning of parental care was illuminated in the themes 'living with sorrow, anguish and constant worry', 'living with guilt and shame', 'relating with carer/care; comfort and hardships' 'coming to terms with difficulties' and 'hoping for a better life for the adult child'. Parental care-giving emerged as a life-long effort. The narratives revealed ongoing grief, sorrow and losses interpreted as chronic sorrow. The narratives disclosed a cultural conflict between the family system and the care system, which was interpreted as a threat to the parental role, but also experiences of receiving comfort and having confidence in the care given. Experiences of stigma were interpreted from the way of labelling illness, narrated experiences of shame and relations with the public and mental health professionals. Parents' persisting in the care-giving role, striving to look after themselves and expressing hopes for the future were interpreted as a process of coming to terms with difficulties. Results suggest that mental health professionals need to be aware of their own attitudes and treatment of families, improve their cooperation with, and support to families, and provide opportunities for family members to meet one another.

Keywords: community care, narratives, parental care-giving, phenomenological hermeneutics, psychiatric nursing, schizophrenia

Introduction

Until recently, and perhaps still, treatment of schizophrenia was based on theories regarding the 'schizophrenic' influence of the family. In addition, patients have learned to blame their families for their illness and families have tended to distance themselves from psychiatric rehabilitation, feeling guilty and afraid and of being criticised (Rutz 1995). A number of factors such as treatment advances, social policy changes and de-institutionalisation have all contributed to increased numbers of people with serious mental illness living in the community. As a result, expectations of the role of the family as care-givers have changed, and families have shouldered many aspects of care for members with mental illness. Today it is recognised that community-based care is facilitated with a supportive family and that this normalises the patient's life world (National Board of Health and Welfare 1999).

Much has been written about the burden that results in the difficulties and suffering experienced by families who are primary carers for an adult with a serious

mental illness (e.g. Bulger *et al*. 1993, Provencher 1996, Bibou-Nakou *et al*. 1997). However, not all care-giving results in an experience of being unduly burdened. Bulger *et al*. (1993) found that care-giving also involved a feeling of satisfaction and that the relationship between parent care-giver and adult child was a central feature of care-giving. Horwitz *et al*. (1996) noted that the amount of support family members give to patients suffering from serious mental illness is very strongly associated with how much support the patients give parents and siblings. Care-giving in families is a process of mutual exchange.

Research into the burden of care-giving contributes to our understanding of the experience of care-giving, but it cannot give us the whole multidimensional picture of care-giving experiences. Plager (1994) and Saunders (1999) call for nonreductionistic approaches in nursing research so as to achieve a better understanding of the reality of the meaning of the family's lived experiences of a severe mental illness. To date, few studies have examined the meaning of mental illness for families. Rose (1996) suggests that this is because professionals devote their caring efforts largely towards the patient. In a recent study Howard (1994) analysed maternal care-giving for adult children with schizophrenia from a life-span perspective. A model describing the findings included stages of learning: perceiving a problem, searching for solutions, enduring the situation and surviving the experiences. Maternal care-giving included positive as well as negative aspects. Tuck *et al*. (1997) found that parents experienced the diagnosis of schizophrenia as a destructive force that transformed the family life trajectory. Active parenting became unending and involved watching, protecting, seeking help, and the sacrifice of personal needs concurrently with the need to maintain a loving connection with the child. In yet another study Rose (1998) interpreted family members' personal experiences of mental illness and found that the majority of families described how they felt 'stuck', though they had been dealing with the illness for many years.

The few studies from the recent literature review carried out for this study that examined the meaning of mental illness for families all focused on the family as primary care-giver: no study of family care-giving of a relative with mental illness cared for by formal care-givers was found. The absence of such studies might be the manifestation of an assumption that care in community settings or hospitals for individuals with severe mental illness leaves the family free from caring responsibilities. However, research on family care-giving for elderly patients living in a nursing home reported that, although family care-givers seemed to feel relief, mostly in terms of their social lives, they still experienced high levels of emotional distress (Stephens *et al*. 1991). Almberg

et al. (1997) found no difference in burnout experiences between care-givers who had an elderly family member with dementia living at home and those whose relative was in an institution. Harper & Lund (1990) reported that wives living with husbands with dementia appeared to be more burdened by symptoms of affection, while those caring for spouses in an institution appeared burdened by symptoms of orientation and daily living. Furthermore, there are indications that family involvement after admission to a nursing home might influence the quality of life of the patient (Hertzberg & Ekman 1996).

It can be argued that family relationships are life long, and that recent changes in the provision of care for people with mental health problems have made it easier to maintain contact and continue to be a source of help and support for relatives with such illnesses. Studies are therefore needed that will elicit families' experiences of mental illness in the context of family care-giving for relatives who are cared for by professionals. The aim of this study was to illuminate the meaning of parental care-giving of a son or daughter with severe mental illness living in a care setting.

Background to the present study

The move from a Swedish psychiatric hospital ward to a more home-like setting, henceforth called 'The Villa', has been followed by means of interviews with clients and nurses before the move (Pejlert *et al*. 1995, 1998) and 1 and 2 years after the move (Pejlert *et al*. 1999, 2000). The clients were people with long-term mental health problems who needed help and guidance with basic ADLs (Activities of Daily Living), medication and finances. Six of the original ten clients who moved from the hospital ward, four women and two men, were still being cared for in The Villa at the end of the project period (2 years). Their ages ranged from 30 to 47 years (median 41, mean 41.6). They were all diagnosed with schizophrenia and had their first contact with psychiatry at the age of 17–21 years (median 20, mean 19). Their last period of hospitalisation ranged from 5 to 11 years (median 6.5, mean 7). All of them received drug treatment and one saw a psychotherapist regularly.

The end of the project coincided with the 1995 Psychiatric Care Reform, when responsibility for long-term psychiatric patients was transferred from the county councils to the local authorities (National Board of Health and Welfare 1992). When local authorities took charge of care it meant a move from The Villa. The care setting with five of the clients and nurses was moved to a group dwelling and one client moved to a flat with support from staff at the group dwelling. The present article concerns parents' narratives, conducted in 1998, about 3 years after the move to the group dwelling/flat.

Subjects

All parents of the six clients were selected for the study. However, two of the clients only had one parent alive. Eight of the parents, three couples, one father and one mother agreed to participate in this study and one couple chose not to participate. Seven of the participants were retired and one was self-employed. At the time of the interview with parents, the clients' contact with their family consisted of visiting the parents (daily (1), at weekends (1) occasionally (1) short supported visits (2)), telephone calls, and parents visiting them in the group dwelling/flat.

Interviews

Audio-taped narrative interviews (Mishler 1986) lasting from about 60–150 minutes were conducted by the researcher in private settings except in the case of one parent who was interviewed by telephone because of the travelling distance. The parents were asked to narrate their relationship to the son/daughter in the past and in the present, and their thoughts and feelings about the future. The interviews were transcribed verbatim by the author.

Ethics

Permission for the research was granted by the Ethics Committee at the Medical Faculty, Umeå University (25, 1993–008). Confidentiality was promised.

Interpretation and results

Interpretation

A phenomenological hermeneutic approach inspired by Ricoeur (1976) and developed at Umeå University, Sweden (e.g. Söderberg *et al.* 1997) and the University of Tromsö, Norway (e.g. Lindseth *et al.* 1994) was used to interpret the meaning of narrated lived experiences within the transcribed interviews.

Naïve reading

Firstly, the text was read with as open a mind as possible in order to obtain a naïve understanding of the meaning of being a parent of a son/daughter suffering from schizophrenia and subject to professional care. The onset of the illness was narrated as a critical event in the life of the family: it was a shock; the parents could not understand what was happening. Narrated images of the son/daughter before the onset of the illness and after that revealed a sorrow for what was lost and what

would never be. The son/daughter's falling ill transformed the families' life completely and had affected it ever since. The narratives revealed multiple loss, sorrows and worries as parents struggled with the care of the son/daughter. The sons/daughters were subject to professional care, but nevertheless the narratives disclosed endless parental care. The families' relationship with healthcare professionals was revealed as trying, getting better, but still ambiguous. The caring episode at The Villa was described as offering a decent life for the son/daughter and a nice community for the families. Real frustration was expressed with the actual life situation for the son/daughter. The parents' hopes for a better life for the sibling after the move from The Villa to the group setting have been dashed. The impression from the naïve reading was that the meaning of being a parent of a son or daughter suffering from schizophrenia cared for by professionals, was interweaved by meanings of parenthood, meanings of relationships with care and meanings of handling the situation.

First structural analysis

The first structural analysis was conducted using narrative categories (cf. Polkinghorne 1988, pp. 13–26, 107–119), and language, i.e. use of pronouns (cf. Aström *et al.* 1993) and metaphors (cf. Häggström & Norberg 1996).

The narratives provided rich and vivid data. The protagonists were the parent/parents and the son/daughter, coactors were siblings, other parents and formal carers. The narrating parent was the author or coauthor of the narrative together with the other parent and the interviewer. The time perspective was mainly the present tense angled towards the future. Apparently idealised memories of the son/daughter before the onset of the illness were frequently reflected in the stories. Expectations of the future expressed hope as well as fear for life of the offspring when the parents would no longer be there to care.

The narrators most often addressed themselves as an 'I/me' followed by 'us/we'. However, all the narrators shifted among pronouns, and shifting from 'I/me' to 'one/you' occurred when talking about something in general or when the story concerned conflicts or difficulties, e.g. 'I went there Saturday night, the staff sat with their feet on the table, watching TV … the residents were in their rooms … I've told them what I think about it … you must be allowed to say what you think … *to change things*'.

Metaphors occurred most frequently in the text when it turned to the parents' relationship with the offspring. Some examples were 'it's my own flesh and blood … you have the heart, as a mother you know' and 'but you know it's difficult … it's like s/he's locked up in her/

himself somehow'. Metaphors were also often used when the narrative was about the son or daughter falling ill as well, for example 'my whole world was falling down … it was like a big black hole'.

Second structural analysis

Next, the text was divided into 'meaning units' of one or several sentences related by content. The 'meaning units' were classified in relation to whom or what they addressed. Briefly, the content was about the traumatic experiences in the onset of the illness, the preillness child, changed relationships, the impact of the illness on families and the offspring's life, endurance in the care-giving role, striving to maintain the balance in family life, criticism of and satisfaction with care, and the meaning of support from other parents with similar experiences. Reflection on the result confirmed the impression from the naïve reading of the text that the meaning of being a parent of an adult son or daughter suffering from schizophrenia cared for by professionals, was interwoven with 'meanings of parenthood', 'meanings of relationships with care' and 'meanings of handling the situation'.

Third structural analysis

To provide a deeper understanding of its meaning, the whole text was read to identify expressions and meanings from three points of view: 'meanings of parenthood', 'meanings of relationships with care' and 'meanings of handling the situation'. 'Meaning units' were identified, condensed, interpreted, related to each other and reflected on, and in this process subthemes were formulated. The subthemes were compared across the interviews, reflected on and organised into five themes.

Living with sorrow, anguish and constant worry

The son/daughter's childhood was described as normal except for one family where the parents recognised school problems during the last few years in school. The preillness history was narrated with sadness, as one of a happy child with lots of friends and with a hopeful future. Initially, with the onset of the illness, narratives revealed great difficulty in interpreting symptoms of the illness. Unusual behaviour was at first regarded as 'teenagers problems'. When the behaviour became more strange parents recognised that they needed help: 'It was so strange one day when we came home … s/he was completely gone … we couldn't reach her/him at all'. The narratives revealed the parents' struggle to try to understand what had happened, and to get some

information about what was wrong, but the information provided was meagre, inadequate and confusing, e.g. 'they all had different explanations'. When the diagnosis was finally explained, the understanding that their child was suffering from a psychiatric disease was narrated as being a shock ('no-one in our family has been in contact with mental illness … it was horrifying'), accompanied by feelings of confusion, anger and despair. Parents were informed about the relatively poor outcome of the disease, that a complete return to preillness function was unusual. Their difficulties in understanding and denial or resistance to the information could be interpreted from such expressions as 'but I thought … you never know, doctors have been wrong before, haven't they'.

The onset of the illness transformed the families' lives. In the narratives, the family history was divided into two periods of time: the time before the illness and the time after the onset of the illness. The narratives revealed sorrow for the lost child: 's/he isn't dead but s/he is so completely changed … you can't really talk to her/him … s/he's like an alien', and his/her lost future: 's/he never had a chance to start living … illness put an end to that'. In families with more than one child, where the siblings were constant reminders of 'what might have been', these images appeared to be especially vivid. It seemed as if the illness itself was accepted but not its consequences. When parents talked about the son's or daughter's actual life situation it was their daily life that was worrying and described as being poor and empty. Worries that the offspring spent too much time on his/her own resting in the bed, about his/her poor physical condition, his/her continuous increase in weight, about dental trouble, too much smoking and coffee drinking were inherent in the narratives. One father expressed his sorrow in these words: 'It's with an aching heart we follow his/her downhill path … it's so sad really … not only does s/he have to live with his/her mental problems, s/he has to look different too'. Although the son or the daughter was living away from home the narratives gave utterance to endless parenting, encompassing care-giving responsibilities and worries about the son or the daughter.

Living with guilt and shame

Encountering psychiatric care was narrated as awakening feelings of guilt. Professionals had a critical attitude or there was an atmosphere on the ward, e.g. 'you've got that feeling when you came to the ward … what are you doing here?'. Family sessions were spoken of with discomfort and appeared to leave parents without help: 'my husband was unemployed at that time and he went to see her/him almost every day. At the family meeting

the therapist said s/he found my husband's visits strange … and rather egoistic too. When we left my husband said: "I'll never see that person again!" '. Another example of this was when siblings were invited to an 'interrogation about their childhood'. It seemed that parents favoured a psychosocial rather than organic model for understanding the development of the disorder. When parents talked about the onset of the illness, psychosocial stress was mentioned as an important cause, e.g. unhappy love, a too demanding parenthood, and difficulties in becoming a parent.

The narratives also revealed feelings of guilt in the way that they were told: apologetic, but with a critical view of the family, sometimes directly expressed: 'of course I wonder why this happened … what I've done wrong'. One parent related her/his thoughts when s/he was forbidden visits at the hospital: 'their explanation was that it was for the best of the child … I was furious … mad … heartbroken … am I that bad for my child I asked myself?'. Despite information-giving to and education of the families about biological factors regarding the development of schizophrenia, it seemed that parents still considered psychosocial factors as an important cause judging from the way in which the narratives dwelled upon this matter. Other ways of viewing the cause of the illness, such as it was fated, or the possibility of being a genetic component of causality, did not seem to offer any reliable way of avoiding feelings of guilt. The possibility of genetic disposition was questioned by some of the parents: 'I know that I am a bit damaged … and … well, you never know how that has affected him/her'.

The disease was never mentioned in terms of the diagnosis; instead expressions such as 'illness', 'disabled', 'something s/he has to take medicine for' were used, a phenomenon that indicates that the diagnosis of schizophrenia was loaded with special meaning. Odd behaviour was narrated as difficult for others to understand and shameful for the family: 'sometimes when s/he comes home and shouts at people at the street … I don't know why … of course they can't understand … just imagine if s/he were to do such things when we are in church … what would people think? Thank God, it hasn't happened yet'. A common theme in the narratives was that of not being good enough as parents. Mothers related siblings' suffering from the consequences of the illness and how they always came second because of the care-giving responsibilities for the child who was ill.

Being in a relationship with nurses/care: comfort and hardships

The participants had a history of about 15–30 years of contact as relatives of people under psychiatric care.

Their first contact with psychiatric care was narrated as leaving them feeling belittled and burdened with guilt, but in the last few years the parent–staff relationship had undergone a decided improvement. A turning point, as it appeared from the narratives, was when clients and staff moved from the hospital ward to reside at The Villa. The stories revealed this change as an event that inspired parents with hope. Their hopes seemed to be fulfilled, the 2 years at The Villa were spoken of with content, such as 'his/her best years since falling ill'. Parents narrated experiences of the son/daughter's improvement, communal meetings (birthday parties, information-giving events, etc.) when parents got to know other parents and clients, and how they always felt welcome when they visited The Villa. For the most part, the caring episode at The Villa was narrated with satisfaction, but some parents questioned the care in expressions such as: 'afterwards I ask myself … was it really that good, or were we so infatuated with it that we thought so?', and 'sometimes I wonder, was it just a dream'. When it was time for the next move to a community setting (group-dwelling, flat) the parents sided with staff to keep the collective together, that staff would accompany the clients. The narratives revealed that care after the move to the community setting had been a disappointment. The parents compared care in the community setting with what it was like before in the hospital, such as: 'so now they've got better places to live … larger rooms to be unhappy in … but nothing more'. Participants reported lack of purposeful activities and rooms for being together. The changed life situation had resulted in much more contact with the son/daughter, phone calls 'night and day', and in some cases frequent visits to the families' home. The narratives disclosed increased awareness of the son/daughter's life and problems, but at the same time increased awareness of parents' inability to influence care. It appeared from the text that the nurses lacked interest in sharing information and cooperating with parents. Furthermore, the enforcement of client-care confidentiality kept the parents even more at a distance. Staff, as well as local authorities, were the subjects of anger in the narratives: local authorities for interpreting the guiding principle of autonomy and integrity as respect for the client's right to decide for him/herself, narrated as 'when s/he has closed the door s/he must be left alone', and the staff for the way they applied the ideas of autonomy and integrity in care. The outcome of this from the parents' perspective was that the clients became isolated and passive, expressed by one parent as: 'you know, our children are shy, afraid of others and don't exactly demand company. They can stay in bed and stare at the ceiling all day long if you let them'. It seemed that parents had difficulties in questioning care and getting

their suggestions for change heard. Suggesting changes was narrated as being a delicate matter. There seemed to be a fear of being seen as critical and that interference with care might have a bad influence on the parent–nurse/client–nurse relationship. Participants reported that suggestions had been met with comments such as: 'we don't take any orders from you'.

The text exposed positive as well as negative aspects of the care and of the nurses. One relief that was expressed was that the son/daughter was safely taken care of by nurses who liked him/her. The nurses were spoken of as being easy to talk with, doing their best, nice and really caring for the son/daughter. However, another picture that emerged from the text was that the staff were lazy, not really interested in their work and sometimes not even fit to do the job. The nurses' opinion that they knew the client better than his/her parents was a source of irritation that emerged from the text. This, together with narrated experiences of being shut out and the ambiguous view of the carer, could be interpreted as competition within the parental role between parents and carers, which constituted a threat.

Coming to terms with difficulties

The narratives disclosed different ways of dealing with life. Concentrating on positive aspects of life and being involved in one's own interests, acceptance of the illness and the hope for a better life-style for the offspring were revealed as being helpful in coping with difficulties. Activities such as official letters (fathers), dialogues with staff, and cooperation with other parents about ways and means to influence care and be an advocate for the son or daughter, together with efforts to 'pep up' the son or daughter were narrated as other ways of dealing with difficulties. Knowing about the son's/daughter's current functioning and care plan was narrated as an important basis for confidence. This, however, was not always possible: 'I guess they consider him/her of age … that it's none of our business … I'm only wondering, have they asked him/her what s/he wants?'.

The communion in family and church emerged as important sources of comfort and support in the narratives. Social support from other families in similar circumstances, in 'the Schizophrenia Association', was narrated as invaluable for persistence in the care-giving role: 'when you have lived it with your own kids … then you really know … we understand each other and can give the best tips about how to deal with problems'. The narratives also revealed that parents' care and attention were rewarded. How important the parents were to their son/daughter was shown in such expressions as, 'when things are bad or when s/he is upset about something … s/he always turns to us'.

Hoping for a better life for the son/daughter

Despite narrated experiences of the son or daughter as being changed, a core part of self not influenced by changes was disclosed in such expressions as: 'has always been easy to like' or 's/he hovers between being happy and so sad … s/he was already that way as a child'. This and 'the old' son/daughter who could now and then be glimpsed seemed to endorse hope, promising possibility of a better life. Narrated attempts at seeking ways to improve life for the son/daughter and support his/her independent choices for a self-directed life such as, 's/he has to get on the right track, but I can't find it for her/him' also revealed a hope for the future. Another indication of hope was the desire for a better understanding of mental illness, a better health care system and a vivid portrayal of care and the son/daughter's life during the 2 years spent at The Villa, which told of an acquired experience of what care could be like. The narratives displayed hope as a sustaining force to seek ways to improve life for the son/daughter, but they also revealed the struggle to remain hopeful: 'we have trampled around in this mess for 26 years now … it's been all ups and downs'.

Some examples of the third structural analysis with subthemes and themes are shown in Table 1.

Interpreted whole and discussion

The meaning of parental care for a son or daughter with schizophrenia living in a community-care setting was illuminated in the themes 'living with sorrow, anguish and constant worry', 'living with guilt and shame', 'relating with carer/care: comfort and severity' 'coming to terms with difficulties' and 'hoping for a better life for the son/daughter'. Parents' experiences were grounded in a changed temporal world. The onset of the illness was narrated as a fateful event that transformed the course of the family. Endless parenting continued to be a force in the parents' life though they did not serve as primary care-givers. Parental care-giving emerged as a life-long effort to help and support the son or daughter suffering from mental illness. Findings suggest that perseverance in the parental care-giving role is based on devotion to the adult son/daughter. These findings are similar to those in studies that examined the primary care-giving role of parents of an adult child suffering from schizophrenia (Howard 1994, Tuck *et al*. 1997). The narratives revealed ongoing grief and sorrow associated with ongoing losses with no visible end, consistent with experiences of 'chronic sorrow'. Chronic sorrow has been described as the periodic recurrence of a permanent pervasive sadness or other grief-related feelings associated with a significant loss (Eakes *et al*. 1998).

Table 1 Third structural analysis, some examples

Meaning unit	Transformation	Sub-theme	Theme
S/he immediately got on well with them ... had pals everywhere ... and then it turned out this way ... it's really tragic.	The son/daughter was so popular. The development is tragic.	Grieving for the lost child	Living with sorrow and constant worry
We were an ordinary family ... but after the onset of his/her illness nothing was the same ... s/he is always in my mind ... the very thought of the life s/he has to live drives me in despair ... it's no life really.	The onset of the illness changed the families' life radically. The parent is sorry and worried, always thinking of the son/daughter.	Being constantly anguished and worried	
S/he's in bad shape and constantly increasing in weight ... now close to 100 kg ... and s/he cares ... a lot actually, ... it ruins his/her self-confidence... but s/he hasn't got the strength to do anything about it.	The parent is worried about the son/daughter's poor condition and physical shape and is critical about the work of the staff.	Worrying about the son/daughter's health	
I have been very critical and down ... felt that we were cursed ... punished.	The parent has accused him/herself and the family of being responsible for the child's illness.	Blaming oneself/family	Living with guilt and shame
I guess we haven't been exactly the best network.	The family have not been good enough.		
It is trying, you can never be sure of what will happen, when things are at their worst ... s/he might roar ... pee from the balcony ... anything.	Abnormal behaviour is embarrassing for the family.	Being ashamed of abnormal behaviour	
S/he knows how to take him/her ... sometimes you have to be definite ... s/he is sensitive to that ... terrific ... you have to set limits too.	The parents praise the carer's way of tackling the son/daughter.	Being satisfied with care	Being in a relationship with carer/care: comfort and hardships
We can't participate in the care-planning ... the carers decide everything ... but it's our child, isn't it.	The parent is critical of not being allowed to participate in the planning of the care for the son/daughter.	Being disappointed with development of care	
We need to have time to ourselves ... take a breather ... so now and then we go to our summer cottage, we have no phone there ... it's wonderful.	Parents have recognised their own need to have time to themselves.	Taking care of own needs	Coming to terms with difficulties
Together we try to have an influence ... that's what we want, but it's difficult ... it's not easy to deal with the issue of integrity in this kind of mental disturbance.	Parents want to have influence over the care but the staff's defence of patient integrity puts obstacles in the way.	Being an advocate for the son/daughter	
It was so nice, such a community ... I got to know some of the other patients quite well ... we were invited to community parties, you always felt welcome there.	Memories of community and being invited and welcomed as a parent in the care setting is promising.	Being hopeful	Hoping for a better life for the son/daughter
S/he wants something to happen ... yesterday s/he phoned me and told me about an excursion they have made and s/he was so happy ... it was good to hear.	It is good to know that the son/daughter has expectations and can enjoy her/himself.	Knowing the son/daughter	
We talked about it and s/he was joking ... quite humorous, like s/he used to be ... at such moments s/he looks normal.	Glimpses of hidden resources engender hope.	Glimpsing resources	

The unresolved grief was associated with ongoing loss, and recent changes in care seemed to be an important trigger of sorrow and worry.

This study explored the long and dismal experience parents had with the mental health system. The findings that they received vague and evasive information about the diagnosis (Main *et al.* 1993, Howard 1994, Tuck *et al.* 1997), that they suffered feelings of being blamed (Winefield & Burnett 1996), and that they were excluded from the treatment of the family member (Hyde & Goldman 1993, Eakes 1995, Winefield & Burnett 1996) are consistent with other studies. In this study, recent changes in care that involved the move from a hospital ward to a more home-like setting invited parents to experience participation and community that aroused hopes for increased cooperation. These hopes were dashed when clients were relocated to a community setting. Parents are expected to devote themselves to the care of their child during infancy and childhood. Parents who continue this form of care into the child's adulthood have been questioned as over-involved or dysfunctional (cf. Laing & Esterson 1970, Minuchin 1974). The view of families as pathogenic may still exist (Rutz 1995) and, if so, it might be a possible explanation for keeping families out of care.

Another way of understanding the lack of cooperation between parents and nurses might be a lack of resources and increased workloads, with priority given to the care of the client, or as a problem of confidentiality. In psychiatric care nurses have to deal with clients' helplessness, loss of privacy and autonomy. Lutzen & Nordin (1994), who studied moral decision-making in psychiatric nursing, found that nurses were aware of the patients' vulnerability, and when they perceived a threat to the patients' safety or well-being they made decisions for the patients to protect them from harm. The defence of the clients' autonomy and integrity in care emerged in the narratives as some kind of red rag to the parents. The parents' view was that the sons' or daughters' judgement was impaired by the illness and leaving him/her alone would only worsen the condition. Conflicts in the parent–nurse relationship seemed to be largely those of power with a diminution of the power of the parents. The nurses' attitude of knowing the client better and their unwillingness to share care planning or cooperate were interpreted as a threat to the parental role in a culture conflict between the family system and the care system. Parents still perceived the adult son or daughter as a child from emotional age, which is quite understandable as the illness often interrupted the separation from parents (Rutz 1995) and people suffering from schizophrenia tend to regress to a less mature state (Hyde & Goldman 1993). The official carers defended the clients' chronological age and confidentiality, and the nurses' power to provide the care without parental interference.

It is of interest that parents always directed their anger towards staff in general, never towards a specific nurse when they narrated situations when they were offended. This might be in accordance with Levinas' (1998) assertion that violence has to be thought of as an action that does not touch the individuality of the other 'by approaching it from an indirect angle' (p. 19), where the other becomes a mass. Parents were critical, but found it generally difficult to express criticism (cf. Hertzberg & Ekman 1996) unless they acted collectively, for example by writing official letters. Winefield & Burnett's (1996) research might provide one angle of reflection on the findings of not involving parents in care. They studied family involvement in care from a staff perspective and found that staff fears of a loss of power, due the exposure of professional shortcuts, served as obstacles to the involvement of parents in care.

As Hertzberg & Ekman (1996) found, results from this study also revealed positive experiences of care. Experiences of comfort and confidence in care, and of being relieved with the assurance that the son or daughter was safely being cared for were evident in the narratives. A place to live has been seen as the most essential element in a community service programme (National Board of Health & Welfare 1999). People who suffer from severe mental illness may present too great a problem to live alone or with informal carers and therefore find themselves relying on formal care. A striking finding by Kasper *et al.* (1992) was that amongst people with severe and persistent mental illness, those who lived in supervised residences were least likely to have unmet needs, even though care and services did not meet all needs.

The phenomenon that the diagnosis was never mentioned by name in the narratives, and of narrated experiences of shame and seeking support amongst other parents in a similar situation indicate experiences of stigma. It is well documented that people with a severe mental illness, such as schizophrenia, are met with negative attitudes from the public (e.g. Greenley 1984, Link 1987, Link *et al.* 1997, Wahl 1999) that severely affect their lives (Link 1987, Rosenfield 1997). Today, there is a growing awareness that such a stigma affects not only the people themselves with severe mental illness themselves but their families as well (Phelan *et al.* 1998, Sommer 1990). Withdrawal from other social contacts because people 'do not understand' testified to negative public attitudes as a presumed source of family stigma (cf. Phelan *et al.* 1998). Furthermore, the results indicated that the relationship with mental health professionals affected the severity of the stigma by awakening feelings of guilt, findings that are in line

with other recent studies (Lefley 1987, Winefield & Burnett 1996, Wahl 1999). These findings suggest that mental health professionals need to be aware of their own attitudes and treatment of family relations.

In this study parents were dealing with the long–term consequences of the illness. However, the meaning of parents' staying power regarding care-giving, the striving to look after themselves and expressions of hopes for the future were interpreted as expressions of 'coming to terms' (cf. Buyssen 1996, p. 96) with the reality of illness. Coming to terms appeared to be primarily related to social relationships in the family and in the family support group, the 'Schizophrenia Association'. Buyssen (1996) argues that important aspects of the process of coming to terms are 'telling the story' and 'comparison with others'. The meaning of self-help relatives' groups who provide opportunities to enlarge one's social network, to share experiences and to give and receive support and learn from each other, have been documented in other studies (e.g. Solomon & Draine 1995, Magliano *et al.* 1998). Lazarus & Folkman (1984, p. 250) argue that social support is a resource, which, while available in the community, must however be cultivated and used. In nursing it may be a mission of special importance to provide opportunities for family members to meet one another.

The final report from the psychiatric reform National Board of Health and Welfare (1999) noted that the needs of relatives of people with mental illness have been neglected for a long time, a statement confirmed by the results from this study. Families need to be more involved in the care of their relative (Saunders 1999), and clients with long-term mental health problems need natural contacts with families and friends (National Board of Health and Welfare 1999). Of course the client's needs are not always congruent with the family's needs. Nursing is built on trust in the client–nurse relationship, and the protection of client confidentiality in conflicts between the clients' rights and the needs of the families raise difficult issues for professionals. However, this and other studies (Howard 1994, 1998, Tuck *et al.* 1997) show that parents will probably be there for their offspring with mental illness. For the benefit of all parties, it seems to be vitally important to find ways of avoiding the uncomfortable relationship that often seems to occur between the family and mental health professionals (Winefield & Burnett 1996, Wahl 1999). Rutz (1995) argues that we have to change our view of families as 'evil and pathogenic' (p. 23) if the goal is to involve them in care and ease their burden. If parents are to become partners we must develop ways to give them information and support and to achieve cooperation, while simultaneously carefully protecting client confidentiality.

Critical considerations

This phenomenological hermeneutic study presents one of several possible interpretations (Ricoeur 1976, p. 11). Furthermore, in a narrative interview method the interviewer is regarded as a cocreator of the text (Mishler 1986, p. 52). The results must therefore be judged in relation to the pre-understanding of the author, who is a nurse, experienced in mental healthcare and nurse education. There are limitations to this study that deserve specific mention. First, as noted, parents in this study had experienced a two-year caring project involving their relatives suffering from mental illness before relocation to the community setting. This suggests the presence of a greater degree of disappointment when faced with care that does not fulfil their expectations. Second, to conduct the interviews with both parents together may have certain advantages as parents remember together and talk about common experiences. The main disadvantage might be that interviews with one parent at a time would have allowed each parent full scope without influence from the spouse, and it is possible that the interviews would have been different or even richer had this been done. The results of this study cannot be generalised, but hopefully the interpretation conveys such insights and meanings that it becomes possible for readers to understand their own practice in a broader context.

References

Almberg B., Grafström M. & Winblad B. (1997) Caring for a demented elderly person – burden and burnout among caregiving relatives. *Journal of Advanced Nursing* **25** (1), 109–116.

Aström G., Norberg A., Jansson L. & Hallberg I.R. (1993) Experienced nurses' narratives about their being in ethically difficult care situations. The problem to act in accordance with one's ethical reasoning and feeling. *Cancer Nursing* **16**, 179–187.

Bibou-Nakou I., Dikaiou M. & Bairactaris C. (1997) Psychosocial dimensions of family burden among two groups of carers looking after psychiatric patients. *Social Psychiatry and Psychiatric Epidemiology* **32** (2), 104–108.

Bulger M.W., Wandersman A. & Goldman C.R. (1993) Burdens and gratifications of caregiving. Appraisal of parental care of adults with schizophrenia. *American Journal of Ortopsychiatry* **63** (2), 255–265.

Buyssen H. (1996) *Traumatic Experiences of Nurses. When Your Profession Becomes a Nightmare*. Jessica Kingsley Publishers, London.

Eakes G.G. (1995) Chronic sorrow: the lived experience of parents of chronically mentally ill individuals. *Archives of Psychiatric Nursing* **9** (2), 77–84.

Eakes G.G., Burke M.L. & Hainsworth M.A. (1998) Middle-range theory of chronic sorrow. *Image: Journal of Nursing Scholarship* **30** (2), 179–184.

Greenley J.R. (1984) Social factors, mental illness and psychiatric care: recent advances from a sociological perspective. *Hospital and Community Psychiatry* **35**, 813–820.

Häggström T. & Norberg A. (1996) Maternal thinking in dementia care. *Journal of Advanced Nursing* 24, 431–438.

Harper S. & Lund D. (1990) Wives, husbands and daughters caring for institutionalized and noninstitutionalized dementia patients: toward a model of caregiving burden. *International Journal of Aging and Human Development* 30 (4), 241–262.

Hertzberg A. & Ekman S. (1996) How the relatives of elderly patients in institutional care perceive the staff. *Scandinavian Journal of Caring Sciences* 10 (4), 205–211.

Horwitz A.V., Reinhard S.C. & Howell-White S. (1996) Caregiving: a reciprocal exchange in families with seriously mentally ill members. *Journal of Health and Social Behaviour* 37, 149–162.

Howard P.B. (1994) Lifelong maternal caregiving for children with schizophrenia. *Archives of Psychiatric Nursing* 8 (2), 107–114.

Howard P.B. (1998) The experience of fathers of adult children with schizophrenia. *Issues in Mental Health Nursing* 19 (4), 399–413.

Hyde A.P. & Goldman C.R. (1993) Common family issues that interfere with the treatment and rehabilitation of people with schizophrenia. *Psychosocial Rehabilitation Journal* 16 (4), 63–74.

Kasper J.A., Steinwachs D.M. & Skinner E.A. (1992) Family perspectives on the service needs of people with serious and persistent mental illness, II: needs for assistance and needs that go unmet. *Innovations and Research* 1 (4), 21–33.

Laing R. & Esterson A. (1970) *Sanity, Madness and the Family: Families of Schizophrenics*. Penguin Books, Harmonsworth.

Lazarus S.R. & Folkman S. (1984) *Stress, Appraisal, and Coping*. Springer Co. Inc., New York.

Lefley H.P. (1987) Impact of mental illness of mental health professionals. *Journal of Nervous and Mental Disease* 175, 613–619.

Levinas E. (1998) *Collected Philosophical Papers*. Duquesne University Press, Pittsburg.

Lindseth A., Maurhaug V., Norberg A. & Uden G. (1994) Registered nurses' and physicians' reflections on their narratives about ethically difficult care episodes. *Journal of Advanced Nursing* 20, 245–250.

Link B.G. (1987) Understanding labelling affects in the area of mental disorders: an assessment of the effects of expectations of rejection. *American Sociological Review* 52, 96–112.

Link B.G., Mirotznic J., Rahav M., Phelan J.C. & Nuttbrock L. (1997) On stigma and its consequences: evidence from a longitudinal study of men with dual diagnosis of mental illness and substance abuse. *Journal of Health and Social Behaviour* 38, 177–190.

Lutzen K. & Nordin C. (1994) Modifying autonomy – a concept grounded in nurses' experiences of moral decision-making in psychiatric practice. *Journal of Medical Ethics* 20 (2), 101–107.

Magliano L., Fadden G., Economu M., Xavier M., Held T., Guarneri M. *et al.* (1998) Social and clinical factors influencing the choice of coping strategies in relatives of patients with schizophrenia: results of the BIOMED I study. *Social Psychiatry and Psychiatric Epidemiology* 33, 413–419.

Main M.C., Gerace L.M. & Camilleri D. (1993) Information sharing concerning schizophrenia in a family member: adult siblings' perspectives. *Archives of Psychiatric Nursing* 73, 147–153.

Minuchin S. (1974) *Families & Family Therapy*. Harvard University Press, Cambridge.

Mishler E. (1986) *Research Interviewing – Context and Narrative*. Harvard University Press, Cambridge, Massachusetts.

National Board of Health and Welfare (1992) *Committee on Psychiatric Care. Welfare and Freedom of Choice*. National Board of Health and Welfare, Volume 73, Stockholm.

National Board of Health and Welfare (1999) *The Psychiatric Care Reform. Final Report of the 1995 Psychiatric Care Reform*. National Board of Health and Welfare, Volume 1, Stockholm.

Pejlert A., Asplund K. & Norberg A. (1995) Stories about living in a hospital ward as narrated by schizophrenic clients. *Journal of Psychiatric and Mental Health Nursing* 2, 269–277.

Pejlert A., Asplund K., Gilje F. & Norberg A. (1998) The meaning of caring for patients on a long-term psychiatric ward as narrated by formal care providers. *Journal of Psychiatric and Mental Health Nursing* 5, 255–264.

Pejlert A., Asplund K. & Norberg A. (1999) Towards recovery. Living in a home-like setting after the move from a hospital ward. *Journal of Clinical Nursing* 8, 663–674.

Pejlert A., Asplund K. & Norberg A. (2000) From a psychiatric ward to a home-like setting: The meaning of caring as narrated by carers. *Journal of Clinical Nursing* 9, 689–700.

Phelan J.C., Bromet E.J. & Link B.G. (1998) Psychiatric illness and family stigma. *Schizophrenia Bulletin* 24 (1), 115–125.

Plager K.A. (1994) Hermeneutic phenomenology: A methodology for family health and health promotion study in nursing. In: P. Benner (Ed.) *Interpretive Phenomenology. Embodiment, Caring and Ethics in Health and Illness*. Sage Publications Inc., Thousand Oaks.

Polkinghorne D.E. (1988) *Narrative Knowing and the Human Sciences*. State University of New York Press, New York.

Provencher H.L. (1996) Objective burden among primary caregivers of persons with chronic schizophrenia. *Journal of Psychiatric and Mental Health Nursing* 3 (3), 181–187.

Ricoeur P. (1976) *Interpretation Theory. Discourse and the Surplus of Meaning*. Christian University Press, Forth Worth, Texas.

Rose L. (1996) Families of psychiatric patients: a critical review and future research directions. *Archives of Psychiatric Nursing* 10 (2), 67–76.

Rose L. (1998) Benefits and limitations of professional–family interactions: the family perspective. *Archives of Psychiatric Nursing* 12 (3), 140–147.

Rosenfield S. (1997) Labelling mental illness: the effects of received services and perceived stigma on life satisfaction. *American Sociological Review* 62, 660–672.

Rutz W. (1995) The need for psychiatric professionalism – an integrative view. *Nordic Journal of Psychiatry* 49 (Suppl. 35), 17–23.

Saunders J.C. (1999) Family functioning in providing care for a family member with schizophrenia. *Issues in Mental Health Nursing* 20, 95–113.

Söderberg A., Gilje F. & Norberg A. (1997) Dignity in situations of ethical difficulty in intensive care. *Intensive and Critical Care Nursing* 13, 135–144.

Solomon P. & Draine J. (1995) Adaptive coping among family members of persons with severe mental illness. *Psychiatric Services* 46 (11), 1156–1160.

Sommer R. (1990) Family advocacy and the mental health system: the recent rise for the Alliance for the Mentally Ill. *Psychiatric Quarterly* 3, 205–221.

Stephens M., Kinney J. & Ogrocki P. (1991) Stressors and well-being among caregivers of older adults with dementia. The in-home versus nursing home experience. *Gerontologist* **31**, 217–223.

Tuck I., du Mont P., Evans G. & Shupe J. (1997) The experience of caring for an adult child with schizophrenia. *Archives of Psychiatric Nursing* **11** (3), 118–125.

Wahl O.F. (1999) Mental health consumers' experience of stigma. *Schizophrenia Bulletin* **25** (3), 467–478.

Winefield H.R. & Burnett P.L. (1996) Barriers to alliance between family and professional caregivers in chronic schizophrenia. *Journal of Mental Health* **5** (3), 223–232.