

EMPIRICAL STUDY

Held to ransom: Parents of self-harming adults describe their lived experience of professional care and caregivers

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Abstract

The aim of the study was to discover and describe lived experiences of professional care and caregivers among parents of adults who self-harm. Narrative interviews were conducted with six parents of daughters with self-harming behaviours and analysed using a phenomenological hermeneutic approach. The meanings of the parents' narratives of their lived experiences of professional care and caregivers were interpreted as their being involved in 'limit situations' comparable to hostage dramas. Several meaningful themes contributed to this interpretation: being trapped in a situation with no escape; being in the prisoner's dock; groping in the dark; and finding glimmers of hope. Parents of daughters who were in care because of self-harming often felt obliged to pay an emotional ransom, which included feelings of being accused, being 'broken', being confused, and feeling lost. Moments of peace occurred as welcome breaks offering a short time of rest for the parents. Situations that were understood by the parents and solved in a peaceful way were experienced as a respite and inspired parents with hope for their daughters' recovery.

Key words: *Lived experience, narratives, phenomenological hermeneutics, psychiatric nursing, self-harm*

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Introduction

Research concerning the relationship between the family members of people with mental health problems and their professional caregivers has shown several problems indicating dissatisfaction and difficulties in this relationship (Ferriter & Huband, 2003; Nicholls & Pernice, 2009; Rapaport, Bellringer, Pinfold, & Huxley, 2006). Family members report experiences of contacts with personnel that were too brief and infrequent, lack of communication, and not being listened to (Ferriter & Huband, 2003). Professional caregivers who work with families report confidentiality as a serious dilemma (Rapaport et al., 2006). The conflict between the patient's right to confidentiality and the family's right to information causes stress in the families and affects the relationship between the family and the professional caregivers (Marshall & Solomon, 2000; Nicholls & Pernice, 2009). Comparable situations are found in the care of

persons who self-harm (Lindgren, Wilstrand, Gilje, & Olofsson, 2004; Wilstrand, Lindgren, Gilje, & Olofsson, 2007).

Self-harm has been described as a way of dealing with severe mental suffering and is often referred to as a coping strategy (Solomon & Farrand, 1996) or a survival strategy (Pembroke, 1998; Reece, 2005; Schoppmann, Schröck, Schnepf, & Büscher, 2007). The self-infliction of physical harm in these cases makes mental suffering easier to manage (Favazza, 1996; Solomon & Farrand, 1996). In the present study, self-harm is defined according to Favazza (1996) as a repeated, impulsive behaviour where tissue damage occurs, but suicide is not the intent. Instead of wishing to die, people who self-harm wish to be relieved from mental suffering.

The prevalence of self-harm is difficult to estimate because many people who self-harm do not seek hospital care (De Leo & Heller, 2004; Hawton, Rodham, Evans, & Weatherall, 2002; Ystgaard, Reinholdt, Husby, & Mehlum, 2003).

However, the prevalence of self-harm in a general population is estimated at between 2% and 6% (Hawton et al., 2002; Klonsky, Oltmanns, & Turkheimer, 2003).

Research on the experiences of family members of people who self-harm has been conducted predominantly with the parents of adolescents, who are shown to perceive self-harm as a confusing phenomenon that evokes negative emotions. The parents described self-harm as a sign of disorder, but not an illness, and as a compulsive and contagious act that is difficult to endure. They asked for professional help, that is, the opportunity to discuss self-harm with professional caregivers (Oldershaw, Richards, Simic & Schmidt, 2008; Rissanen, Kylmä & Laukkanen, 2008). Comparable situations and needs are seen among mothers of people who are suicidal (Daly, 2005). They experience themselves as failed mothers, rejected, and alone. They also experience hopelessness, powerlessness, and the need to 'walk on eggshells' and keep an emotional distance. Research shows that parental experience of dealing with self-harming adolescents is characterised by feelings of guilt, shame, distress, and loneliness (McDonald, O'Brien, & Jackson, 2007; Oldershaw, et al., 2008; Raphael, Clarke, & Kumar, 2006). Parental strategies to help self-harming adolescents described by Rissanen, Kylmä, and Laukkanen (2009) included encouraging adolescents to help themselves by performing activities alone or with other people, and accepting help from safe and trusting human relationships. However, to be able to help their children, parents needed both information about the phenomenon of self-harming and access to help for the whole family.

In summary, research has been conducted predominantly among parents of adolescents who self-harm. Studies among the family members of adults who self-harm are sparse, and no research has been found that focuses on the meanings of their lived experience of professional care. As mentioned, family members and professional caregivers face difficulties in the areas of confidentiality and autonomy. It seems reasonable to believe that these issues are more challenging when the child becomes an adult. Therefore, the aim of the present study was to discover and describe lived experiences of professional care and caregivers among parents of adults who self-harm.

Materials and methods

Participants

Six parents of adult children who self-harm participated in the study. Four parents responded to

invitational advertisements in two local newspapers, and the fifth and sixth parents were recommended by one of the other participants. All six participants were between 45 and 55 years of age, five were women, all were married and had other children, and were regularly employed in various sectors.

Context

The participants' self-harming daughters were between 21 and 25 years of age and they were all admitted to outpatient care. They had been engaged in cutting, burning, and scratching themselves, but at the time of the interview they did not self-harm. Whether this was temporarily or permanent is hard to assess.

Four of them had moved out of their parents' home: one was living with a partner, two lived in shared apartments with friends, and one lived on her own. The other two lived mainly on their own; however, during periods of unstable mental health, when they needed more support, they moved back home with their parents.

Narrative interviews

Narrative interviews (Mishler, 1986) were conducted at a time and place agreeable to the participants, usually in their own home or at the researchers' workplace. One of the interviews was conducted by telephone in agreement with the participant because of long distance. The first author conducted five of the interviews, but not the sixth because of familiarity with the participant's story. The last author conducted the interview with the sixth participant. The interviews began with questions concerning the parents' and their daughters' backgrounds. The main question was, 'Please, tell me about situations when you met professional care and caregivers as a parent to a daughter who self-harm'. Whenever the interviewees did not spontaneously reflect on the narrative, their reflections were solicited with questions such as 'What did you think/feel/do in this situation?' (cf. Drew, 1993). Clarifying questions such as, 'In what way did the healthcare professionals' behaviour cause you to feel better [or worse]?' allowed the interviewer to attain deeper understanding of their experiences.

The parents' narratives concerned their lived experiences of their daughters' professional care and caregivers at all levels of outpatient and inpatient child, adolescent, and adult psychiatric care, acute and emergency care, and primary healthcare. They also described their experiences with professionals in the social service system. The narratives covered several years and included specific

situations that had occurred at any time during the whole course of the daughters' ill-health.

The interviews ranged from 30 to 85 min (median = 72 min). All interviews were tape-recorded and transcribed verbatim (including pauses, laughter, and crying) by the first author.

Ethical considerations

There was a risk that the interviewees could feel that their privacy or dignity was violated by the personal and emotionally evocative questions. On the other hand, having someone listen to their narratives could also be experienced as a relief (Gaydos, 2005). The interviewers tried to protect the participants by being sensitive to their reactions during the interviews.

Both oral and written information about the study was provided and when participants decided to participate they gave their written informed consent. They were informed that participation in the study was voluntary and that they could end their participation whenever they liked without giving any reason for their decision. The study was approved by the Research Ethics Committee of the Medical Faculty (dnr 08-034M), Umeå University, Umeå, Sweden.

Interpretation process

The interviews were interpreted using a phenomenological hermeneutic approach inspired by Ricoeur (1976), further developed by Lindseth and Norberg (2004), and used in several subsequent studies (Enarsson, Sandman, & Hellzén, 2008; Talseth, Gilje, & Norberg, 2001). Phenomenology aims to uncover, describe, and explain the lived experience through structures of meaning, and hermeneutics aims to interpret and understand human consciousness. The interpretation in the phenomenological hermeneutic approach is a dialectic process between the whole and parts of the text, between understanding and explanation, between de-contextualisation and re-contextualisation, and between what the text says and what it points to (Ricoeur, 1976).

The interpretative process consists of three phases: naïve reading, structural analysis, and comprehensive understanding, which together form a hermeneutic circle. The naïve reading aims to achieve an initial understanding of various meanings associated with the phenomenon and suggests ideas for further analysis. The subsequent structural analyses confirm or reject the ideas from the naïve reading, and the comprehensive understanding is formulated from a combination of the authors' pre-understandings, the findings of the naïve reading

and the structural analyses, and the relevant literature (Lindseth & Norberg, 2004; Ricoeur, 1976).

First, to get a naïve understanding of possible meanings of the text, the interviews were listened to and then the transcribed text was read through several times. Second, to validate the ideas from the naïve reading, several structural analyses were performed. The structural analysis was not a linear process, instead it was a movement back and forth between the whole and the structures of the text. The text was divided into meaning units, i.e. words, sentences, paragraphs, and metaphors relating to various meanings that could be ascribed to parents' experience of professional care and caregivers. The meaning units were condensed and formulated as codes, while simultaneously, the nuances of the situations, paragraphs with special meanings and metaphors, were marked in the text using different colours. The relationships between codes with similar meanings were reflected on, and the codes were then sorted into subthemes. Continuing reflections on the relationships between the subthemes resulted in the formulation of 10 subthemes and four themes; being trapped in a situation with no escape, being in the prisoner's dock, groping in the dark, and finding glimmers of hope. During the interpretative process the authors discussed every step until consensus was achieved. To check for any meaning units that invalidated the themes, the whole text was read through again, but nothing to reject the themes could be found.

Findings

Naïve reading

The underlying meaning of parents' lived experiences with professional care and caregivers was interpreted as a hostage drama, where the daughter was held hostage. Within the drama there are visible and invisible 'enemies' including laws and professionals within both the healthcare system and the social service system. The parents' need to be constantly on their guard is predominant, along with experiences of not being listened to, not being seen, not being taken into account, and being excluded from participating in their daughters' care. The parents' expressed feelings of shame over having a daughter with mental health problems and feelings of guilt and self-blame: 'It's my fault; I have done something wrong'.

Parents' experiences also included feelings of peace and of being comforted, listened to, and taken seriously in some meetings with some professional caregivers. Caregivers who showed compassion and an honest willingness to help were experienced as

genuine, reliable, and helpful, which allowed parents to see some hope for their daughter.

Themes and subthemes

Below themes are presented bolded, and subthemes are presented in italics and illustrated by quotations. The subthemes are described separately, even though they were not discrete but interwoven among and within each other. Some of the quotations mention a woman named as Tina. This name was chosen and used by the authors instead of the daughters' real names.

Being trapped in a situation with no escape means losing confidence in the healthcare system and feeling hoodwinked.

Losing confidence in the healthcare system

Parents described how they had had confidence in the healthcare system and had tried, often over a long time, to motivate their daughters to seek help. When, at last, the daughters finally accepted help, however, the provided healthcare appeared to be deficient and their expectations were ruined:

Naturally, I thought that they couldn't cut themselves on the ward. Damn it, on the ward they really cut themselves! Then the caregivers said to me, 'Soon we [won't have] any drinking glasses left because of your daughter; she has broken every one [of them].' I said, 'What? Don't you have them under control?'

Parents wished to receive help for their daughters, support and relief for themselves, and most of all hope. 'I want hope [starts to cry]. I want to feel that there's a solution. I need to know what we can request and ... [crying] ... how to treat her'. However, once their daughters were taken into the healthcare system it became apparent that the care facility was just a repository. Furthermore, caregivers were seen to ignore the self-harming act, neglecting the patients' anxiety, and turning a blind eye to what was happening on the ward. A mother who slept over on the ward reported:

One night I woke up because they were raising hell upstairs. They had been sneaking in to one another // It was like the Stockholm Bloodbath in one room. Three girls were in there, cutting themselves, they triggered each other.

Losing confidence in the healthcare system also meant the parents were constantly occupied with

the mission of being available. Parents felt trapped between their desire to be a parent and their urge to compensate for inferior care: 'I was her therapist instead of just being her mother. To get rid of the anxiety we would talk for hours; she should have had that help from the care providers instead'. One way parents compensated for deficient care was by visiting their daughter on the ward. Parents experienced the visits as 'a necessary evil' that they could not allow themselves to resist.

The parents also expressed need for support of their own from professional caregivers; however, deficient care forced them to seek support and help from others, such as family members, friends, or workmates:

I have searched for help and for opportunities to share my thoughts with other people. One of my cousins especially guided me so that I knew what I could ask for and demand.

Constantly seeking answers, help, and support fostered feelings of powerlessness and helplessness in the parents. One parent said: 'What am I going to do with my kid? I can't watch her fall apart in pieces; I can't handle that'.

Feeling hoodwinked

Being officially offered help for their daughter, only to find out that the care facility was just a repository, left parents feeling hoodwinked, as did being invited to take part in care that they could not understand or that the 'goal' of which was not to cure their daughter but to manage her. One parent cited a professional caregiver's comment about the care offered to people who self-harm, 'They're like a huge fire with a lot of small fires around them. The small fires are the self-harm and it's them we put out; we leave the huge fire alone'. The parents often experienced confusing information about their daughters' illness and care:

When she was in inpatient care the caregiver argued that it was better for our daughter not to have a diagnosis. If she did, she would have to carry that baggage for the rest of her life.

Such statements were difficult to understand in light of the situation they were used to in somatic healthcare, where a diagnosis is usually essential to getting proper care.

Parents also felt hoodwinked when they had not been taken seriously when they tried to inform the caregivers about worries concerning their daughters' illness. If someone had listened to them earlier,

many years of suffering would have been saved for their daughter:

If only I'd been more persistent and said 'She's not just an ordinary girl, something is wrong with her'. She's lost so many years unnecessarily. 'Please, listen to what we're saying, something about her isn't right and we need help'.

Feeling hoodwinked was also about feeling threatened, urged to 'give the daughter up', and in fact cheated. Special difficulties emerged if parents were divorced and lived in separate communities. Experiences of being cheated occurred when caregivers, despite the fact that the parent had sole custody of the daughter, persuaded the daughter to change her place of domicile to the place where the other parent lived:

Then they [the caregivers] had discovered that a child who has passed 16 years of age can change the place of domicile to the other parent // So, they took my daughter to a place where she could do just that, without my knowledge. I had sole custody and they went behind my back!

Being in the prisoner's dock meant feeling accused by caregivers and being 'broken' as parents.

Feeling accused

Parents were shocked to realise that the professional caregivers viewed their daughters' self-harm as their fault as parents. Being blamed for having excessively high demands on their daughter and for being bad parents, they felt like utter failures and in the end that they were worthless as parents.

It was a shock being blamed; I felt that the first time my daughter was in mental health care. Feelings of guilt and shame, but most of all it felt like a failure. In the end I felt I was of no use as a parent.

Being 'broken'

Being 'broken' occurred when parents who stood up for their daughters', as well as their own rights, and called the professional care into question experienced professional caregivers' attitudes towards them as troublesome, difficult, and very hard to handle. When they asked for alternative treatment, they were accused of destroying their daughter's care and professional caregivers slandered the parents in front of their daughters as a way of dealing with the situation. 'After that they decided to crack me; it was their goal. They said to my daughter, "Your mother

doesn't want you to receive care, she's destroying everything", and so on'.

Groping in the dark meant feeling invisible, being confused, being lost, and negotiating and trying to bridge gaps between all the various parties involved.

Feeling invisible

Parents felt invisible when they were not acknowledged as significant others in their daughters' lives. Furthermore, as parents they wanted the professional caregivers to ask how they felt and whether they too needed some support. Not being seen as significant to their daughters was frightening:

It scares me that they forget the most important people in my daughter's life. They need to see the significant others. We're the ones who are the main caregivers and we have to keep it together around the person who is ill.

Feeling invisible was also about parents who felt forced to stand aside, watching as their daughters fell through the cracks in the healthcare system. It was described as a war between the communities and the county council over who was going to take responsibility for their daughters' care. The slowness of the healthcare system was cause for much anger and despair: 'When partners in the healthcare system don't co-operate nor communicate with each other it makes me both bloody upset and depressed'. During periods of inpatient care, parents felt especially set aside. They believed that their daughters still needed their help and support, but they were made to believe that visiting hours were regarded as bad for their daughters and caregivers kept asking them, 'Why do you run here so often?'

Feeling invisible was also provoked by difficulties concerning confidentiality, both in inpatient and outpatient care, when the daughters reached the age of majority. Doubts arose, such as; Am I not her parent anymore? What is my part in all this? What insights do I have? When the daughter reached majority information began to be withheld from her parents in the name of confidentiality, even when the daughter had given her consent to share information with her parents. Parents wanted information regarding how to behave and what to do as parents to help their newly adult daughter. As one parent expressed it,

I needed help to know how to behave. I am a parent, not a carer. We don't have the professional

education to be a therapist. I just wanted some kind of tools instead of being helpless.

Feeling invisible was also about being ignored and not taken seriously as parents. Staff covered up for their co-workers' bad behaviour towards the parents, neglected to call parents to the clinic when the care was being planned. Parents said that although professional caregivers expected them to take responsibility and provide support for their daughter, they didn't give parents the opportunity to participate in making decisions: 'We weren't asked about what we thought, how we thought things should be solved. On the other hand, we are the one affected by their decisions'.

Finally, feeling invisible was also a reflection of being cut off from society. Having a daughter who engaged in self-harm was a matter of secrecy and feelings of shame among the parents. People around them avoided contact and friends did not visit anymore. As one parent reflected on the stigmatization of mental illness:

The psychiatric clinic is in the back side of the hospital; I think it's crazy. I want to be treated with dignity; it shouldn't matter which illness I suffer from. That's the big difference, I think, people who suffer from mental illness are labelled.

Being confused

Being confused refers to experiencing situations where contradictory information about professional care or unavailable offers of care are presented. For example, some parents and their daughters were told about a special treatment home, however, after further information and sometimes after visiting, they were informed that there were no places available at the moment. Parents also found that information concerning available support for their daughters was difficult to access and hard to grasp. When they asked for more support for their daughter, they got the message that there was no support available. Misunderstandings occurred when parents received information from someone other than the professional caregivers that their desired support for their daughter was actually available. Although the desired support was available from another care provider, parents felt uncertain:

I asked at the care meeting whether someone could visit Tina if necessary? There was nobody [who could visit] was the answer I got. Now I've got the information that there was someone who could have come. There were personnel from the community who were available if needed.

Being confused was also provoked by mixed messages sent when professional caregivers told the parents not to feel guilty for their daughters' illness despite the fact that the parents had neither said anything about feeling guilty, nor actually felt guilty. When professional caregivers gave strange answers to certain requests, it was also confusing:

I said, 'I want you to call me if she's feeling worse. It's noted in her medical record that this is what she wants. I know that she'll be calmer if I could come then'. The caregiver said something that I didn't hear, so I said, 'Sorry, what did you say?' Then she said she thought I had nice hair. I said, 'Did you understand what I said? I want to be contacted if my daughter is feeling worse.' She mumbled an answer and then she left. I still don't know if she understood what I'd said.

Being lost

Being lost was about parents being invited to take part in their daughters' care, but not being given the necessary information about what was expected from them or what duties the professional caregivers would be handing over to the parents:

I've joined these group sessions. The chairs stood in a circle and I was placed in one of them and my daughter in another. The other members of the staff sat in the other chairs. They didn't say anything; everybody just looked at my daughter and me. Did they expect me to start this meeting or what?

Negotiating and bridging gaps

Negotiating and bridging gaps concerned functioning as a negotiator in several directions, within the family, as well as among healthcare staff and public authorities. The daughter's self-harming behaviour influenced the whole family. Difficulties that arose in the parents' relationship were often related to the caregivers' neglect of informing and involving both parents in care planning. Parents felt the need to 'take it slowly' with their daughter, which influenced the whole family to tiptoe around her. As one parent said, 'You have to be careful when talking to Tina—it's like walking on eggshells'. The need to negotiate among staff emerged when parents felt there were different opinions among the caregivers regarding care provided. Negotiating among public authorities was difficult to handle. They struggled for their daughters' rights and were eager to receive best care available. They argued with several actors within the public authorities regarding which treatment would

be best for their daughter. To be able to succeed in negotiating, parents had to be aware of their rights; however, they had to be cautious when they talked with the care providers. As one parent said,

You really have to think twice before saying anything. How should I express myself so that this person doesn't think that I'm barging in on their territory, only making a suggestion, like maybe it can be done in this way?

Negotiating and bridging gaps was also about being a bridge between their daughter and healthcare, and being available when their daughter contacted them and needed to tell somebody about the professional caregivers' treatment of her. However, sometimes parents tried to justify professional caregivers' sometimes rough behaviour towards their daughter. One mother told us, 'One of these caregivers was rather rough towards Tina, but I didn't take it so hard because she was rather cocky herself'. Furthermore, negotiating and bridging gaps meant being forced to speak up as parents on behalf of their daughter when she was unable. When this happened, professional caregivers had been irritated and told the parents not to engage. Negotiating and bridging gaps was also about the pressure parents felt trying to fulfil their daughters' need for family on the one hand, while trying to take the healthcare systems' rules and restrictions into consideration on the other: 'It's difficult to satisfy her need to be with her little sister and at the same time consider the rules for visiting the ward'.

Finding glimmers of hope applied both when parents felt valued and when they felt moments of release.

Feeling valued

Parents felt valued when they were invited to participate in professional care and allowed to have several family members visited their daughter despite visitation rules on the ward. Feeling valued was also about being listened to and having their worries taken seriously. As one parent reflected, 'A parent knows their child better than anyone else; therefore, they need to be heard. When a parent is worried then it's often well founded'. Professional caregivers with enough self-confidence to invite parents to take part in the care of their daughter contributed to parents' feeling valued, inspired confidence in themselves as parents, and validated them as valuable people in their daughters' lives. They gave information about their daughters'

recovery process and communicated with them as parents in a dialogue.

Feeling released

Parents were able to feel released when the caregivers did not accuse them of doing the wrong things. Parents were also able to get their needs met when healthcare was accessible to them, which contributed to the feeling of release. Professional caregivers with their own insights into different types of suffering were more likely to understand and convey compassion. One parent said, 'Caregivers with their own experience of suffering—maybe they had a tough and shady life behind them, and then they educated themselves—they were the ones who were the best in meeting us as parents'. Furthermore, the feeling of release also came from professional caregivers who provided answers and support when parents asked questions about self-harm or what to do under certain circumstances:

I said, 'This isn't working anymore; what can we do?' Then I got confirmed that the right thing to do was to take the car and go to the hospital; it was an emergency. That was all that I needed just then, some kind of support that it was okay. I didn't want to destroy the treatment or anything.

Comprehensive understanding and reflections

The last step of the interpretation, the comprehensive understanding, leads to a critical in-depth interpretation. Critical reflections (Lindseth & Norberg, 2004) on the researchers' pre-understandings, the sense of the naïve reading, the findings from the structural analyses, the research question, the context of the study, and relevant literature, resulted in a comprehensive understanding of the parent's experience of the professional care and caregivers, which is comparable to their being involved in a hostage situation.

Parents lived experiences of professional care and caregivers, initially help-seeking and filled with hope, turned into a situation with no available escape. In this study, the interpretation is that parents are involved in what Jaspers (1932/2000, pp. 96–104) called a 'limit situation', from which they cannot escape and against which they must struggle to create meaning. The situation in this case can be likened to a hostage drama where their daughter is the hostage. Parents of a daughter in a hostage situation must come up with a ransom, which is how parents feel when facing deficient and sometimes

hostile care. The parents pay an emotional ransom when they are in the prisoner's dock, being accused as well as broken, and when they are groping in the dark, feeling invisible, confused, and lost.

Caring deeply, as these parents did, about a person who suffers is experienced as a limit situation in life, an unbearable situation that has to be resolved; for these parents accepting deficient care was better than being without any care at all. Moments of despair were common ingredients in the parents' lived experiences of professional care and caregivers. However, situations occurred when the parents searched for solutions in several directions. By negotiating and bridging gaps, both verbally and in practice, within the family and among staff and public authorities, parents tried to make sense of these limit situations and make them manageable. Moments of peace occurred as welcome breaks, offering a short time of rest for the parents. Situations that were understood by the parents and solved in a peaceful way were experienced as moments of release and inspired them with hope for their daughters' recovery.

The findings from our structural analysis are in line with Wilkinson and McAndrew (2008), and are also confirmed by Ewertzon, Lützen, Svensson, and Andershed (2010), showing that family members' experiences of being excluded from care are related to experiences of powerlessness, lack of confirmation and cooperation, isolation, and feelings of alienation. In the context of psychiatric care Ewertzon, Lützen, Svensson, and Andershed (2008) described alienation as powerlessness, meaninglessness, and social isolation were applicable. Smith (2002) reported that a tendency was seen among caregivers to distance themselves from self-harming patients and their family members, possibly due to a feeling that their problems may be insoluble. Previous research (Wilstrand et al., 2007) showed caregivers viewed patients who self-harm as 'hopeless cases', taking time, and resources from those who were 'really ill'.

Parents in the present study were eager to get best available professional care for their daughters, to find every possible glimmer of hope for their child's recovery from self-harm. Recovery research indicates that supportive relationships have a great impact on how people recover from mental health illness (Davidson, 2003; Denhov, 2003; Topor et al., 2006). By 'being with', families and long-time friends can represent a continuity that extends back into the person's pre-illness history. The recovery process is unique and personal in nature, but though recovery happens on an individual level, it also has an impact on social relationships. When a person recovers it means that other people in his or hers surroundings also have to 'recover'.

Furthermore, families, friends, and others who have similar experiences in settings outside psychiatry can be bearers of hope for a future that differs from a present life marked by suffering and limitations (Topor et al., 2006). Like the parents in this study, people who self-harm emphasize the importance of being seen as valuable human beings by caregivers (Lindgren et al., 2004). Caregivers who listen and provide insight and cooperation in care can foster hope for a future that includes recovery from self-harm. These findings are in line with Andershed and Ternstedt (2000, 2001) who emphasise that a respectful approach to relatives consist of openness, conformation, and cooperation.

Methodological reflections

In this study the participants were recruited by advertising in local newspapers. Six parents participated in the study, however, trustworthiness in a qualitative study is gained more by the richness of each interview than by sample size (Sandelowski, 1995). The participants were five mothers and one father, and none of the parents had sons who self-harmed. This is a limitation of the study, and to be able to disclose gender differences further investigations should strive to include more male participants. One of the interviews was conducted by telephone. An important question is whether it is possible to maintain good quality from a lifeworld perspective by making telephone interviews. On the one hand, the interviewer fails to notice, for example, eye contact and body language. On the other hand, participants may prefer the relative anonymity and feel freer to express themselves, and thereby the data gets rich anyhow. The parents who contacted us were willing to be interviewed, wanted the best professional care available for their daughters, and left no stone unturned in their search for access to the most effective care. All the narratives were spontaneous, with few interruptions from the interviewer, which indicates that the participants spoke freely about what mattered to them. A strength of the narratives was that the parents reflected both on memories and situations from years ago and on experiences from the recent past and present. During the interpretation process all authors reflected critically on the text and took into consideration their pre-understandings. The interpretative process is described in a way that makes it possible for the reader to follow the interpretation from naïve reading to comprehensive understanding. Ricoeur (1976) argues that there is more than one possible interpretation of a text (pp. 78–79), the results presented here represent what we consider to be the most credible understanding of the texts.

Relevance for practice

Parents of daughters who self-harm can be seen to be involved in limit situations. Although the daughters in this study were adults, the parents were still their parents and naturally they wanted the best care available for their daughters; however, the parents were not acknowledged by the professional caregivers. The parents felt neglected and perceived that they were seen as demanding visitors causing challenges and difficulties for the professional caregivers. There were, however, some caregivers who 'stuck out' from the rest and wanted the parents to be a part of their daughter's care. These caregivers were especially valuable to the parents as they inspired both relief and hope for their daughter's future. The findings show that being the parent of a daughter who self-harms is associated with high levels of frustration and anger in the dialogue with caregivers. Much of the responsibility for fruitful communications lies with the professional caregivers. It is obvious that caregivers in such situations must reconsider their attitudes and behaviours towards the parents and learn to acknowledge parents as valuable resources. Professional caregivers should also consider carefully how to involve family members in caring for the person who self-harms. An open dialogue with families may contribute to feelings of relief among all involved.

An important question arising from this study is why these dysfunctional relationships between parents and professional caregivers occur. To further explore the interactions between people who self-harm, their family members, and caregivers, it would be valuable to perform participant observations in different settings providing care for people who self-harm.

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