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Self-harm – hovering between hope and despair

Experiences and interactions in a health care context

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ABSTRACT

Background The definition of self-harm used in this project is repeated, impulsive behaviour causing tissue damage, yet not intended as a suicide attempt. Instead of wishing to die, the person who self-harms wishes to be relieved from anxiety. The thesis comprises four studies and the overall aim was to describe experiences of care among people who self-harm, professional caregivers, and close relatives (parents), and to explore interpretative repertoires that jointly construct the interaction between people who self-harm and their professional caregivers.

Methods The participants were nine women who self-harmed (I), six nurses, three of each sex (II), five mothers and one stepfather (III), and six women who self-harmed in two psychiatric inpatient wards and their caregivers (IV). Data were collected through narrative interviews (I, II, III), participant observations (IV), and informal interviews (IV). The interviews lasted between 40 and 50 minutes (I), between 40 and 65 minutes (II), and between 30 and 85 minutes (III). The observations including informal interviews in study IV comprised 150 hours of descriptive observations and 40 hours of focused observations. The data were analysed using qualitative content analysis (I, II), phenomenological hermeneutics (III), and discursive psychology (IV).

Results People who self-harmed experienced care as inferior, not satisfying their needs. The findings presented a paradox; on the one hand, the women realised that society considered self-harm an inappropriate way to alleviate mental suffering, and on the other hand, they experienced self-harm as the only way to survive and to foster hope in themselves (I). Caregivers felt powerless and burdened when unable to identify and satisfy the women's needs. Feelings of fear, frustration, and abandonment created a significant burden for caregivers (II). Parents' lived experience of the professional care and caregivers of their self-harming adult children could be described as a hostage drama. As in a hostage situation, parents felt held to emotional ransom by deficient care and sometimes hostile caregivers (III). The interpretative repertoires that jointly constructed the interaction between those who self-harmed and their professional caregivers, were for the caregivers a fostering and a supportive repertoire, and for the women who self-harmed a victim and an expert repertoire. The interactions between a fostering caregiver and a woman as expert or as victim, and between a supportive caregiver and a woman as victim, were complicated and promoted feelings of hopelessness among the participants. Interactions

between a supportive caregiver and a woman as expert were more satisfying and raised hope among the participants (IV).

Synthesis of findings Hope and hopelessness ran together as a thread of meaning throughout the studies. All participants experienced and expressed hope and hopelessness in various ways. The self-harming women hovered between hope and hopelessness, hoping for help and support, but led back to hopelessness by their experiences in care. The women used self-harm as a way to cope and to maintain hope in themselves. The parents initially had confidence in healthcare and hoped for help. However, their experiences of meeting deficient care often made them feel hopeless. Parents paid an emotional ransom when they accepted deficient care for their daughters. The caregivers felt frustrated, angry, and powerless, and their view of self-harm as an endless behaviour led to hopelessness. However, they struggled to see the women's abilities, not only their difficulties, and described how they had to try to see self-harm in another way. Caregivers who were convinced that it was possible to stop self-harming and leave it behind were able to bring hope to themselves, to parents, and to the women who self-harmed. The present studies suggest that there is a difference between self-harm and suicide attempts or suicide. Other researchers echo these findings.

Conclusions Paradoxically, self-harm usually seems to be a life sustaining act, a way of raising hope in oneself. The importance of caregivers who listen and try to understand people who self-harm, as well as their close family members, is evident. By asking open-ended questions and being non-judgemental, listening, and showing a genuine interest in the person's lived experience; caregivers can inspire hope in people who self-harm.

Keywords: discursive psychology, experiences, hope, hopelessness, interactions, narratives, phenomenological hermeneutics, psychiatric nursing, qualitative content analysis, self-harm

SVENSKT ABSTRAKT

Bakgrund Självskadebeteende definieras i denna avhandling som ett upprepat, impulsivt beteende där hudskada uppstår. Avsikten med handlingen är inte att begå självmord, stället har personen en önskan att lindra ångest. Avhandlingen består av fyra delstudier och det övergripande syftet var att beskriva erfarenheter av vård bland personer med självskadebeteende, professionella vårdare och närstående (föräldrar), samt att belysa tolkningsrepertoarer som konstruerar interaktionen mellan personer med självskadebeteende och deras professionella vårdare.

Metod Deltagarna var nio kvinnor med självskadebeteende (I), sex sjuksköterskor, tre av vardera kön (II), fem mammor och en styvpappa (III) samt sex kvinnor med självskadebeteende som vårdades vid två psykiatriska slutenvårdsavdelningar och deras professionella vårdare (IV). Datainsamlingsmetoder var narrativa intervjuer (I, II, III), deltagande observationer samt informella intervjuer (IV). De narrativa intervjuerna varade mellan 40 och 50 minuter (I), mellan 40 och 65 minuter (II) samt mellan 30 och 85 minuter (III). Beskrivande deltagande observationer genomfördes, totalt 150 timmar, varav ca 40 timmar var fokuserade deltagande observationer. Data analyserades med hjälp av kvalitativ innehållsanalys (I, II), fenomenologisk hermeneutik (III) samt diskurspsykologi (IV).

Resultat Personerna med självskadebeteende upplevde att vården var undermålig och att den inte tillfredställde deras behov. Resultaten visar en paradox, å ena sidan insåg kvinnorna att samhället i stort anser att självskadebeteende är ett oacceptabelt sätt att hantera psykiskt lidande, å andra sidan, upplevde kvinnorna att självskadandet var det som gjorde det möjligt att överleva och att inge sig själv hopp (I). Professionella vårdare kände sig maktlösa och tyngda när de inte kunde identifiera och tillfredsställa kvinnornas behov av vård. Vårdarnas rädsla, frustration och känsla av övergivenhet, vilka medförde en känsla av att vara belastad, framkom (II). Den levda erfarenheten av professionell vård och vårdare bland föräldrar till vuxna barn med självskadebeteende beskrevs som ett gisslandrama. Föräldrar till en dotter i en gisslansituation betalade en känslomässig lösensumma när de mötte en undermålig och ibland fientlig vård (III). De dominerande tolkningsrepertoarerna som tillsammans konstruerade interaktionen för vårdarna var en fostrande och en stödjande repertoar. För kvinnorna med självskadebeteende dominerade en offer och en expertrepertoar. Interaktionen mellan en fostrande vårdare och kvinna

som expert eller offer, samt en stödjande vårdare och en kvinna som offer, var mer komplicerad och ingav hopplöshet bland deltagarna. Interaktionen mellan en stödjande vårdare och en kvinna som expert var mer tillfredsställande och främjade hopp bland deltagarna.

Syntes av resultat Hopp och hopplöshet visade sig vara ”en röd tråd” genom delstudierna. Alla deltagare upplevde och uttryckte hopp och hopplöshet på olika sätt. Kvinnorna svävade mellan känslor av hopp och hopplöshet, med önskningar om hjälp och stöd men deras erfarenheter av vård ingav hopplöshet. Kvinnorna använde självskada som en hanteringsstrategi och som ett sätt att inge sig själv hopp. Föräldrarna hade initialt ett förtroende för vården och hade förhoppningar om hjälp, men deras erfarenheter av att möta en undermålig vård ingav istället en känsla av hopplöshet. Föräldrarna betalade en känslomässig lösensumma när de accepterade en dålig vård för sin dotter. Vårdarna kände sig frustrerade, arga och maktlösa och deras syn på självskadebeteende som något ändlöst ingav hopplöshet. Vårdarna kämpade för att se kvinnornas förmågor, inte bara deras svårigheter och försökte förstå självskadebeteende. Vårdare som var övertygade om att det var möjligt att sluta skada sig och lämna det bakom sig lyckades inge sig själv, föräldrarna och kvinnorna med självskadebeteende hopp. Resultaten från föreliggande studier tyder på en skillnad mellan självskadebeteende och självmordsförsök eller självmord, vilket även stöds av andra forskare.

Slutsatser Paradoxalt nog verkar självskadebeteende vara ett livsuppehållande beteende, ett sätt att inge sig själv hopp. Betydelsen av vårdare som lyssnar och försöker förstå personen som skadar sig och närstående är tydlig. Genom att ställa öppna frågor och tala på ett icke dömande sätt, samt genom att lyssna och visa ett genuint intresse för personens upplevelser, kan vårdare förmedla hopp.

Nyckelord: berättelser, diskurspsykologi, fenomenologisk hermeneutik, hopp, hopplöshet, interaktion, kvalitativ innehållsanalys, psykiatrisk omvårdnad, självskada, upplevelser

ABBREVIATIONS

CBT	Cognitive Behavioural Therapy
DBT	Dialectical Behavioural Therapy
DSH	Deliberate Self-Harm syndrome
DSM (IV & V)	Diagnostic and Statistical Manual of Mental Disorders
ISSS	International Society for the Study of Self-injury
MBT	Mentalization Based Therapy
NICE	National Institute for Clinical Excellence
NSH	National Self-Harm network, a voluntary organisation in the UK
NSSI	Non-Suicidal Self-Injury

ORIGINAL PAPERS

This thesis is based on the following papers. In the text they will be referred to by their Roman numerals:

I Lindgren B-M., Wilstrand C., Gilje F. & Olofsson B. (2004) Struggling for hopefulness: a qualitative study of Swedish women who self-harm. *Journal of Psychiatric and Mental Health Nursing*, **11**, 284-291. doi: 10.1111/j.1365-2850.2004.00712.x

II Wilstrand C., Lindgren B-M., Gilje F. & Olofsson B. (2007) Being burdened and balancing boundaries: a qualitative study of nurses' experiences caring for patients who self-harm. *Journal of Psychiatric and Mental Health Nursing*, **14**, 72-78. doi: 10.1111/j.1365-2850.2007.01045.x

III Lindgren B-M., Åström S. & Graneheim U.H. (2010) Held to ransom: Parents of self-harming adults describe their lived experience of professional care and caregivers. *International Journal of Qualitative Studies on Health and Well-being*, **5**, 5482 - doi: 10.3402/qhw.v5i3.5482.

IV Lindgren B-M., Öster I., Åström. S. & Graneheim U.H. (2011) 'They don't understand … you cut yourself in order to live.' Interpretative repertoires jointly constructing interactions between adult women who self-harm and professional caregivers. *International Journal of Qualitative Studies on Health and Well-being*, **6**: 7254 - doi: 10.3402/qhw.v6i3.7254.

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INTRODUCTION

> *"I needed to kill something in me, this awful feeling like worms tunnelling along my nerves. So when I discovered the razor blade, cutting, if you'll believe me, was my gesture of hope. That first time, when I was twelve, was like some kind of miracle, a revelation" (Kettlewell 1999 p. 57).*

Inflicting harm on one's own body is not a new phenomenon, old expressions such as "pulling out your hair in despair" suggest that this has been a known phenomenon throughout the centuries. Stories about saints who have starved and tortured themselves in different ways, e.g. Catherine of Siena, are described in the literature (Hällström 1999; Skårderud 2008). Johannisson (1997) writes about Rachel Hertz, a young woman in Copenhagen who, in 1793, swallowed needles which then "wandered around" in her body and later had to be removed by surgery. Gould and Pyle (1896) (referred to in Favazza 1996) compiled medical reports on the 19th-century phenomenon of "needle girls" – women who stuck needles in themselves, predominantly in their abdomens. Today, the body, male or female, and its appearance is focal in movies, fashion, commercials, and other media. Women's attitudes towards their own bodies, their self-esteem, and their contextual resources have an impact on their management of social stressors and influences from such media. However, self-harm seems to be a response not to perceived pressures to be beautiful, but rather to a psychological need that is not possible for the person to alleviate in any other way.

Memoirs (Kettlewell 1999; Pålsson 2004; Åkerman 2004) and personal stories (Pembroke 1998; 2006a; 2006b; Åkerman 2009) have been written about the life with self-harm, and Pembroke (1998; 2006a; 2006b) insists that caregivers learn directly from those who self-harm. Mental health care could be improved, she avers, if only caregivers would listen to the people who self-harm, who are the primary experts. In describing her own path to recovery from self-harm, Åkerman (2009 p.10) writes, "Many times I have wished there was a miracle drug that I could deliver so that everything would suddenly be fine, but there isn't. There are as many ways to be cured as there are self-harmers" (my translation).

I became a registered nurse specialised in psychiatric care in 1989. Since 1995 I have worked at a small specialist unit with people, predominantly women, suffering from eating disorders, and since 2002 I have combined working as a nurse with working as a lecturer at the Department of Nursing. My understanding of eating disorders was, and still is, that they are a means

of communication; the person tries to communicate, without words, his or her difficulties by avoiding or using food in various ways. However, eating disorders such as anorexia nervosa and bulimia nervosa can also be understood as self-harming behaviours. Overt self-harming behaviour occurred among only some of the people I met as patients. However, people with self-harming behaviour, especially cutting or burning, were frequently admitted to psychiatric inpatient care at the clinic, and the care provided did not seem to help them. A common opinion among colleagues at the psychiatric clinic was that these people were manipulative attention seekers who were difficult to treat. Back then, I did not acknowledge self-harm as a way to communicate, as I did eating disorders, and with my limited experience of treating these persons, I adopted my colleagues' view of them – or at least I did not reflect upon this view in any special way.

When I started my master's studies in nursing, there was an on-going education project among the staff at the psychiatric clinic about using DBT (Dialectical Behavioural Therapy) with people with borderline personality disorder and self-harming behaviour. My curiosity was aroused and, in line with my master's studies and together with a colleague, Cecilia, I planned and conducted studies I and II in this thesis. We wanted to know how people who self-harmed experienced the care they received and what sort of care they desired (I). Furthermore, we wanted to know how nurses in psychiatric inpatient care experienced caring for persons who self-harm (II). The findings stimulated to further research, and when funding was in place, I was able to proceed to doctoral studies and continue with studies III and IV.

BACKGROUND

Concepts of self-harm

The literature on self-harm uses various concepts to describe overlapping phenomena, e.g. *deliberate self-harm syndrome (DSH)* (Pattison & Kahan 1983; Favazza 1996; Allen et al. 1997), *self-mutilation* (Favazza 1996), *self-injurious behaviour* (Solomon & Farrand 1996), *self-wounding* (Tantam & Whittaker 1992), *non-suicidal self-injury (NSSI)*, (ISSS 2007) and *parasuicide* (Linehan 1993). Ross and Heath (2002) and Mangnall and Yurkovich (2008) highlight methodoligical problems, for example in estimating prevalence, due to when different concepts are used interchangeably.

In the following I will use the concept self-harm as it used in the Swedish language, excluding severe and immediately life-threatening acts such as the amputation of body parts. In this project, self-harm is defined according to Favazza's (1996) concept of self-mutilation as a repeated, impulsive behaviour where tissue damage occurs, but suicide is not attempted. Instead of wishing to die, the person who self-harms wish to be relieved of emotional pain.

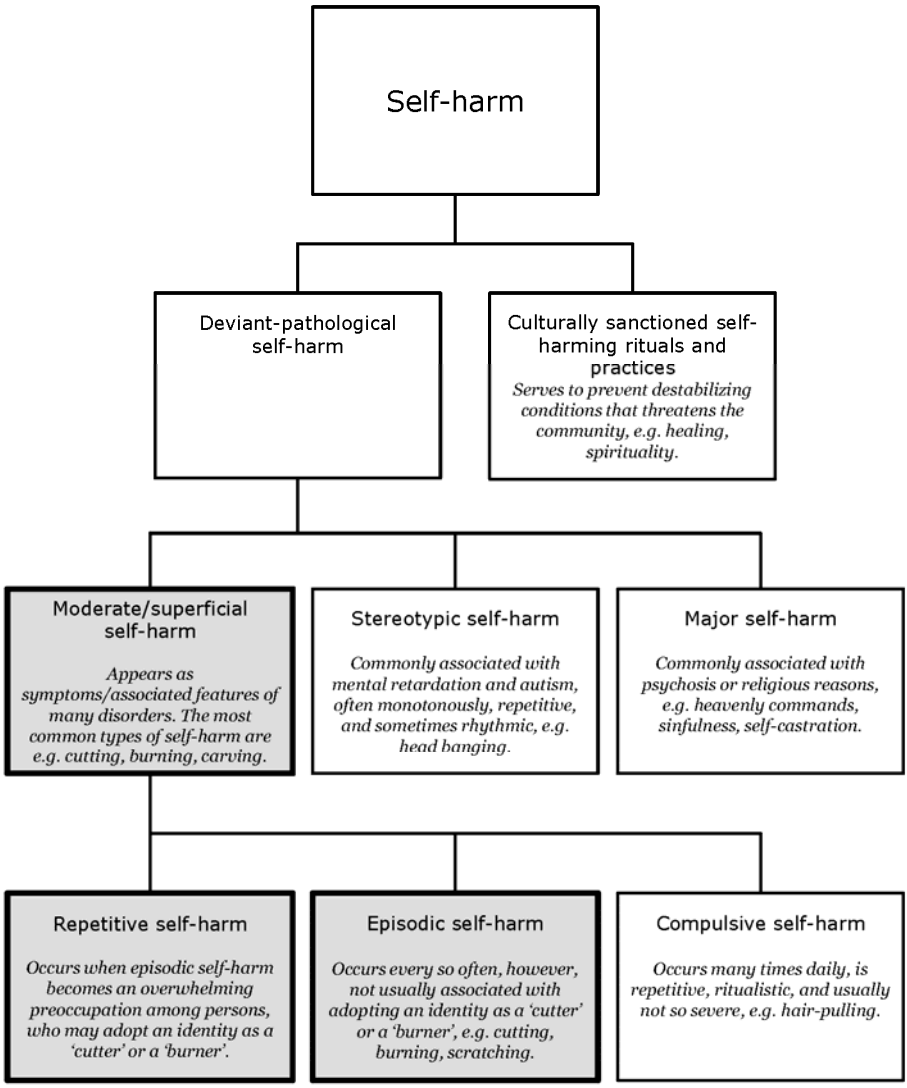
Opinions diverge about whether or not there are differences between the concepts of self-harm and attempted suicide. Menninger (1938) modified Sigmund Freud's 1920 theory of the life instinct (eros) and death instinct (thanatos) and looked upon self-mutilation as a form of self-healing, wherein self-inflicted physical injury is an attempt to avoid the annihilation of the self. Since then, the concepts and definitions of self-mutilation and attempted suicide have been further developed (Graff & Mallin 1967; Ross & McKay 1979). Pattison and Kahan (1983) described deliberate self-harm syndrome (DSH), which excluded attempted suicide and differed from suicidal behaviour in several ways such as low mortality, sense of relief after self-harming, prevalence among young people, and long-term pattern. More recent reviews confirmed these differences (Winchel & Stanley 1991; Tantam & Whittaker 1992).

According to the Diagnostic and Statistical Manual of Mental Disorders, DSM-IV (APA 1995), self-harming behaviour is one criterion among others within borderline personality disorder. However, the NICE guideline (2004) describes self-harm as an expression of personal distress, not an illness, with many varied causes (National Collaborating Centre for Mental Health 2004).

The proposed fifth revised edition of DSM suggests a new diagnosis, non-suicidal self-injury (NSSI) (APA 2011, www.dsm5.org).

The figure shows an overview of self-harming behaviour inspired by Favazza's (1996) classification. The most common form of self-harm is the moderate or superficial type that can include, for example, cutting, scratching, skin-picking, and burning. Favazza (1996) further breaks down moderate or superficial self-harm into three types: repetitive, episodic, and compulsive. Compulsive self-harm is usually seen among people with an obsessive-compulsive disorder and differs in its character from the other two types by being more repetitive and ritualistic. This project concerns moderate or superficial self-harm that is repetitive and episodic. They are both impulsive acts, the difference between them appears to be in whether or not the person self-identifies as a self-harmer. People who self-harm episodically usually do not identify themselves as 'cutters' or 'burners', while people who repeatedly self-harm do.

Similar to Favazza's description of moderate/superficial self-harm (1996), the International Society for the Study of Self-injury (ISSS 2007) define NSSI as the deliberate, direct, and self-inflicted destruction of body tissue resulting in immediate tissue damage, for purposes not socially sanctioned and without suicidal intent.



Overview of self-harming behaviour inspired by Favazza's classification (1996).

Prevalence of self-harm

Estimates of prevalence vary depending upon the population studied and assessment tools used, and the prevalence of self-harm is especially difficult to estimate due to the use of different concepts of self-harm (Ross & Heath 2002; Mangnall & Yurkovich 2008). Furthermore, people who self-harm may not seek hospital care (Samuelsson 2004) and male self-harmers are often not visible in the statistics as their self-harm is often categorised as accidental (Taylor 2003). Despite these difficulties, studies estimate the prevalence of self-harm in a general population to about 4% to 6% (Hawton et al. 2002; Klonsky, Oltmanns & Turkheimer 2003), and clinical experience shows increasing incidents of self-harm, predominantly among adolescents and young adults (Sommerfeldt & Skårderud 2009). Approximately 15% of those who self-harm in the United Kingdom and Sweden seek acute and emergency care (National Collaborating Centre for Mental Health 2004; Social Board of Health and Welfare 2004), and approximately 15% of those who attend hospital because of self-harm seek hospital care again within one year (Owens, Horrocks & House 2002).

The international Child & Adolescent Self-harm in Europe study (Madge et al. 2008) reported cutting behaviour as the most common self-harming behaviour in teenagers. Studies of self-harm prevalence in college populations suggest that about 6% are active and 'chronic' self-harmers (Whitlock, Eckenrode & Silverman 2006; Gollust, Eisenberg & Golberstein 2008), while as many as 13% to 25% of adolescents and young adults surveyed in schools have some history of self-harm (Rodham & Hawton 2009). Opinions diverge on whether or not there are sex differences in the prevalence of self-harm. Some authors report no differences (Klonsky et al. 2003; Marchetto 2006), while others report that self-harm is more common among women (Hawton et al. 2002; Ystgaard et al. 2003; Madge et al. 2008; Landstedt & Gillander Gådin 2011). The main gender differences appear to be in the methods of self-harm. Women seem more likely to cut themselves, whereas men appear more likely to burn or to hit themselves (Laye-Gindhu & Schonert-Reichl 2005; Claes, Vandereycken & Vertommen 2007). In a Swedish study among 14-year-old boys and girls self-harm was almost as common in boys as in girls (Bjärehed & Lundh 2008).

In a trend across psychiatric, forensic, and nonclinical populations (Maden, Chamberlain & Gunn 2000; Guertin, Lloyd-Richardson & Spirito 2001; Gratz 2006), rates of self-harm are reportedly higher in Caucasians than non-Caucasians, but other studies do not report this link between ethnicity and self-harm (Whitlock et al. 2006).

Zahl and Hawton (2004) and Cooper et al. (2005) reported that multiple self-harming episodes, male sex and higher age were predisposing factors for suicide.

Explanatory models of self-harm

Self-harming behaviour can be explained from different perspectives. *Biochemical theories* of self-harm include suggestions that it may be a reaction to decreased serotonergic activity (Audenaert et al. 2001) or that it may increase the production of endorphins that reduce dysphoria (Dallam 1997; DiPalma 1997). Because the effects of endorphins include the suppression of pain and the regulation of emotions, one theory is that people harm themselves to induce these generally pleasurable effects. Auto-addictive behaviour can occur when tolerance develops, requiring repetitive self-harming behaviour to prevent withdrawal (Konicki & Schultz 1989; Russ 1992).

Psychodynamic theory links self-harming behaviour to developmental deficits, possibly the result of child abuse, which may be triggered by loss and abandonment (Gallop 2002; Machoian 2001). When people who self-harm lack an intimate, empathic relationship with someone close, they have no outlet to communicate their feelings and their needs. Subsequent feelings of being neither listened to nor cared for exacerbate their doubts, which could lead to increasing psychological distress (Machoian 2001).

Object relation theory (Sigrell 2000) focuses on internal representations of objects that develop during childhood. Gallop (2002) reported that children who grow up with positive responses from their parents develop an internalised sense of themselves as worthwhile people; if, on the other hand, parental responses are primarily negative, children may not develop that positive sense of self, resulting in serious deficits in their capacity to self-soothe and a lack of object consistency. Machoian (2001) suggested that self-harming behaviour might represent anger towards another person or to oneself, a cry for help, or an effort to coerce compliance from another person.

Trauma theory explains self-harm through focusing on the person's experiences of trauma. People exposed to horrible events have been found to be more likely to suffer from psychological harm. In this theory, self-harm – unlike childhood abuse or other uncontrollable traumas – can be controlled and used as an emotional regulator (Herman 1997; Gallop 2002).

Self-harm as a *socially constructed phenomenon* (Burr 2003) is supported by the multiple meanings of self-harm and the lack of a definitive meaning. This view holds that self-harm is determined by history, culture, and tradition (McAllister 2003). Johansson (2010) reported how meaning was produced in relation to self-harm, and how this production of meaning also involved particular constructions of self-harmer identity associated with 'normality' and 'abnormality'. Self-harm was identified as 'normal' (i.e. 'that's how they are') within a certain group of people, such as young people with mental or emotional problems or so-called 'emos'. Self-harm as 'abnormal' behaviour appeared predominantly on the individual level in psychiatric discourse.

Gender aspects

Brickman (2004) posits that research on self-harm has created the role of the 'person who self-harms'. During the first half of 1960, several articles were published describing and interpreting self-harming behaviour as a female phenomenon. The typical self-harmer was established as a young, attractive, intelligent woman, who looked 'normal' on the surface. The most explicit description is provided by Graff and Mallin (1967); 'In summary, the cutter is an attractive, intelligent, unmarried young woman, who is either promiscuous or overly afraid of sex, easily addicted, and unable to relate successfully to others. She is an older one in a group of siblings with a cold, domineering mother and a withdrawn, passive, hypercritical father. She slashes her wrists indiscriminately and repeatedly at the slightest provocation, but she does not commit suicide' (Graff & Mallin 1967 p.38). Ståhl (2007) wrote that the typical view of the self-harming female teenager becomes a foundation for her identity process. By adopting the stereotypical description, the teenager identified as a 'self-harming girl' who should therefore have access to help. As Johannisson (2006) explains, 'When a diagnosis is medically established with a name and a detailed description, culturally authorised, and exposed in the media, it tends to lead caregivers to interpret signs and symptoms as typical of the diagnosis, and draw patients to see the typical signs of the diagnosis in themselves' (author's translation) (Johannisson 2006 p. 31).

Pipher (1998) links women's self-harm to western culture's oppression over the role of women. As young girls, they grow up believing that girls and boys are of equal value, but when they become teenagers they discover the lack of equality between sexes. The fact that some of the women who self-harm have a history of sexual abuse (Anderson 1999; McAndrew & Warne 2005) and other violations suggests that there may be unequal living conditions for women and men. Landstedt (2010) reported similar results about unequal

living conditions. Eduars (2007) argues that the myth of the equal society allows a girl or a woman with a history of abuse to experience it as her own failure to take responsibility for ensuring her equality. The abuse is then seen as her own fault and not a social problem.

A report from Sweden (Social Board of Health and Wellfare 2004) suggests that young men may have different reasons for self-harm than young women. Taylor (2003) suggests that men who self-harm are an almost 'invisible population' (Taylor 2003), although men and women treated in inpatient units may have similar rates of self-harm (Hawton et al. 2002; O'Loughlin & Sherwood 2005). Taylor (2003) shows that men's reported reasons for self-harm were almost the same as women's, however, there were differences in the methods used and in the severity of self-harm. Men tended to hurt themselves more severely than women and reported high levels of shame over their self-harm. The social expectation that men should be 'stronger' and more 'able to cope' was a particular issue for the interviewed men, which led to them feeling that they were not 'real men'. Ståhl (2007) and Hogg (2010) reported similar findings. Courtney (2000) argues that men and boys who self-harm may feel more deviant and vulnerable because of the 'gender code' that expects people who self-harm to be women and girls.

In summary, self-harm can be understood from a variety of perspectives that may contribute to its understanding and treatment. The gender aspects, for example, may increase the risk that men and women who self-harm avoid seeking hospital care for their self-harm, men because of feelings of shame provoked by the 'gender code' ('real men do not self-harm') and women because of feelings of guilt and self-blame. If so, there may be a risk for the under-reporting of self-harm and for both men and women to go without proper care. There is probably not one single 'grand theory' that can explain self-harming behaviour. In my opinion, it is important to understand all of these theoretical aspects of self-harm and to reflect upon how care is influenced by popular and institutional (mis)understandings of self-harm. Psychiatric inpatient care today is organised from a predominantly medical perspective, in which diagnostic labels have a great impact on the care provided (Berg & Hallberg 2000; Hummelvoll & Severinsson 2001; O'Donovan 2007a), and patterns of nursing activity observed on acute psychiatric wards tend largely to be focused on procedures, such as ward administration, patient observation, door duties, and locating or escorting patients (Bee et al. 2006). While the dominant medical perspective is clearly valuable, and procedures are essential, it seems that other explanatory and treatment theories about self-harm have been pushed into the shadows and paid less attention than they deserve.

Treatment

Traditional therapeutic models are usually not fruitful in treating self-harm and failures are common in the therapeutic alliance (Fonagy & Bateman 2006). There is an international consensus about avoiding psychiatric inpatient care for persons who self-harm and limiting it to short periods if it is unavoidable (Fonagy & Bateman 2006; Oldham, 2006). Gunderson and Ridolfi (2001) argue that it is important to respect people's own self-assessments of their capacities, and not to admit a person who self-harms to inpatient care just for 'safety reasons'. More research is needed into the treatment of self-harm, because evidence for the efficacy of any method is weak. Some methods, however, including CBT, DBT, and MBT (Crawford & Kumar 2007; Bateman & Fonagy 2008; Mehlum & Holseth 2009) do show promising results and should be investigated further.

Cognitive Behavioural Therapy (CBT) is a psychotherapeutic approach that aims to solve problems with dysfunctional emotions, behaviours, and cognitions through a goal-oriented, systematic process. The treatment can be conducted as individual therapy and in group settings, and the techniques are often self-help applications. Some clinicians and researchers are more cognitively oriented while others are oriented more towards behaviour. These two traditions, rooted in rather different theories, find common ground in focusing on the 'here and now' and alleviating symptoms. CBT therapists often use techniques similar to those used in DBT (Sterner 2006; Slee et al. 2008).

Dialectical Behavioural Therapy (DBT) developed from cognitive therapy and learning theory and has a philosophical basis in Zen Buddhism. The treatment combines individual therapy with group therapy and focuses on education and training in skills for emotion regulation. Core strategies in DBT are the use of 'validation' and 'mindfulness'. According to Linehan (1993) the therapist validates the patient by acknowledging that the patient's responses make sense and are understandable within the patient's current life context and situation. The therapist validates and thoroughly discusses the patient's point of view, emotions, and attitudes. Mindfulness is a means for patients to try to take control of their 'inner life' and develop skills for emotion regulation. Techniques often include homework, role-playing, psycho-pedagogy, and training (Linehan 1993; 1994).

Mentalization Based Therapy (MBT) is a psychodynamic treatment initially developed for people with borderline personality disorder (Bateman & Fonagy 2006). Mentalization in psychotherapy is a process based upon shared attention in which the therapist tries to understand the patient's

thoughts and emotions in order to help the individual to develop self-understanding. In common with DBT, the primary goal of MBT is for the patient to develop more effective emotional control; at the same time, MBT encourages the person to develop safer and better relations to other people. MBT therapists position themselves as 'non-knowers' and avoid taking the position of expert (Mehlum & Jensen 2006).

Pharmaceutical treatment is the primary intervention reported for patients' who self-harm (O'Donovan 2007a; O'Donovan 2007b); however, there is no specific medication for self-harming. The prescribed medication is usually aimed to treat co-morbidity such as depression or bipolar disorder (e.g. Nose, Cipriani & Biancosino 2006; Bridge et al. 2007) and to reduce repetition of self-harm through controlling the other condition. Evidence for the efficacy of pharmaceutical treatment in reducing self-harm is weak, and further research is needed (Klonsky & Muehlenkamp 2007; O'Donovan 2007a).

Nursing interventions

The nurse–patient relationship has often been described as the core of psychiatric nursing (Peplau 1952; 1997; Halldorsdottir 2008; Barker & Buchanan-Barker 2010) and creating a caring relationship has been likened to building a bridge between the nurse and the patient (Barker & Buchanan-Barker 2004b; Barker & Buchanan-Barker 2010; Halldorsdottir 1996; 2008).

The therapeutic alliance is very important in psychiatric care. The concept of this alliance, like that of self-harm, has been labelled several different ways in the literature: 'therapeutic alliance', 'therapeutic relationship', 'working alliance', and 'helping alliance' have been used interchangeably. Today there is no more precise accepted description of alliance beyond that of a collaborative and affective bond, formulated or negotiated, between the patient and the therapist (Horvath & Bedi 2002; Martin, Garske & Davis 2000; Saketopoulou 1999). Therapeutic alliance has featured predominantly in psychotherapeutic relationships; however, interest in the concept of alliance has been growing among researchers in fields outside of psychotherapy (e.g. Cruz & Pincus 2002; Howgego et al. 2003). Johansson (2006) found that characteristics of caregivers in good therapeutic alliances in both outpatient and inpatient psychiatric care were warmth, empathy, understanding, patience (allowing sufficient time), and attention to the patient's personal needs. To achieve these characteristics, nurses need to converse with and listen empathetically to each patient as a unique individual.

The Tidal Model, a philosophy of nursing theoretically and practically developed by Barker (2000; 2001a), Buchanan-Barker (2004), Fletcher and Stevenson (2001), and Stevenson and Fletcher (2002), focuses on lived experience and the critical role of narratives in communicating that experience (Barker 2001b; Barker & Buchanan-Barker 2004a). The Tidal Model, described as both a theory and a model (Cutcliffe, Hyrkas & McKenna 2009), is primarily a way of thinking about what needs to be done to enable the process of recovery. The term 'recovery' usually refers to medical recovery, i.e. cure. However, in this model, recovery means 'getting going again' or 'life-recovery' (Collier 2010) involving personal development and change. The Tidal Model emphasises the patient's experience, rather than the behaviour, illness, or disorder that affects the patient. Therefore, in the Tidal Model the term 'person in care' is preferred to 'patient'. The Tidal Model suggests practitioners' first question should be, 'How do we tailor care to fit the specific needs of this person, in light of this life story and this unique lived experience, to empower the beginning or further advance of a voyage of recovery?' (Barker & Buchanan-Barker 2010). As described by Barker and Buchanan-Barker (2010), the Tidal Model focuses on helping people to recover their lives as fully as possible by reclaiming the personal story of their distress and difficulty. Caregivers help people in care to identify, describe, and begin to address the issues, problems, or difficulties that had brought them to a crisis point in their lives, and thus to begin to re-join the flow of life.

One nursing intervention commonly used to prevent self-harm is observation. Observations can range from looking in on the patient every 60 minutes to not leaving the patient alone at all. Several terms, for example 'special', 'close', 'formal,' and 'continuous' observation, are used interchangeably to describe the procedure when one caregiver is assigned to observe a patient in psychiatric inpatient care (O'Donovan 2007a). A case study, however, reported that replacing 'special observations' with other structured activities to prevent self-harm contributed to a reduction in patient self-harm (Dodds & Bowles 2001).

Other nursing interventions to prevent self-harm or suicide include 'no-harm' or 'no-suicide' contracts (used interchangeably in the literature) that refer to verbal or written agreements between the person-in-care and a caregiver (O'Donovan 2007a). Other reported interventions to prevent self-harm were removing objects that might be used as ligatures and keeping the person-in-care in pyjamas, nightgowns, or hospital gowns to ensure their safety and prevent them from leaving the ward (O'Donovan 2007a).

Harm minimisation (or risk reduction) assumes that caregivers accept self-

harm as a valid strategy for survival (Pembroke 2006a). This, however, does not mean that caregivers should merely stand by and watch, or (in an extreme interpretation) encourage, self-harm. Instead it means being realistic about people who self-harm and seeking to minimise damage and maximise safety. Harm minimisation takes into account information about basic anatomy, physiology, first aid, wound care, correct usage of dressings, and even safer ways to self-harm. It also attends, in parallel with physical harm minimisation, to more emotional, psychological, and social aspects, defined by the individual, by for example assisting people to feel proud of their appearance, to present confidently, and to manage negative responses from others (National Self-Harm Network 2000; National Collaborating Centre for Mental Health (NICE) 2004; Pembroke 2006a). However, according to NICE-guidelines (2004) harm-minimisation strategies should not be used with people who self-harm by poisoning because there are no safe limits in self-poisoning. According to Edwards and Hewitt (2011) the therapeutic approach of harm minimisation is not necessarily contrary to the purpose of care when care is concerned with psychological, rather than purely physical, harms. On the contrary, harm minimisation may be seen first as a means of strengthening the therapeutic relationship, not merely reducing physical harm in the short term, and it may allow caregivers to explore alternative future coping strategies with the person-in-care in which supervised self-harm could be a safety net against more damaging self-harm. According to NICE-guidelines (2004) people who have self-harmed should be treated on the same bases as any other patient, but caregivers should take full account of the distress associated with self-harm.

In summary, studies have indicated that current approaches to treatment and nursing interventions that focus on prevention are ineffective in reducing self-harming behaviours (Hawton et al. 1998; NICE 2004; Duffin 2006; Crawford & Kumar 2007). Treatments with DBT, CBT, and MBT have shown promising results (Crawford & Kumar 2007; Mehlum & Holseth 2009), however, there is a need for more research. More research is also needed to evaluate the efficacy of harm minimisation and other new interventions.

Experiences of self-harm from different perspectives

Experiences of self-harm can be described from different points of view: of living with self-harming behaviour, having a close relationship with a person who self-harms, and caring for people who self-harm.

Living with self-harming behaviour

Research shows self-harm as a coping-strategy (Solomon & Farrand 1996; Hodgson 2004; Hall & Place 2010), a survival strategy (Reece 2005; Schoppmann et al. 2007), and a way to relieve emotional pain (Holm & Severinsson 2010). Similar conclusions are presented by Harris (2000) in her analysis of letters from people who self-harm. She argues that self-harm can be viewed as a logical consequence of various circumstances and living conditions – the only way to stay alive. When self-harm is understood from that perspective, it becomes logical. Furthermore, Harris report that people who self-harm often feel misunderstood and in receipt of inferior treatment from both their professional caregivers and their close family and friends.

Shaw (Shaw & Hogg 2004) reports her own experience of engaging in self-harm as well as her experience of providing support to those who self-harm. She reports self-harm as a predominantly private behaviour. A person who self-harms may see the world as an alien and lonely place and feel different from other people (Shaw & Hogg 2004; Simpson 2006) and 'outside and beyond' normal everyday life (Shaw & Hogg 2004; Hodgson 2004). People who self-harm describe feelings of hopelessness, powerlessness, vulnerability, and lack of control over their own lives, and these feelings are often related to the self-harming behaviour. Self-harm may be understood as a way of dealing with feelings of powerlessness, since individuals who self-harm have reported that their self-harm decreased when their feelings of powerlessness decreased (Paris 2003; Söderberg 2004).

McAndrew and Warne (2005) performed a case study using feminist methods and psychoanalytical concepts to explore the meaning of conflicts experienced by three women who self-harmed and reported experiences of not being listened to, attended to, or taken seriously. According to Hodgson (2004), who analyzed in-depth interviews with women with self-harming behaviour via e-mail, knowledge gained through conversations with those who self-harm may allow cutting to begin to be understood as an issue not necessarily linked to psychological illnesses or disorders. She points out the importance of learning how to react to and help persons who self-harm who want to be helped, rather than merely labelling them with a diagnosis.

Motz (2010) describes the psychotherapeutic treatment of a woman who self-harmed and reports that self-harm can be seen as a violent communication against the self, written on the body. She argues that self-harm should be seen as a typically female expression of violence, a hidden violence, often directed to hidden parts of the body. Furthermore, she report

self-harms as not wholly destructive, but entailing important hopeful and self-preservative aims for self-healing.

In a review of empirical research on self-reported functions of self-injury, Klonsky (2007) found converging evidence for an affect-regulation function followed by strong support for a self-punishment function. Similar results were shown by Rissanen, Kylmä and Laukkanen (2008a). Nehls (1999) interviewed people about their experiences of living with borderline personality disorder and self-harming behaviour and found experiences of living with a label, being seen as manipulative, and having a limited access to care. Some of the conclusions of the study were that mental health care for people who self-harm could be improved by confronting prejudices, understanding self-harm, and offering opportunities for dialogue. Perseius and co-workers (2005) investigated the life situations, suffering, and perceptions of encounters with psychiatric care among patients with borderline personality disorder and found that they experienced life on the edge, as a balancing act on a slick wire over a volcano, marked by struggles for health and dignity.

Several researchers (e.g. Harris 2000; Smith 2002; Warm, Murray & Fox 2002; McAndrew & Warne 2005; Perseius et al. 2005) report experiences of care from the point of view of people who self-harm. Bywaters and Rolfe (2002) describe experiences of care among persons who self-harm in a report for the National Self-Harm network (NCH), a voluntary organisation in UK. Their results show that people who self-harm often feel that caregivers think that taking care of them is a waste of time and that they are 'hopeless cases' who are going to self-harm repeatedly. These findings are echoed by Ribe (2009) and others. Smith (2002) interviewed three people who self-harmed who said that it was helpful when caregivers engaged them in conversation, but felt that caregivers made themselves unreachable and preferred to offer pharmaceuticals instead of dialogue.

In summary living with self-harming behaviour is in no way 'a walk in the park'. When a person who self-harms believes that behaviour is the only way to stay alive, it is not difficult to imagine this person's suffering. Self-harming behaviour is contradictory in its effects, because while it is a way of healing the self, it not socially accepted, and so leads to further problems. Those who self-harm describe experiences of care that are predominantly negative. I believe it is important to try to understand and listen to their stories in order to increase their participation in their own care.

Having a close relationship with a person who self-harms

Research on having a close relationship with a person who self-harms is relatively sparse, however the research to date report parents' experiences of self-harm having a 'ripple effect' on their families (Trepal, Wester & MacDonald, 2006; Raphael, Clarke & Kumal, 2006; Rissanen, Kylmä & Laukkanen 2008b). Rissanen et al. (2008b) studied parents' understanding of self-harm and found that parents had little knowledge of the phenomenon itself, but that it evoked strong negative feelings when it occurred in their own family. Daly (2005) reports mothers' experiences of living with teenagers who self-harm as including feelings of failing as a mother, and being isolated, helpless, and powerless. Mothers also feel they are 'walking on eggshells' and need to maintain an emotional distance from their own child due to the potential risk against the possibility of the child's next suicide attempt being successful. Raphael, Clarke and Kumar (2006) report that parents of young people who self-harm experience the incident of self-harm as extremely traumatic, leading to feelings of helplessness and concerns about their ability to cope as parents. Parents also report a lack of information and support from health care professionals. Similar results are also shown in a study by McDonald, O'Brien and Jackson (2007) that found mothers' experiences of dealing with self-harming adolescents and their effects on their own well-being, as well as their families', were characterized by feelings of guilt and shame, distress, and loneliness.

In summary, the effects of being a parent of a child who self-harms have consequences on the entire families' well-being. Parents express feelings of guilt and shame, loneliness, helplessness, and powerlessness. Studies about experiences of care from the parents' point of view are sparse, however those available describe care as unsatisfactory, mainly because of the lack of information and support from professional caregivers.

Caring for people who self-harm

Studies about caring for people who self-harm are conducted most often in acute and emergency care, and less frequently in psychiatric care. Caregivers most often report people who self-harm as manipulative and attention seeking. They feel anxious about how to address and care for people who self-harm, and they frequently report feelings of frustration, anger, and helplessness (Hopkins 2002; McAllister et al. 2002; Anderson, Standen & Noon 2003; Friedman et al. 2006).

In a study by Thompson, Powis and Carradice (2008) psychiatric nurses in community care talk about their experiences of caring for people who self-

harm. The nurses find self-harm difficult to understand, and emotionally draining to care for. They have constantly to assess the potential risk of self-harm. O'Donovan and Gijbels (2006) interviewed psychiatric nurses about their perceptions of self-harm and factors influencing how they care for people who self-harm, and they found that self-harm is understood as a complex behaviour. Psychiatric nurses try to maintain a patient-centred perspective and to plan care together with the patient, with prevention and security as the first priorities.

Starr (2004) describes her own experiences of working with adolescents who self-harm. Before she learned DBT she experienced frustration and anger towards those, often young girls, who deliberately harmed themselves. After DBT-education she participated in a DBT group and heard the stories these girls told of their intense emotional pain and their struggles to survive. This experience helped her, as a primary care nurse practitioner, to gain a new understanding of people who self-harm.

Caring for people who self-harm is usually experienced in a negative way. Feelings of frustration, anger, hopelessness, and powerlessness are frequently reported, as are difficulties in understanding self-harm and uncertainty about how to care for thesepeople. Special training in DBT, however, led at least in one case to a new understanding of people who self-harm, and such training may be helpful for other nurses who work with people who self-harm

RATIONAL FOR THE THESIS

Several studies highlight the need for more knowledge about self-harm, how self-harm can be understood, and how to manage caring for people who self-harm (e.g. Hopkins 2002; McAllister et al. 2002; Anderson et al. 2003; Friedman et al. 2006). Studies about caring for people who self-harm have often been conducted in acute and emergency care (McElroy & Sheppard 1999; McAllister et al. 2002). The literature reports predominantly negative attitudes towards patients who self-harm (McHale & Felton 2010). Staff members feel anxious about how to speak with and care for patients who self-harm, and feelings of frustration, anger, and helplessness are frequently reported (Anderson et al. 2003; Friedman et al. 2006). The caregivers describe patients who self-harm as 'hopeless cases' who take time and attention away from other patients (McAllister et al. 2002). Further studies conducted in psychiatric care are needed to guide and improve psychiatric nursing care for people who self-harm.

Research on self-harm from the view of persons who self-harm (e.g. Nehls 1999; Shaw & Hogg 2004) is sparse, as is research into the experiences of the family and close friends involved in their care (Daly 2005; McDonald et al. 2007; Rissanen et al. 2008b). More studies are needed in both of these areas.

Research reports experiences of self-harm as described by people who self-harm and their caregivers, both casual (family and close friends) and professional. The studies report overwhelming feelings of frustration, distress, powerlessness, and emotional strain surrounding the experiences of self-harm and the interactions related to it. However, to date I have not found any study that observed the actual interactions between people who self-harm and their casual and/or professional caregivers.

The care of people who self-harm requires attention to both the individual and the family context, because many who self-harm are young people still living with their family of origin. Because interactions are often experienced emotionally as positive or negative, their relationships with family and/or professional caregivers are extremely important to people who self-harm. It is similarly important, therefore, to conduct observational studies that describe the interactions between all parties involved in the care of people who self-harm.

As self-harming behaviour is complex and the contextual factors in care organisations care delivery and social factors are varied, it is important to create new knowledge on experiences and interactions between persons who self-harm, relatives/family and professional caregivers.

The results of these studies may offer knowledge that contributes towards the development of more suitable individualized nursing care programmes for inpatient care and intervention programmes for people who self-harm.

AIM

The overall aim of this thesis was to describe experiences of care among people who self-harm, professional caregivers, and parents, and to explore interpretative repertoires that jointly construct the interaction between people who self-harm and their professional caregivers.

Specific aims for the papers

Paper I — To describe how people who self-harm experience received care and their desired care.

Paper II — To describe nurses' experience caring for psychiatric patients who self-harm.

Paper III — To discover and describe lived experiences of professional care and caregivers among parents of adults who self-harm.

Paper IV — To explore interpretative repertoires that jointly construct the interaction between adult women who self-harm and professional caregivers in psychiatric inpatient care.

MATERIALS AND METHODS

In order to understand experiences of self-harm and interactions between people who self-harm and their professional caregivers, I chose several methods of data collection and data analysis. An overview of participants and methods used for collecting and analysing data is shown in Table 1.

Table 1. Participants, data-collection methods and year, and data-analysis methods.

Study	Participants	Data collection and year	Data analysis
I	9 women who self-harmed	Narrative research interviews, 2000	Qualitative content analysis
II	6 registered nurses (3 women and 3 men)	Narrative research interviews, 2002	Qualitative content analysis
III	6 Six parents (5 women and 1 man)	Narrative research interviews, 2008–2009	Phenomenological hermeneutical analysis
IV	6 women who self-harmed and their professional caregivers	Participant observations and informal interviews, 2009–2010	Discursive psychology

Context

This thesis included experiences and interactions from various kinds of care settings. People who self-harm are cared for in various outpatient and inpatient settings. Outpatient care can include small treatment homes as well as different outpatientclinics. Inpatient care is usually given in locked acute psychiatric wards, but also in forensic psychiatric wards. In both acute and forensic psychiatric care, patients are admitted voluntarily, in line with the Health and Medical Services Act (SFS 1982:763) and involuntarily, in line with the Compulsory Psychiatric Care Act (SFS 1991:1128) and the Forensic Psychiatry Care Act (SFS 1991:1129). Patients at the wards vary in age, sex, and ethnicity, and suffer from various disorders including depression, anxiety, schizophrenia and other psychotic disorders, and drug addiction.

Study I was conducted in community mental health service facilities and at a psychiatric clinic in northern Sweden, although the participants described experiences from various areas of Sweden and even abroad. Study II was conducted with caregivers who worked in two acute psychiatric wards and one forensic psychiatric ward. The patients in these wards suffered from various kinds of psychiatric disorders and the doors were locked at all three wards. In study III, the parents of six self-harming daughters between the ages of 21 and 25 years, all admitted to outpatient care, were interviewed. Four of the daughters 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 remaining 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. Study IV was conducted in a locked acute psychiatric ward in each of two psychiatric clinics in northern Sweden. Some patients in these wards had been admitted voluntarily, others involuntarily; they varied in age, sex, and ethnicity; and they suffered from various kinds of psychiatric disorders.

Participants

Overall inclusion criteria were (I, IV) adult men or women with a history of self-harm as defined in Favazza's classification of 'moderate or superficial self-harm that is repetitive or episodic' (see figure) (II) professional caregivers of people who fulfilled the selected definition of self-harming behaviour, and (III) parents of adult children who fulfilled the selected definition of self-harming behaviour.

Professional caregivers who provided outpatient care for people who self-harmed at the psychiatric clinic and social service personnel (I) were informed of the aim of the study. They were asked to give written and verbal information about the study to their patients/clients and to contact me if any were interested in taking part in an interview about their experiences of inpatient or outpatient care. The people who self-harmed in study I had been discharged at the time of the interview. A total of nine Swedish women between the ages of 19 and 35 (median age 25) participated. The participants self-reported borderline personality disorder (5), anxiety syndrome (1), or depression (1). Two women refrained from reporting a diagnosis. Five had received inpatient psychiatric care during the previous year.

The participants in study II were recruited from four acute psychiatric wards. The head nurses at each ward gave written and verbal information to all nurses in the wards about participating in an interview study of caring for patients who self-harm. The exclusion criterion was nurses who had

participated in DBT education or training. Six nurses, three men and three women, between the ages of 27 and 53 (median age 38.5), from three of the wards participated. The nurses had worked in psychiatric care from 1 to 18 years (median 9.5). Two were generalist nurses, four had specialist training in psychiatric nursing, and one of these four had additional education in psychotherapy.

In response to advertising in local newspapers, four parents contacted the researchers about study III and agreed to participate. Two more parents were referred by one of the participants, for a total of six participating parents. They were between the ages of 45 and 55 (median age 49), and at the time of the interviews their daughters were aged between 21 and 25.

Two registered psychiatric nurses at each ward (IV) gave written and verbal information to patients fulfilling the definition of self-harm about the purpose of the study, requested their participation, and contacted the researcher when a patient was interested in participating. Six women, three at each ward, between 21 and 37 years old (median age 23.5) participated. Three of the women were admitted to involuntarily care, in line with the Compulsory Psychiatric Care Act (SFS 1991:1128), and three to voluntarily care, in line with the Health and Medical Services Act (SFS 1982:763). The women self-reported their diagnosis, as well as their current medication and treatment. One woman reported no diagnosis and the other five women reported one to three diagnoses; i.e. personality disorder, eating disorder, anxiety syndrome, psychosis, bipolar disorder, depression, and Asperger syndrome. Their self-reported current medications included antidepressants, clozapine, benzodiazepines, hypnotics, painkillers, and acid-reducing medicines, and one of the women was treated with electroconvulsive therapy.

Data collection

Narrative research interviews (I, II, III)

Narrative interviews were chosen to learn about the participants' actual lived experiences. A narrative interview is a dialectic process in which the interviewer and narrator jointly discuss meanings of the phenomenon under study, most often the narrator's life experiences and reflections on those experiences (Mishler 1986; Riessman 1993). The interviewees were asked to relate their lived experiences of being cared for (I), caring for people who self-harm (II), and interacting with caregivers of their daughters who self-harmed (III). The narratives were followed up by exploratory questions.

Whenever the interviewees did not spontaneously reflect on the narrative, their reflections were solicited.

Study I concerned participants' lived experiences of 'received care' and 'desired care'. The participants were prompted to talk about their lived experiences with the following questions: 'How would you describe the care you received?', 'Tell me, how you were treated by the staff?', 'How do you think the care should have been?', and 'How would you want to have been treated by the staff?'. One of the interviews occurred in the participant's home at her request, while the others were conducted in a secluded room at a psychiatric clinic. The interviews, ranging from 40 to 50 minutes, were audiotaped and transcribed verbatim by a secretary familiar with transcribing research interviews. Study II about nurses lived experiences of caring for patients who self-harm focused on two questions: 'Can you please describe a satisfying experience of caring for a patient who self-harmed?', and 'Can you please describe an unsatisfying experience of caring for a patient who self-harmed?'. Questions clarifying and exploring these experiences were asked to collect more in-depth descriptions. The interviews, ranging from 40 to 65 minutes, were conducted in a secluded room at a psychiatric clinic, audiotaped, and transcribed verbatim into text by a secretary familiar with transcribing research interviews. Study III concerned the lived experiences of professional care and caregivers as described by parents of a daughter who self-harmed. Questions clarifying and exploring these experiences, such as 'What way did the healthcare professional do to make you feel better?', and 'What do you mean when you say awful?', were asked to gain a deeper understanding of the parents' experiences. The tape-recorded interviews ranged from 30 to 85 minutes, and they were transcribed verbatim, including pauses, laughter, and crying, by the author (BML).

Participant observation (IV)

I chose an ethnographic approach to illuminate the interaction between women who self-harm and their professional caregivers. Ethnography describes the patterns of behaviour of individuals and groups of people within a particular culture (Roper & Shapira 2000), in this case a psychiatric inpatient ward. Ethnography is a process of learning about people by learning from and with them. The ethnograph researcher has three methods for collecting data: participant observation, formal and informal interviews, and examination of available related documents (Roper & Shapira 2000).

Study IV employed participant observation and informal interviews (c.f. Roper & Shapira 2000; Patton 2002). Participant observation offers

researchers the opportunity to share certain experiences with the study group and it has previously been used in studies conducted in psychiatric care (Bray 1999; Johansson, Skärsäter & Danielsson 2007; Schoppman et al. 2007). The observations took place over three months in 2009 and three months in 2010, during the week (Monday to Friday), from 6:00 a.m. to 10:00 p.m. Approximately 150 hours of descriptive observations were conducted, including about 40 hours of focused observations and informal interviews.

The researcher can take various roles in particapant observation depending upon the focus of the observation. In this study, I was a passive participant, an 'observer-as-participant' (Roper & Shapira 2000). The observed women who self-harmed and their professional caregivers were informed about the purpose of the observations, and I was visible to everyone in the ward, but not involved in the care of the women who self-harmed or in a working relationship with the caregivers. The observations were performed in common and staff areas and occasionally in the woman's room or in a parlour. During the descriptive observations I observed actions related to the healthcare environment and to the routines of the wards, which later served as context in the analysis. The focused observations were centred on interactions between the women who self-harmed and their professional caregivers. The data in study IV comprises the participant observations and informal interviews I transcribed to text.

Informal interviews (IV)

Informal interviews were used to validate the observations and to gather unobservable data, for example a person's thoughts, (c.f. Roper & Shapira 2000). The informal interviews following some of the focused observations were not prearranged. These interviews could occur anywhere, for example in an office or in the observed woman's own room, and the primary value of these conversations was the immediate feedback obtained after observing the situation. By asking professional caregivers and women who self-harmed, individually, to reflect upon their experiences of the observed situation and their feelings and thoughts about the interactions, I was able to broaden my understanding of the observations; these informal interviews I then transcribed into text for analysis.

Data analysis

Qualitative content analysis (I, II)

To describe experiences of self-harm among people who self-harm and their

professional caregivers the interviews were analysed using qualitative content analysis. The epistemology of qualitative content analysis is unclear; however, it is an interpretive process, focusing on subject and context, dealing with differences and similarities between and within parts of the texts (Graneheim & Lundman 2004). Content analysis is a method of analysing written and verbal communication in a systematic way (Krippendorff 2004) that can be used to analyse a person's or a group's experiences and reflections (Down-Wamboldt 1992).

In studies I and II the interview texts were read, reread, and audited for consistency with the audiotapes for an initial understanding of the participants' descriptions of their lived experiences of care (I) and caring (II). The entire text was divided into condensed meaning units comprising several words, sentences, or phrases related to the aim. In study I each condensed meaning unit was grouped according to the four interview questions. In addition, positive or negative descriptions were coded (+ or −) and categories designating a main focus of the meaning unit were labeled. Since it was clearly apparent that the condensed meaning units coded as 'positive received care' was the same descriptions as, and interwoven with, descriptions of 'desired care', these were combined. Through further abstractions sub-themes and themes were formulated. In study II the condensed meaning units were coded and sorted into three different categories: experiences in relation to the patient; experiences in relation to staff, and experiences in relation to self. Through further abstractions, sub-themes and themes were formulated for the data in the study as well.

Throughout all the analytic processes, categories, sub-themes and themes were compared with the interview texts, and through a process of reflection and discussion about the interpretations and the abstractions into sub-themes and themes the authors of these studies reached consensus.

Phenomenological hermeneutical analysis (III)

Interviews with parents of a daughter who self-harmed were subjected to phenomenological hermeneutical analysis to discover and describe their lived experiences of their daughters' professional care and caregivers. Phenomenology aims systematically to uncover, describe, and explain the essence of lived experience of a phenomenon through structures of meaning. The phenomenological idea of going to 'back to the things themselves' aims to do full justice to the lived experience (Husserl 1970).

Hermeneutics is both the philosophy of understanding and the science of textual interpretation (Geanellos 1998). Interpretation is an attempt to grasp

and recreate meaning; it seeks to make clear or bring to light fragmentary, confusing, and hidden meanings in order to allow more complete or different meanings to become apparent (Heidegger 1962; Gadamer 2004). According to Heidegger (1962), Gadamer (2004), and Geanellos (1998), access to 'truth' is gained when essential hermeneutic issues include the nature of interpretative understanding, the influence of pre-understandings, perspective questioning of the text, and the debate regarding the evaluation of the interpretations. However, the 'truth' does not mean the one and only truth, it means one of several possible interpretations of the meanings attached to the research phenomenon.

Phenomenological hermeneutical analysis was inspired by Ricoeur (1976), further developed by Lindseth and Norberg (2004), and previously used by Talseth et al. (1999), Graneheim et al. (2005), and Enarsson, Sandman and Hellzén (2008), among others. The analysis consists of three phases (naïve reading, structural analysis, and comprehensive understanding), which involve a dialectical process between parts of the text and the whole, between being close to and distanced from the text, and between focusing on what the text says and what understandings the text opens up for (Ricoeur 1976; Lindseth & Norberg 2004).

First, to gain a naïve understanding of the possible meanings of the text, the interviews were listened to and the transcribed text was read through several times. Second, to validate the ideas from the naïve reading, several structural analyses were performed. The text was divided into meaning units, i.e. words, sentences, paragraphs, and metaphors related to various meanings that could be ascribed to parents' experiences of professional care and caregivers. The meaning units were condensed and formulated as codes, while 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 upon and the codes were then sorted into subthemes. The structural analysis was not a linear process; rather, it moved back and forth between the whole and the structures of the text. Continuing reflections upon the relationships between the subthemes resulted in the formulation of themes and a comprehensive understanding of parents' lived experiences of professional care and caregivers. 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.

Discursive psychology (IV)

In order to illuminate interpretative repertoires that construct the interaction between adult persons who self-harm and their professional caregivers, I used the concept of interpretative repertoires from discursive psychology (Edley 2001; Potter & Wetherell 2001; Taylor 2001a; 2001b; Wetherell 2001a; 2001b). Discursive psychology is a method that stems from social constructionism (Edley 2001), and interpretative repertoires are relatively coherent ways of talking about objects and events. The language used in social conversations are usually made up of a patchwork of 'quotations' from various interpretative repertoires, and they can be flexible and also full of contradiction. Discursive psychologists examine how people use language to construct their lived experience of the world and of themselves through social processes in daily life, in which people negotiate between available identities and use available social structures of interpretative repertories (Edley 2001; Potter & Wetherell 2001; Taylor 2001a).

Language has an important role in the social construction of identities, relations, and systems of knowledge. Furthermore, 'identity' is an implicitly social concept, and not reliant on the psychological concept of personality. The key issue is that we as humans, 'identify objects', and the identities we confer upon each other have more to do with our own purposes than the nature of the thing or person identified. The language we use to make up human identities, especially dichotomies such as masculine/feminine, sane/insane, hetero/homosexual, and so on, reflect socially constructed identities rather than the essence of any person. Our knowledge and how we percieve and represent our view of the world is historical, culturally specific, and contingent. We apprehend the world and create knowledge through social interactions in which we develop norms about 'mutual truth' and argue about what is true or untrue. Thus, the words used are important in this view as language constitutes the social world, personal and group identities, social relationships, and our values and beliefs (Burr 2003). Some interpretative repertoires are culturally dominant (hegemonic) and are therefore more socially accepted as 'the truth' (Edley 2001; Potter & Wetherell 2001), while others are marginalized (Burr 2003).

This analysis began with the verbatim transcriptions of the field notes and recordings from the observations and informal interviews. I read through the texts several times to get a feeling for the overall material and a sense of the interpretative repertoires used by the women and the professional caregivers (cf. Potter & Wetherell 2001; Taylor 2001a; Wetherell 2001a; 2001b). The next step was to read the focused observations, including the informal

interviews, and code significant words and passages according to potential themes and subthemes, such as ‘control’, ‘power struggle’, ‘solidarity’, and so on. After reading and coding the entire material, individual summaries were written describing the interpretative repertoires of each of the women. To deepen the understanding, the summaries were read through several times (cf. Öster et al. 2007; Potter & Wetherell 2001; Taylor 2001a; Wetherell 2001a; 2001b). I then read through the material once again and wrote down page references from the texts where a certain repertoire appeared. The other authors continuously evaluated and validated the ongoing analysis. The analysis resulted in four interpretative repertoires that jointly constructed the interaction between the women and their caregivers.

ETHICAL CONSIDERATIONS

The chief physicians of the psychiatric clinic and the Research Ethics Committee at the Medical Faculty Umeå University, Umeå, Sweden, approved study I and II (§ 00/392 and § 02/069). The chief physicians of the psychiatric clinics and The Regional Ethical Review Board in Umeå, Sweden, approved study III and IV (Dnr 08-034M and Dnr 2010-73-32).

Several ethical aspects were taken into consideration in this project. It is questionable whether it is ethically defendable to interview people who suffer from mental illness. There may be a risk of them disclosing more than they really want to. Family members and close friends of such people may feel guilty if they volunteer too much information about their loved ones. Patients and professional caregivers may experience observation as a violation of their privacy and all interviewees may experience such a violation when questions are personal and concern emotional experiences. On the other hand, having one's narratives listened to can be experienced as a relief (Gaydos 2005). The risk of violating the privacy of both patients and professional caregivers occurs with observational methods. Patients in psychiatric settings are vulnerable, as they are dependent on healthcare professionals, and professional caregivers may experience themselves as 'not being good enough' as caregivers. Therefore, all participants were informed that their participation was entirely voluntary and they could end their participation at any time without being required to give a reason and without incurring any consequences for themselves, their family members, or their treatment. Both verbal and written information were given to the participants and they were asked for their informed consent to participate. Whenever conditions for the observations changed, for example when participants went to another room, the researcher again confirmed their consent to the observation. On one occasion, the participant did not want me to attend the meeting. During all observations, I wore a badge with my name and affiliation. During the period of observations, new patients were admitted to care at the wards. These patients were informed about the aim of the study and my focus on the women who self-harmed. None of the other patients had any objections to my observations; on the contrary, they welcomed my interest in focusing on inpatient psychiatric care.

The participants in each study were presented as anonymously as possible. The women's diagnostic labels, current medications, and ages are not presented in connection with any woman in particular, in order to make it more difficult for anyone to identify them. The same considerations were

taken when presenting the participating parents and the participating professional caregivers. Fictitious names were used for any citations and quotations in the findings to protect their identities.

All members of the research team were experienced in working with people who suffer from mental illness. I observed the participants' reactions during the interviews and observations, ready to end the data collection if any participant seemed to be in pain or expressed discomfort. This was never necessary. The researcher's needs for personal support, especially during data collection, were met by helpful supervision within the research group.

FINDINGS

The overall aims of this project were to describe experiences of care among people who self-harm, their close family, and caregivers, and to illuminate the interpretative repertoires that jointly construct the interactions between people who self-harm and their professional caregivers. In the following presentation of the findings I refer to the people who self-harm as 'the women', their participating family members as 'the parents', and the professional caregivers as 'caregivers'.

The findings are drawn both from interviews about experiences of care and caregiving and from observations of interactions among the women and their caregivers. I present the findings from each study first, followed by a synthesis of the findings concerning the interactions and experiences of the participants in this project.

Study I

The women described their experiences of both acute and emergency inpatient and outpatient adult psychiatric care, within Sweden and abroad. They also described their experiences of contact with staff from the national social service system.

The women's main expectation of care was that they be confirmed as entire, complex people. Being confirmed fostered hope and a whole spectrum of positive possibilities; not being confirmed stifled hope and encouraged negativity. Being confirmed versus not being confirmed comprised several positive/negative perceptual dichotomies, such as feeling seen/not seen, valued/stigmatised, connected/disconnected, believed/doubted, and understood/misunderstood. The women described their expectations and experiences of being viewed as human beings with assets, aspirations, longings, and needs, and not only as people with difficulties. They felt understood when staff tried to explore their reasons for self-harming; asked how they felt; talked openly with them about what they did and why they did it; and discussed healthy ways the women could express themselves. The women felt confirmed when caregivers believed in them and seemed convinced that things could be better. They wanted to participate in planning and implementing their own care and to be able to take responsibility for their own needs and actions. A 'homelike' environment where they felt safe, secure, and confirmed as human beings fostered hopefulness and allowed the women to feel they could grow as human beings.

However, the women also experienced judgemental care in which self-harming actions were labelled with negative values and diagnostic criteria. Caregivers' attitudes in these settings communicated lack of respect, and the women felt objectified, treated like 'things' and 'machines' without a 'soul', and subject to 'professional stigma'. The power of stigma, shame, and disbelief predominated over the spark of human spirit in these cases. The women felt misunderstood and alienated by caregivers' hesitancy and avoidance of the subject, as if talking about self-harm could 'infect other people', and as if avoiding the subject could make it disappear. Unsatisfying, unconfirming experiences of care fostered hopelessness in the women.

The findings presented a paradox in the women's understandings of their own behaviour. On the one hand, the women realized that society as a whole considers self-harm an inappropriate way to alleviate mental suffering; on the other hand, they themselves experienced self-harm as the only way to survive and to maintain hope in themselves.

Study II

The caregivers negotiated several boundaries in their work with women who self-harm. They described the work as a challenge, yet they also described experiences of understanding, engagement, hopefulness, and being able to help. They described the difficulty of dealing with their own personal feelings when caring for a woman's self-inflicted wounds, while not rewarding the woman with reinforcing attention to the self-harming act. The caregivers also emphasized the importance of support from co-workers and management. They described experiences of not feeling alone, sharing personal feelings, and being confirmed by co-workers, as well as the need for clinical supervision and debriefing after difficult events. Caregivers imagined what it would be like if nurses who understood people who self-harm could provide care in small specialised units with adequate finances, trained staff, and sufficient time available for care.

However, caregivers were also burdened with heavy emotional responses of uncertainty and fear, and they often felt overcome and powerless caring for patients at risk of repeatedly harming themselves. Caregivers needed to be on guard at all times, always aware of the risk of a woman's fatal self-harm, and this could evoke anger towards the women. They described the women's self-harm as a forceful action towards people around them and reported that co-workers sometimes lost control of their emotions, shouting at a woman, grasping her arm tightly, and humiliating her. They also described the women as manipulative and deceptive and reported that they felt cheated. The caregivers described their different strategies for dealing with the

difficulties in caring for a woman's self-inflicted wounds while trying to avoid reinforcing the self-harming act. They described the frustration of trying to balance close observation with respect for the women's privacy. The caregivers also felt disconnected from co-workers, unheard by managers, and unsupported by insufficient staff involvement in debriefings. The caregivers acknowledged their lack of understanding of the women's problems, and not knowing how to care for the women's seemingly endless problems made them lose hope. Caregivers were burdened by feelings of fear, frustration, and abandonment.

Study III

The parents described their experiences of primary healthcare, inpatient and outpatient child and adolescent psychiatric care, acute and emergency care, and contacts with staff in the social service system.

The analysis of the parents' experiences of professional care and caregivers revealed 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'. Being in a situation with no escape describes the parents' constant search for answers, help, and support for their daughter, as well as their desire to be a parent and their urge to compensate for deficient care. Being trapped in the situation made the parents feel hopeless. Being in the prisoner's dock describes parent's feelings of worthlessness and parental failure, especially when caregivers spoke badly about them or accused them in front of their daughters, which also incurred hopelessness in the parents. Groping in the dark descibes parents' feeling invisible, being confused, feeling lost, and negotiating and trying to bridge gaps between all the parties involved. Groping in the dark was a third aspect of growing hopelessness in parents, however, parents found glimmers of hope when caregivers seemed to listen seriously to them or to their daughters and they felt valued, listened to, and relieved of guilt and responsibility of care.

The parents' experience of their daughters' professional care and caregivers was akin to being in a hostage situation. Parents, initially help-seeking and filled with hope, found themselves in a situation with no apparent escape. Facing deficient and sometimes hostile care, the parents paid an emotional ransom when being in the prisoner's dock, accused and broken as failed parents, groping in the dark, feeling invisible, confused, and lost. Caring deeply, as these parents did, about a person who suffers was an unbearable situation that had to be resolved; for these parents, accepting deficient care was better than being leaving their daughter with no care at all. Moments of despair were common in the parents' experiences of professional care and

caregivers. However, 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 manage and make sense of the situation. 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 relief and inspired them with hope for their daughters' recovery.

Study IV

The aim in study IV was to explore the interpretative repertoires that jointly construct the interaction between adult women who self-harm and their professional caregivers in psychiatric inpatient care. For the caregivers the dominating repertoires were a 'fostering repertoire' and a 'supportive repertoire', and for the women who self-harmed the dominating repertoires were a 'victim repertoire' and an 'expert repertoire'. The women and the caregivers were positioned, and positioned themselves and people around them, within these repertoires as 'equals', 'underdogs', or authorities.

Caregivers took on an authoritative position within the fostering repertoire. Using a fostering repertoire meant positioning oneself as being the one who carries the knowledge about what is for example right or wrong. The fostering caregiver tried to 'raise' the women by setting demands and limits. Caregivers took on more equal positions in the supportive repertoire. In a supportive atmosphere, positive feedback, concern for people around them, and the caregivers' use of empowering argumentation predominated. The caregivers listened, showed an interest in the women and how best to help them, and encouraged the women to adopt a position from which they could express their needs. However, caregivers sometimes assumed an underdog position in sympathy with the women, which restricted how they could interact with them.

The women positioned themselves as underdogs in the victim repertoire, which expressed their feeling of being restricted, from living with locked doors to not having access to needed support from the caregivers. A common consequence for women using this repertoire was waiting. Alternatively, in the expert repertoire, women positioned themselves as authorities and struggled for the preferential right of interpretation, which could lead to verbal fights with caregivers as both parties argued for the preferential right of interpretation. Common consequences of these situations were questioning, distrust, rejection, and defiance.

The interactions between a fostering caregiver and a woman in either role (expert or victim) were usually described as unsatisfying by both parts, and characterised by a struggle about who had the preferential right of interpretation. Consequences of this struggle were shown in uncertainty, as well as in a restricted ability to act. Inflexible ward rules, disrespect for one another, and a non-listening approach contributed to the unsatisfactory experiences. The interactions between a supportive caregiver and a woman as a victim reinforced the underdog position taken by the woman, and allowed both woman and caregiver to blame rules and restrictions for lack of progress. The interactions among these repertoires fostered hopelessness on both sides.

Interactions between a supportive caregiver and a woman as an expert were described as more equal and included satisfying experiences. When the interactions were more equal, they were filled with a sense of communion between the women and the caregivers, based on respect for each other as individuals. It was important to acknowledge the woman's own strength, potential, knowledge about herself, and right to define her own needs. The interactions among these repertoires fostered hope among the participants.

Synthesis of findings

Hope and hopelessness formed a thread of meaning throughout the studies. All participants experienced and expressed hope and hopelessness in various ways. The women hovered between hope and despair, hoping for help and support while their experiences of care bred mostly hopelessness. The women used self-harm both as a way to cope and as a way to raise their own hopes in themselves. The parents begin with confidence in the healthcare system and hope for help. However, their experiences of deficient care often led to hopelessness. The parents paid an emotional ransom when they accepted deficient care for their daughter. The caregivers felt frustrated, angry, and powerless, and their view of self-harm as an insoluble behaviour led them to feel hopeless about their caring abilities for these women. However, they struggled to see the women's abilities, not only their difficulties, and described how they tried to see self-harm in another way. Caregivers who were convinced that it was possible for a woman to stop self-harming permanently were able to instill hope in themselves, the parents, and the women who self-harmed. The present studies suggest that there is a difference between self-harm and suicide attempts or suicide. Other researchers echo these findings.

DISCUSSION

The overall aim of this thesis was to describe experiences of care among people who self-harm, professional caregivers, and parents, and to explore interpretative repertoires that jointly construct the interaction between people who self-harm and their professional caregivers. The interactions between the caregivers and the women who self-harmed were characterised by a struggle for the preferential right of interpretation in various situations, most commonly whether or not the self-harming act was an acceptable strategy to reduce mental suffering. Common attitudes in these situations were questioning, distrust, and rejection. The experiences and interactions among the participants in this project were marked most significantly by the dichotomy of hope and hopelessness.

Loss of hope and hostility towards a person's self-harm can be experienced as 'malignant alienation' (Pembroke 2006a). 'Malignant alienation' refers to a process that may be common among psychiatric inpatients. It is characterised by a progressive change for the worse in relationships with others, including loss of sympathy and support from caregivers, who describe the patients' behaviour as provocative, unreasonable, or lacking independence, and patients themselves as 'difficult to treat' (Morgan 1979).

Watts and Morgan (1994) discuss the important components of malignant alienation in four parts: *patient factors*, *staff factors*, *staff-patient interaction*, and *hospital environment*. *Patient factors* interpersonal capacity, marital isolation, distorted communication of dependency needs, and help negation (Fawcett, Leff & Bunney 1969). The findings in the present thesis echo the description of the patients that Morgan (1979) refers to, as well as the experiences reported by others (McAllister et al. 2002; Friedman et al. 2006; Pembroke 2006a; Ribe 2009). One interpretative repertoire used by the women was 'a victim repertoire', and for the women it meant being restricted, from living with locked doors to not having access to needed support from the caregivers. A common consequence for the women was waiting (IV). The women (I, IV) described the care provided as a long period of waiting, and the observations confirmed these waiting periods (IV). Women in care waited for meals, waited for pharmaceuticals, waited for times to smoke, waited for times to go out, and waited for decisions about their care (I, IV). Caregivers were also subjected to waiting (IV), for physicians, for medical decisions about care, for decisions from social services, etc. Often situations that included waiting led to discussions and disagreements between the women and their caregivers about rules and

restrictions. The women who self-harmed (I, IV) described being helped by someone who listened to them, took them seriously, and treated them with respect, however, they did not necessarily feel understood by these people. These findings are supported by Söderberg (2004), who reported that one way of gaining trust is by being fully present and listening, asking questions, trying to grasp an impression of the actual situation, and showing respect. Söderberg (2004) further describes standing by and fully identifying with the person who self-harms as contributing to that person's recovery. Honesty, sincerity, and reliability have been shown to be grounds for winning the trust of people who have difficulty trusting others (Livesley 2005; Oldham 2006).

Staff factors refer to hospital staffs' vulnerability to unrealistic expectations and aspiration for caregiving, called 'narcissistic snares' by Maltsberger and Buie (1974). The three most common snares were the aspirations to 'heal all, know all and love all' (Watts & Morgan 1994). *Staff-patient interactions* refer to caregivers' awareness of which patients provoke strong negative feelings in them, and how they, as caregivers, deal with these feelings to understand the alienation process (Watts & Morgan 1994). In the present studies (II, IV), as well as in other research (c.f. Breeze & Repper 1998; Berg & Hallberg 2000), people who self-harm are often described as 'difficult patients'. Breeze and Repper (1998) defined 'difficult patients' as patients who threatened the staff's feelings of competence and control and 'battled for power'. Caregivers in the present studies (II, IV) described patients' self-harm as a forceful action towards persons around them. They reported that they had noticed staff losing control of their emotions and shouting at the patient, grasping the patient's arm tightly, and humiliating the patient (II). Language has an important role in the social construction of identities, relations, and systems of knowledge. The words we use are important because our language constitutes our social world, constructed identities, social relationships, and our values and beliefs (Burr 2003). When caring for people who self-harm (and others in need of care) it is important to be aware of the words used in conversations with the person-in-care, their close family and friends, and one's own co-workers (Allen 2007).

The parents in study III felt they were 'in the prisoner's dock' because of the caregivers' accusitory and dismissive attitudes towards them. Caregivers spoke badly about the parents in front of their daughters and accused them of undermining their daughters' care. The parents were 'groping in the dark', feeling invisible, confused, and lost. Their experiences were similar to those described by Watts and Morgan (1994) and Pembroke (2006a). It is reasonable to believe that 'malignant alienation' can occur in the interaction between caregivers and parents as well as between caregives and patients; therefore, caregivers need to be sensitive when meeting parents and other

close family and friends. When Watts and Morgan (1994) describe the *hospital environment factors* they refer to Winnicott (1949), who likened the demands of caring for the difficult patient to those of a mother caring for a demanding baby. Winnicott (1949) admitted that however much he liked his difficult patients he could not avoid hating and fearing them. The more aware he was of his aversion, the less likely it would determine how he treated those patients. He saw his antipathy towards some patients as normal, but pointed out that it was important for caregivers in the hospital environment to be open with each other about their feelings about patients.

Feelings of hopelessness were expressed in all the participant groups in the studies this thesis comprises. The women (I, IV) and the parents (III) expressed hopelessness when they recounted the difficulty of receiving help and the feeling that caregivers viewed people who self-harmed as 'hopeless cases'. The caregivers (II) unwittingly confirmed the views of the women and their parents by expressing their own views of the women who self-harmed as 'hopeless cases'. According to Watts and Morgan (1994), a clinical strategy to prevent and manage the alienation suggested by these results could be the provision of clinical supervision, in which caregivers would have the opportunity to speak openly about any negative feelings towards their patients. Countertransference is inevitable in all caregiver-patient interactions. Conscious countertransference can usually be controlled and can be used as a tool in the interaction with the patient. However, when countertransference is unconscious, it can lead to destructive acting out by caregivers (Watts & Morgan 2004). It is reasonable to believe that unconscious countertransference is one of the phenomena that influence these interactions and it seems to work both ways: when the people who self-harm feel hopeless, so do their caregivers; when the people who self-harm feel hope, again, so do their caregivers. Therefore it is important that caregivers become aware of, acknowledge, and be able to talk about their feelings.

The caregivers in the studies lacked support from co-workers and management and they expressed a need for support and clinical supervision (II). Difficulties in communication among the caregivers led to uncertainties about how to act and how to respond within inflexible ward rules. A non-listening approach on both parts contributed to unsatisfying experiences among the participants (IV). Clinical supervision has been shown to be effective in peer support and stress relief for nurses and as a means of promoting professional accountability and the development of skills and knowledge (Brunero & Stein-Parbury 2008). Hodgson (2004) calls for interdisciplinary cooperation in order for professionals to learn from each

other, as well as from people who self-harm and their close family and friends.

I believe that clinical supervision of professional caregivers may strengthen and improve nursing practice. By having time to meet, talk, listen, and take one another seriously, care providers may support each other in their hope for the person who self-harms. Clinical supervision gives the caregivers opportunities to reflect upon their experiences and thoughts with each other. It seems reasonable to believe that unconscious countertransference may become a conscious phenomenon through clinical supervision, and may then be used as a tool in the caregiver-patient relationship.

The caregiver-patient relationship is always asymmetrical (Kasén 2002), because the caregiver has the power to define the conditions for care. Findings from this thesis acknowledge asymmetry in this relation, usually, but not always, in terms of the caregivers being in control of the conditions. The women (I, IV) described experiences of not being able to take part in the care provided for them. The caregivers usually had preferential rights of interpretation, even concerng the women' feelings (IV). The parents (III) described being exluded from planning care for their daughters, while being expected to support caregivers' decisions. Caregivers in studies II and IV described a somewhat contradictory opinion. They described caring for people who self-harm as a 'cat and mouse game' (II). When they searched through the women's things for sharp edges e.g. razors, they often failed. Women who were determined to cut themselves could have had hidden objects somewhere else and could cut themselves anyway. Caregivers also related that the women who did want help wanted it on their own terms (IV).

Caregivers described caring for people who self-harm as a challenge, but also reported positive experiences of understanding, engagement, hopefulness, and being able to help (II). The women talked about the importance of being seen as human beings with assets, and of being listened to and confirmed (I, IV). In the interaction between the women who self-harmed and the caregivers, the caregivers who used a supportive repertoire tried to be thoughtful, to help, to listen to the women, and to use empowering strategies. Caregivers imagined how they would want to be treated if they were the ones who needed care, which sometimes led them to break ward rules in sympathy with the women (IV). Inspiring hope is an important aim in mental health care (Farran, Herth & Popovich 1995; Talseth et al. 1999; Cutcliffe & Barker 2002). Holm and Severinsson (2011) report that women who self-harm are able to change their behaviour when they feel confirmed, safe, and trusted, and that building and maintaining trust and hope seemed to be the key in the recovery process.

As described earlier, time spent as an inpatient was filled with waiting (I, IV), and the caregivers wished that they could spend more time with the women doing things together. Caregivers also talked about never giving up hope for the women's recovery (II). The parents (III) struggled to find and maintain hope and talked about their hopes for their daughter's future. Caregivers, who acted as facilitators and interpreters of the women's scars, helped the women to construct meaning, accept that the scars were a part of them, and learn not feel compelled to hide them or to bei ashamed of them (IV).

Daufault and Martocchio (1985) define hope as a multidimensional, dynamic power that allows one to look at the future with faith. Spinoza (1677) describes hope as a view of the future that accepts the possibility of both good and bad, and finds joy either way. According to Fromm (1968), hope and faith are interdependent because hope is the mood that follows upon faith, and faith can not last without hope (p. 25). Farran and co-workers (1995) describe hope as a kind of coping strategy, which can lead to expanded functioning. As hopeful people feel more positive, their expressed thoughts and actions become more adaptive, and their relationships with others and the world become more positive. However, Lindholm (1995) posits that hope may have a deeper human meaning than as a mere coping strategy; at a deeper level hope crosses a psychic border, allowing a person to find new strength, new energy, and new meaning. According to Kylmä and Vehviläinen-Julkunen (1997), the essence of hope is faith in a new day and one's ability to avoid or to manage difficulties.

Hume and Platt (2007) did a qualitative exploration of service-users' views on appropriate interventions for the prevention and management of self-harm. They reported a clear preference for interventions focused on the provision of immediate aftercare, and they acknowledged that such management did not necessarily involve the prevention of self-harm. Personal circumstances and life history were major influences on the choice of interventions for self-harm.

The women in our study (I) who self-harmed reported the value of caregivers who saw, listened to, valued, and confirmed them as human beings. The interpersonal and physical milieu of their care was also important. A homelike, rather than a hospital-like, ambience with a private room was seen as an environment where they could feel secure and safe and grow as a human being. The caregivers (II) imagining better care for people who self-harm suggested small, well-funded units with caregivers who were allowed sufficient time and were genuinely interested in working with people who self-harm. According to Pembroke (1998; 2006a; 2006b), Hewitt-Taylor

(2004), Laugharne and Priebe (2006), and Söderberg (2008), this is similar to an empowering approach, which when used by caregivers can support the woman's self-confidence and self-esteem. The studies in the present thesis confirm that women need to be encouraged and given time to talk about their experiences and their descriptions of their current, as well as more long-term, needs and strengths, resources and interests.

Empowering is characterised by active listening and respect for the human being as the leading actor in her own life. It also requires having faith in the person's capacity to find her own solutions and strategies, and being prepared to support the person in carrying through on her plans. In other words, the person who self-harms is the expert on her own life, and the caregiver needs to listen to her and to empower her to find her own solutions. In the Tidal Model, described earlier, the caregiver helps the person-in-care to identify, describe, and begin to address the issues, problems, or difficulties that brought them to this particular point, and, thus, to begin to rejoin the flow of life. This model exemplifies empowering strategies used to help people to recover their lives (Barker & Buchanan-Barker, 2010). Using the term 'life-recovery', Collier (2010) suggests that medical recovery should be subordinated and the role of psychiatric classification reduced in the understanding of a person's own lived experience. Furthermore, improved symptoms, such as fewer incidents of self-harm, might be irrelevant to the person's actual process of growth and discovery. Therefore caregivers must be aware of, feel comfortable with, and be willing to adopt the role identity of a supportive caregiver, rather than an authoritative 'fosterer', when caring for people who self-harm.

METHODOLOGICAL CONSIDERATIONS

This thesis incorporated different qualitative research methods. The mix of methods used for data collection and data analysis in the different studies were chosen to answer research questions about the experiences of care among women who self-harm, their parents, and their professional caregivers, and to explore the interactions between all the parties. According to Patton (2002), the credibility of qualitative research relies upon the use of rigorous methods, the credibility of the researcher, and the researcher's philosophical belief in the value of qualitative inquiry. The earlier descriptions of methods, data collection, and data analysis should contribute to the credibility of this thesis.

The participants were nine women (I), six nurses (II), six parents (III), and six women who self-harmed and their professional caregivers (IV). It may be argued that the number of participants in each study was small; however, trustworthiness in a qualitative study is gained more by the richness of each interview than by the sample size (Sandelowski 1995). All of the participants who self-harmed were women (I, IV), and this may be considered as a limitation. An inclusion criterion for participating in the project was men *and* women who self-harm. In study I the participants were women and they received outpatient care of various kinds. In study IV no men were admitted to inpatient care for self-harming behaviour during the periods of data collection. That self-harm is more visible among women has been reported previously (Hawton et al. 2002; Ystgaard et al. 2003; Madge et al. 2008; Landstedt & Gillander Gådin 2011). This may explain, at least in part, why only women who self-harmed participated in the present project. The women (I, IV) self-reported their diagnoses, medications, and current treatment; possible psychopathologies may have influenced their descriptions. People who self-harm deserve care and attention based on respect. They have the right to speak out and be heard about their experiences, in their own words, unfiltered through assumptions based on any diagnosis or psychopathology; therefore, I chose not to read any medical records.

The participating parents (five mothers and one stepfather) were recruited through a newspaper advertisement. It may be argued that these parents were a highly selected and homogeneous group of people who wanted to be interviewed about their experiences, and that predominantly negative experiences might therefore be expected in their narratives. However, the parents in study III, while eager to tell their stories, reported both negative and positive experiences. A strength of the narratives was that the parents

reflected both on memories and situations from years ago and on recent experiences. They also took into consideration how they may have influenced the interaction with the professional caregivers.

The participating professional caregivers in studies II and IV were women and men with a wide range of experience in caring for people who self-harm. We did not gather any information about their histories or present life situations that could have influenced their interactions with the women who self-harmed (c.f. Berg, Hallberg & Norberg 1998). However, they were willing to talk about their experiences and participate in the observation study.

Participant observations were performed in study IV. Participants' views of observers and observers' own pre-understandings may both bias the collection of ethnographic data (Roper & Shapira 2000). I did my observations in two psychiatric inpatient wards at two clinics in the region. The two wards were different in many ways, however, there were no obvious differences in the care of the women who self-harmed, and the women's descriptions of being cared for did not vary by ward. Although there is a risk that a participant observer may become too involved in the observed situation and have difficulty retaining neutrality, participant observation offers the opportunity of establishing good contacts and gaining more natural insights into the individual perspectives of the study population (Roper & Shapira 2000).

The women who self-harmed were eager to help me in my research on self-harm, and they were willing to let me observe situations when they struggled. They might have withheld information if my role on the ward had been unclear to them, not knowing whether information given to me would be passed on to the professional caregivers. Similarly, the caregivers might have withheld information from me, as a researcher, due to an unclear role. However, I believe the participating women and caregivers were both open and curious. The process of thoroughly informing the participants on each ward before the observations started prevented misunderstandings regarding my role as a researcher.

My background has influenced the interpretive process; however, during the process of analysis the researchers repeatedly discussed our interpretations, reflected critically on the texts, and took into consideration our pre-understandings as researchers and as psychiatric nurses. The interpretation procedures are described so as to make it possible for the reader to follow the analytic process, and quotations from the texts help the reader to judge whether our interpretations are credible. Ricoeur (1976) argues that there is

more than one possible interpretation of a text (pp. 78–79); the results presented for each study are what we considered the most credible understanding of the texts. After the analysis, the data were translated into English. When preparing the manuscripts the difficulty of finding exact translations for specific words meanings likely affected some of the descriptions of the data.

CONCLUSIONS AND CLINICAL IMPLICATIONS

The thesis provides additional understanding of the complicated experiences and interactions between women who self-harm, their parents, and their caregivers. The findings echoe results from other researchers that suggest an important difference between self-harm and attempted or completed suicide. Paradoxically, though, self-harm usually seems to be a life-sustaining strategy, a way of promoting hope in one's self. It has been described as a way of communicating, through violence directed at one's own body, and an attempt to reach out to others in the hope of provoking a desired response. I do not believe that self-harm should be 'normalised'. However, if we professionals can acknowledge self-harm as a way of self-soothing and a way of raising one's hopes in oneself, then our way of interacting with people who self-harm and with each other will be more satisfying for all parties. The importance of working with caregivers who listen and try sincerely to understand, for both the people who self-harm and the people who love them, is evident. By asking open-ended questions and talking in a non-judgemental way, by listening and showing genuine interest in the person's lived experience, caregivers can inspire hope, which may in turn support recovery.

As shown in the findings, psychiatric inpatient care is based mainly on pharmaceutical and medical care, centred on decisions taken by the psychiatrist about such things as medication and permission to leave the ward between meals. Consequences, especially for the women in care, included much unscheduled time on the ward and many hours of waiting. Psychotherapeutic interventions and nursing interventions should be added to the standard inpatient care. Analysis of the experiences of care from the perspectives of both the women who self-harmed and the caregivers reveals feelings of frustration, anger, invisibility (being neither seen nor listened to), and abandoment. The time spent in inpatient care was filled with waiting. I believe that at least some of the described and observed disagreements and discussions among the women and the caregivers could be avoided if time on the ward were scheduled with structured activities and oppportunities for conversations between the women and the caregivers, as this would reduce waiting and increase meaning in the care experience. One of the women (I) experienced questions from caregivers' as expressions of their genuine interest in her as a human being. Scheduled moments to talk with caregivers could support women's feelings of being valued and confirmed as human

beings.

The burdens reported by professional caregivers and the importance of releiving these burdens need to be taken seriously, not only for the health of the caregivers, but also because they may adversely affect the care milieu and increase the turmoil of inpatients' lives. Offering professional caregivers the opportunity to take part in clinical supervision could be one way of dealing with these reported burdens. Clinical supervision could also lead to increased understanding and knowledge about managing self-harm, which would support the caregivers and give them opportunities to talk openly about their experiences of caring for people who self-harm.

The Tidal Model, described in the Background section, could be introduced in practice as a way of working with people who self-harm and thinking about what is needed to support them on their journey towards recovery. In the model, tides are a metaphor for lived experience; tides ebb and flow, change constantly, and are full of possibilities. Working within this model means using an everyday language that is specific to the person-in-care and the caregiver. Assessments and care plans are written in the person's own words and signed by both the patient and the caregiver. Two assumptions underlie the model: people are their stories, and change is constant. The structured way of working together, on the premises of the lived experience of the person-in-care, are in line with what many of the women in the present studies desired.

As described in the findings, nursing strategies are frequently aimed to prevent self-harm, and the goal of care is to stop the person from self-harming at once. However, people who self-harm have usually engaged in self-harming behaviour for a long time before they enter care, and it is obviously a very large step to quit instantly. One nursing strategy that could be used until the person is able to stop self-harming voluntarily involves harm minimisation approaches. Harm minimisation may evoke ethically difficult feelings among caregivers, but it is recommended in the NICE guidelines (2004). Harm minimisation focuses on risk-reduction; it includes psycho-educative ingredients, as well as psychological and social supports defined by the individual.

The parents who participated (III) felt neglected by the caregivers, who they perceived saw them as demanding, challenging, and difficult to deal with. Caregivers who differed from the rest and wanted the parents to be a part of their daughter's care were especially valuable to the parents, as they inspired both relief and hope for their daughter's future. It may be difficult to allow family members or friends to participate in care if the individual who self-

harms does not want them to be involved; however, caregivers can have an on-going discussion with the person about what can and cannot be shared with people who are concerned about them. Family and friends may be supported with factual information about the phenomenon of self-harm and with opportunities to talk about their own situation and position in relation to the person who self-harms. Many people who self-harm are young and in some way still dependent on their families. Therefore, it is important to support continuing personal contact between them, appropriate to the development or abatement of the self-harming behaviour.

FURTHER RESEARCH

Further research should explore the content of care provided in psychiatric inpatient wards. For example, it would be valuable to apply critical discourse analysis to the official documents and guidelines that set up the conditions of inpatient care.

Intervention research could usefully focus on improving inpatient care for people who self-harm by developing, implementing and evaluating different nursing interventions, the effects of the caring milieu, especially in psychiatric mixed units, and evaluating different psychotherapeutic methods. Furthermore, intervention research to develop outpatient individualized nursing care programs in order to develop support strategies in daily life. Such outpatient programs should be flexible and person oriented, and aims to follow and support the person who self-harm through the labyrints in the society, e.g. related to education, health management, health care contacts and social challenges.

Research on interventions offered to family members and friends of people who self-harm may not only lead to improvements that will help to releive their burdens, but also contribute to the care of people who self-harm.

It is also very important to conduct studies with men who self-harm, in order to detect differences and similarities between men and women with self-harming behaviour.

SVENSK SAMMANFATTNING

Självskadebeteende definieras i denna avhandling som ett upprepat, impulsivt beteende där hudskada uppstår. Personens avsikt med handlingen är inte att begå självmord utan snarare att lindra ångest. Studier visar att mellan 4–6% i en normalpopulation har ett självskadebeteende. Enligt en amerikansk studie förekommer ett aktivt och ”kroniskt” självskadebeteende hos 6% av collegeungdomarna, medan så många som 13–25% av ungdomar och unga vuxna någon gång har skadat sig själva. En europeisk studie visar att det vanligaste sättet att skada sig bland tonåringar är att skära sig. Bland vårdgivare finns en uppfattning om att självskadebeteende bland tonårsflickor har ökat vilket beläggs i en kartläggning gjord av Socialstyrelsen. I flera studier framkommer ingen skillnad mellan män och kvinnor medan åter andra studier rapporterar att fenomenet är vanligare hos kvinnor. En svensk studie visar att självskadebeteende hos fjortonåringar är lika vanligt bland pojkar som bland flickor. Det är i stället sättet att skada sig på som skiljer mellan könen. Kvinnor verkar vara mer benägna att skära sig, medan män bränner eller slår sig själva.

Upplevelser av självskadebeteende kan beskrivas utifrån olika perspektiv. Personer som lever med ett självskadebeteende beskriver beteendet som en hanteringsstrategi och som ett sätt att överleva. Studier rapporterar övervägande negativa erfarenheter av vård och bemötande bland personer med självskadebeteende. De upplever att vårdarna tycker att det är slöseri med tid att vårda dem eftersom de ändå kommer att skära sig om och om igen. Vidare framkommer att personer med självskadebeteende ofta upplever att de blir missförstådda och att de uppfattas som manipulativa och uppmärksamhetssökande. Personer som skadar sig själva rapporterar att den främsta orsaken till självskadandet var att hantera känslor som upplevdes svåra, till exempel stress, ångest och spänningar. Andra motiv kan vara en vilja att straffa sig själv för att man känner sig misslyckad eller inte tycker om sig själv.

Det finns få studier om närståendes upplevelser i samband med självskadebeteende. De studier som identifierats beskriver föräldrars förståelse av självskadebeteende. Det framkommer att föräldrar har begränsade kunskaper om beteendet i sig, men de berättar att det väcker starka negativa känslor när beteendet uppkommer i den egna familjen. Vikten av att diskutera självskadebeteende i bland annat preventivt hälsoarbete och vid föräldramöten i skolan lyfts fram. I en studie om erfarenheter av att vara mamma till en ”självmordsnära” tonåring är känslor av att vara misslyckad

som mamma, att känna sig ensam, hjälplös och maktlös dominerande. Vidare framkommer en känsla av att livet med en självmordsnära tonåring innebär att ”gå på äggskal” samt ett behov av att hålla en känslomässig distans. Känslor av skuld, skam och vånda lyfts fram. Studier visar även på bristande information och stöd till närstående från professionella vårdgivare.

Upplevelser av att vårda personer med självskadebeteende belyses i ett antal studier. Studier genomförda vid främst akutmottagningar visar att vårdare i många fall har negativa attityder till personer med självskadebeteende. Känslor som dominerar hos vårdarna är frustration, ilska, hjälplöshet och stress. Vidare rapporteras att vårdare känner sig nervösa och har svårigheter att kommunicera med och vårda personer som skadar sig själva. Studier visar att psykiatrisjuksköterskor förstår självskadande som ett komplext beteende. De försöker upprätthålla en patientcentrerad inställning och planerar vården tillsammans med personerna med självskadebeteende. I första hand prioriteras arbete med prevention och säkerhet. De lyfter å ena sidan fram värdet av engagemang men å andra sidan problemet att akutpsykiatriska vårdavdelningar är begränsade ur terapeutisk synvinkel eftersom de upplevs som stressiga platser. Vidare framkommer den känslomässiga påfrestningen som det innebär att vårda dessa personer och att ständigt bedöma potentiell risk för självskada.

Avhandlingen består av fyra delstudier. Dess övergripande syfte var att beskriva erfarenheter av vård bland personer med självskadebeteende, professionella vårdare och närstående (föräldrar), samt att belysa tolkningsrepertoarer som konstruerar interaktionen mellan personer med självskadebeteende och deras professionella vårdare.

Studie I syftade till att beskriva upplevelser av vård och bemötande bland personer med självskadebeteende samt hur de önskade att vården skulle vara. Intervjuer genomfördes med nio kvinnor med självskadebeteende, mellan 19 och 35 år (median 25 år). Intervjuerna varade mellan 40 och 50 minuter och analyserades med hjälp av kvalitativ innehållsanalys. Kvinnornas erfarenheter var från såväl nationell som internationell vård. De berättade om upplevelser från psykiatrisk sluten- och öppenvård samt från somatisk akutvård. De berättade även om upplevelser från socialpsykiatrisk vård.

I resultatet framkommer att kvinnorna förväntade sig att bli bekräftade när de sökte vård. Ett bekräftande bemötande ingav hopp medan ett icke-bekräftande bemötande ingav hopplöshet. Kvinnornas upplevelser handlade om positiva och negativa aspekter av att bli sedd – inte bli sedd, vara värdefull – bli stigmatiserad, ha tillhörighet – vara avskärmad, bli trodd – bli

ifrågasatt samt bli förstådd – inte bli förstådd. Vidare beskrev kvinnorna sina förväntningar och upplevelser av att bli sedda som en människa med förmågor, önskningar och behov och inte som en människa med bara svårigheter. De kände sig förstådda när personalen utforskade orsakerna till självskadebeteendet och frågade om deras mående, när personalen talade öppet om självskadehändelsen likväl som när personalen uppmuntrade andra, mer hälsosamma sätt att uttrycka sina behov på. Kvinnorna beskrev att de kände sig bekräftade när personalen trodde på dem och när de förmedlade att det kan bli bättre. De påtalade vikten av att tillåtas vara delaktiga i sin egen vård och vårdplanering samt att uppmanas att ta ansvar för sina egna behov och handlingar. Kvinnorna lyfte fram vikten av en hemlik miljö där de kände sig trygga och säkra och där de kunde växa som människor. Erfarenheter som upplevdes tillfredsställande ingav hopp.

Kvinnorna upplevde vidare att självskadebeteende ofta bedömdes som negativt och som en sjukdom. De beskrev att personalen visade bristande respekt för dem och de kände att de blev behandlade som objekt, en sak utan själ vilket upplevdes som en ”professionell” stigmatisering. De erfor att stigmatiseringen dominerade vilket bidrog till känslor av skam, misstroende och att inte bli tagen på allvar samt att bli sedd som ”ett hopplöst fall”. Kvinnorna upplevde att de inte blev trodda när personalen undvek att tala om självskadebeteendet, som om beteendet skulle ”smitta” andra människor, ”talar man inte om det så finns det inte”. Erfarenheter som upplevdes otillfredsställande ingav hopplöshet.

Resultaten visade på en paradox: å ena sidan insåg kvinnorna att samhället i stort anser att självskadebeteende är ett oacceptabelt sätt att hantera psykiskt lidande, å andra sidan upplevde kvinnorna att självskadandet gjorde det möjligt att överleva – ett sätt att inge sig själv hopp.

Studie II syftade till att belysa upplevelser av att vårda personer med självskadebeteende i psykiatrisk slutenvård. Sex sjuksköterskor, tre kvinnor och tre män mellan 27 och 53 år (median 38,5 år) intervjuades om sina erfarenheter. Intervjuerna varade mellan 40 och 65 minuter, och även de analyserades med hjälp av kvalitativ innehållsanalys.

I resultatet framkommer att när sjuksköterskorna kände att de kunde balansera och sätta gränser upplevdes vården av personer med självskadebeteende som en utmaning. De beskrev en förståelse, ett engagemang, en hoppfullhet och en känsla av att kunna hjälpa. Vidare beskrevs svårigheter likväl som strategier för att kunna hantera sina egna känslor när de till exempel skulle sköta om sår efter en självskadehändelse. Behovet av att lyckas balansera mellan att ta hand om såret och samtidigt inte ge

särskild uppmärksamhet till den självskadande handlingen upplevdes tillfredsställande. Sjuksköterskorna lyfte fram behovet av stöd från kollegor och arbetsledning. De beskrev känslor av att inte känna sig ensamma, kunna dela känslor och bli bekräftade av kollegor. Behovet av handledning och även debriefing vid särskilda händelser betonades. Sjuksköterskorna beskrev en vision av hur vården av personer med självskadebeteende skulle kunna vara. De som arbetade skulle ha en förståelse för kvinnorna och deras självskadebeteende, de skulle erbjuda vård på små enheter utan att blanda patienter med olika problem. Vidare en vård med tillräckliga ekonomiska resurser, välutbildad personal och tillräckligt med tid för erbjuden vård.

I resultatet framkommer även att sjuksköterskorna upplevde vården av personer med självskadebeteende som en belastning. De kände sig maktlösa och tyngda när de inte kunde identifiera och tillfredsställa kvinnornas behov av vård. Sjuksköterskornas upplevde rädsla, osäkerhet, maktlöshet och hopplöshet. De beskrev upplevelser av att de hela tiden måste vara på sin vakt eftersom risken alltid fanns för att en allvarlig, ibland dödlig, självskada skulle inträffa. Det medförde känslor av frustration och ilska gentemot kvinnorna och sjuksköterskorna beskrev självskadebeteendet som en kraftfull handling riktad mot andra människor. Vidare berättade sjuksköterskorna om situationer när de bevittnat hur deras kollegor ibland tappat behärskningen, till exempel genom att skrika till personen som skadat sig själv, ta ett hårt tag om personens arm eller genom att förödmjuka personen. Sjuksköterskorna beskrev kvinnorna som manipulativa, att kvinnorna kunde vilseleda dem och att de kände sig lurade av dem. De beskrev också en känsla av att vara övergiven av såväl kollegor som arbetsledning och organisation. Sjuksköterskorna beskrev även sin brist på förståelse för kvinnornas problem och de upplevde en brist på kunskap om hur de skulle vårda dem. Kvinnornas problem upplevdes som ändlösa vilket ingav hopplöshet.

Studie III syftade till att belysa innebörder i föräldrars levda erfarenheter av professionell vård och vårdare bland föräldrar till en person med självskadebeteende. Fem mammor och en styvpappa, mellan 45 och 55 år (median 49 år) ombads att berätta om sina erfarenheter. Intervjuerna varade mellan 30 och 85 minuter och analyserades med hjälp av fenomenologisk hermeneutik. Föräldrarna berättade om erfarenheter från öppen respektive sluten barn-, ungdoms- och vuxenpsykiatrisk vård, somatisk akutvård samt primärvård. Även berättelser om erfarenheter av kontakter med personer från andra behandlings- och stödfunktioner i samhället förekom.

Resultatet visar att den levda erfarenheten av professionell vård och vårdare bland föräldrar till vuxna döttrar med självskadebeteende utgjordes av fyra

teman: ”vara fångad i en situation utan återvändo”, ”sitta på de anklagades bänk”, ”famla i mörker” samt ”hitta gnistor av hopp”. Vara fångad i en situation utan återvändo handlade om föräldrar som hela tiden sökte svar, hjälp och stöd åt sin dotter. De önskade att ”bara få vara föräldrar” till sina döttrar men upplevde samtidigt att de var tvungna att kompensera för en undermålig vård. Att vara fångad i en situation utan återvändo ingav hopplöshet hos föräldrarna. Sitta på de anklagades bänk handlade om att känna sig värdelös och totalt misslyckad som förälder. Det handlade också om att känna sig ”nedbruten” som förälder när personal baktalade föräldrarna i samtal med deras döttrar. Famla i mörker handlade om att känna sig osynlig, vara förvirrad och vilse samt att förhandla och överbrygga klyftor mellan alla inblandade parter. Föräldrarna fann även gnistor av hopp när de kände sig värdefulla, blev lyssnade på och upplevde lindring vilket ingav hopp.

Resultaten visar även att föräldrarnas levda erfarenheter av professionell vård och vårdare kan tolkas som ett gisslandrama. Föräldrarnas levda erfarenheter, initialt hjälpsökande och fyllda med hopp, vändes till att de var fångade i en situation utan återvändo. I denna situation var deras dotter gisslan och föräldrarna till en dotter i en gisslansituation betalade en känslomässig lösensumma när de mötte en undermålig och ibland fientlig vård. Föräldrarna ”betalade” den känslomässiga lösensumman när de satt på de anklagades bänk, blev anklagade och ”nedbrutna”, likväl som när de famlade i mörkret och kändes sig osynliga, förvirrade och vilsna. Föräldrarnas djupa engagemang i vården av en dotter som lider var en outhärdlig situation som måste lösas, vilket innebar att det var bättre att acceptera en undermålig vård än att vara utan vård. Den levda erfarenheten från professionell vård och vårdare dominerades av tillfällen när förtvivlan var vanligt. Situationer förekom när föräldrarna sökte lösningar i olika riktningar. Genom att, både muntligt och i handling, inom familjen såväl som mellan vårdare och olika myndighetsnivåer, förhandla och överbrygga klyftor försökte föräldrarna göra situationen mer hanterbar. Mer vilsamma situationer förekom: välkomna pauser som erbjöd en stunds lindring för föräldrarna. Situationer som upplevdes möjliga att förstå och som löstes på ett mer rofyllt sätt ingav hopp om dotterns tillfrisknande.

Studie IV syftade till att belysa tolkningsreportoarer som konstruerar interaktionen mellan personer med självskadebeteende och deras professionella vårdare. Sex kvinnor med självskadebeteende som vårdades vid två psykiatriska slutenvårdsavdelningar och deras professionella vårdare deltog i studien. Beskrivande deltagande observationer samt informella intervjuer genomfördes, motsvarande totalt 150 timmar, varav cirka 40 timmar var fokuserade deltagande observationer. Data analyserades med

hjälp av diskurspsykologi. Resultatet visar att de dominerande tolkningsrepertoarerna som tillsammans konstruerade interaktionen för vårdarna var en fostrande och en stödjande repertoar. För kvinnorna med självskadebeteende dominerade en offer- och respektive en expertrepertoar. Kvinnorna likväl som vårdarna positionerade sig och positionerades inom tolkningsreportoarerna. De intog en jämlik position, en underordnad position och/eller en överordnad position.

Vårdarna intog en överordnad position inom den fostrande repertoaren. Interaktionen mellan den fostrande vårdaren och en kvinna med självskadebeteende karaktäriserades av kampen om vem av dem som hade tolkningsföreträde. Konsekvenserna av denna kamp var osäkerhet och en begränsad möjlighet att handla. Vårdare intog företrädesvis en jämlik position inom den stödjande repertoaren. Det handlade om en stödjande atmosfär, positiv feedback, omtanke om människor runt omkring dem och den stödjande vårdaren fokuserade på kvinnans självbestämmande. Den stödjande vårdaren lyssnade och visade ett intresse för kvinnorna och hur de kunde hjälpa kvinnan att föra sin egen talan och uttrycka sina behov. Den stödjande vårdaren tog ibland en underordnad position tillsammans med kvinnan. Det innebar att vårdaren då hade en begränsad möjlighet att interagera med kvinnorna till exempel när det gällde systemet för kontaktpersoner och deras uppdrag.

Kvinnorna intog en underordnad position inom offerrepertoaren, vilket för dem innebar att vara begränsade när det gällde allt från den låsta dörren till att inte få det stöd som behövdes från vårdare. En vanlig konsekvens av detta var väntan. Kvinnorna intog en överordnad position och kämpade om tolkningsföreträdet inom expertrepertoaren. Verbala kamper förekom där båda parter argumenterade för vem som hade rätt. Konsekvenser av dessa kamper var ifrågasättande, misstroende, avvisande och trots.

Interaktionen mellan en fostrande vårdare och en kvinna som var expert eller ett offer beskrevs av båda parter som övervägande otillfredsställande. Oflexibla regler på vårdavdelningen, bristande respekt för varandra likväl som en icke-lyssnande hållning bidrog till den otillfredsställande interaktionen. Interaktionen mellan en stödjande vårdare och en kvinna som var ett offer stärkte kvinnans underordnade position och möjliggjorde för henne, och för vårdarna, att gömma sig bakom regler och begränsningar. Interaktionen mellan dessa repertoarer var komplicerad och ingav hopplöshet bland deltagarna.

Interaktionen mellan en stödjande vårdare och en kvinna som var expert beskrevs som mer jämlik och mer tillfredsställande. När interaktionen

karaktäriserades av en känsla av gemenskap beskrevs den mer jämlik. Det var viktigt att bemöta varandra med respekt och att ta hänsyn till kvinnornas egen styrka, möjligheter, kunskap om sig själv samt att lyfta fram hennes rätt att identifiera och uttrycka sina behov. Interaktionen mellan dessa repertoarer var tillfredsställande och främjade hopp bland deltagarna.

Sammanfattande resultat Hopp och hopplöshet visade sig vara en röd tråd genom delstudierna. Alla deltagare upplevde och uttryckte hopp och hopplöshet på olika sätt. Kvinnorna svävade mellan känslor av hopp och hopplöshet, med önskningar om hjälp och stöd men deras erfarenheter av vård ingav hopplöshet. Kvinnorna använde självskada som en hanterings-strategi och som ett sätt att inge sig själv hopp. Föräldrarna hade initialt ett förtroende för vården och hade förhoppningar om hjälp, men deras erfarenheter av att möta en undermålig vård ingav istället en känsla av hopplöshet. Föräldrarna betalade en känslomässig lösensumma när de accepterade en dålig vård för sin dotter. Vårdarna kände sig frustrerade, arga och maktlösa och deras syn på självskadebeteende som något ändlöst ingav hopplöshet. Emellertid kämpade vårdarna för att se kvinnornas förmågor, inte bara deras svårigheter, och de försökte förstå självskadebeteendet. De vårdare som var övertygade om att det var möjligt att sluta skada sig och lämna det bakom sig lyckades inge sig själva, föräldrarna och kvinnorna med självskadebeteende hopp. Resultaten från studierna tyder på en skillnad mellan självskadebeteende och självmordsförsök eller självmord, detta stöds även av andra forskare.

Slutsatser och kliniska implikationer Avhandlingen har bidragit till en ökad förståelse för upplevelserna hos kvinnor med självskadebeteende, föräldrar och vårdare såväl som den komplicerade interaktionen dememellan. Paradoxalt nog så verkar självskadebeteende vara ett sätt att kommunicera och att trösta sig själv, vidare ett livsuppehållande beteende, ett sätt att inge sig själv hopp. Den vård som erbjuds inom psykiatrisk slutenvård domineras av de medicinska inslagen där fokus ligger på beslut som läkare ska ta om medicinering, permissioner osv. Det innebar många gånger att den tid som man vistas på vårdavdelningen domineras av väntan på beslut av olika slag. Det är min övertygelse att åtminstone en del av de beskrivna och observerade meningsskiljaktigheterna som uppstod mellan kvinnorna och vårdarna skulle kunna undvikas. Ett mer strukturerat innehåll i den slutna psykiatriska vården, där regelbundna tider för till exempel fysisk aktivitet och dagliga samtal, skulle bidra till minskad tid för väntan och ett mer meningsfullt innehåll i vården. Betydelsen av vårdare som lyssnar och försöker förstå personen som skadar sig och de närstående är tydlig. Genom att ställa öppna frågor, tala på ett icke dömande sätt, lyssna

och visa ett genuint intresse för personens upplevelser, kan vårdare förmedla hopp.

Genom att erbjuda vårdpersonal handledning i sitt arbete kan en del av den börda som vårdare beskrev minskas. Handledning kan även bidra till en ökad förståelse och möjlighet att hantera självskadebeteende, samt en möjlighet att få prata med kollegor om sina erfarenheter och därigenom få och kunna ge stöd till varandra.

Den psykiatriska omvårdnaden skulle kunna utvecklas t.ex. genom att använda ”Tidal Model” som ett sätt att arbeta och tänka kring vilken typ av stöd som behövs för att en person med självskadebeteende ska kunna återhämta sig. Modellen använder tidvatten som en metafor för levd erfarenhet, livet som ebb och flod, konstant föränderligt och fullt av möjligheter. Två grundläggande antaganden ligger till grund för modellen: människor är sin historia och förändring är konstant. En viktig ingrediens är att använda ett vardagligt språk specifikt för varje enskild person. Arbetssättet är strukturerat och vårdaren arbetar tillsammans med personen. Bedömningar och vårdplaner skrivs med personens egna ord och signeras av personen själv och av vårdaren.

Omvårdnadsstrategier som avser att förhindra självskadebeteende t.ex. övervakning, konsekvenser vid självskadeincident osv. har visat sig vara verkningslösa. Kliniska riktlinjer utvecklade i Storbritannien förespråkar arbete med ”riskreduktion” till personer med långvarigt självskadebeteende (exklusive överdoseringar av läkemedel) som bedöms ha svårt att helt sluta skada sig. Det betyder att man arbetar med metoder som innebär att personen ska kunna skada sig själv men på ett ”säkrare”, mindre farligt sätt. Riskreduktion innehåller psykopedagogiska inslag samt psykologiskt och socialt stöd utifrån de behov som personen själv beskriver.

Föräldrarna berättade om sin utsatta position och om sina erfarenheter från kontakter med vården. I mötet med vårdare som såg föräldern som en resurs och bjöd in till deltagande, ingavs föräldern hopp. Det kan ibland vara svårt att inbjuda närstående till att vara delaktiga i vården, särskilt om personen som vårdas inte själv tillåter det. Oavsett så skulle en mer öppen dialog mellan vårdare, den som vårdas och närstående kunna bidra till ett bättre samarbete dememellan. Ytterligare ett sätt att erbjuda närstående stöd skulle kunna vara att organisera stödgrupper för närstående.

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