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This thesis is based on the following papers referred to in the text by their Roman numerals:


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INTRODUCTION

As a nurse who has specialized in the fields of cancer and pain management I have on many occasions cared for families in end-of-life care. It is both a demanding and a rewarding experience to be close to a family in situations that sometimes can be very peaceful while others can be experienced as a turmoil depending on the circumstances. These experiences have aroused questions about what it is like to be the next-of-kin in end-of-life care. I was curious and wanted to know more about their experiences in this context.

Andershed, one of my supervisors has found that there were occasions when experiences of not being able to cope sufficiently with situations in the end-of-life care could contribute to the next-of-kin feeling inadequate (1998, 2006). These findings made us curious as to whether situations such as those could involve experiences of guilt and shame and if so what these experiences might consist of. A secondary analysis of interviews with next-of-kin concerning their experiences of end-of-life care was conducted. This study became the first step into my doctoral studies and during my time as a doctoral student I have gained knowledge about how next-of-kin in end-of-life care experience guilt and shame. This knowledge has provided some answers but has also shown that there still are important questions that need to be answered.
BACKGROUND

In this section of the thesis the specific concepts used in the text, aspects of how end-of-life care in Sweden have been developed, research concerning next-of-kin in end-of-life care, research concerning guilt and shame, and research concerning next-of-kin’s experiences of guilt and shame in end-of-life care are presented. The text is presented under five headings:

- Concepts
- Aspects of end-of-life care in a Swedish perspective
- Next-of-kin in end-of-life care
- Guilt and shame
- Next-of-kin’s experiences of guilt and shame in end-of-life care

Concepts

Palliative care

Palliative care is defined by the World Health Organization (WHO, 2012) as a team approach that improves the quality of life of patients and their families facing a life-threatening illness, through the prevention, assessment and treatment of pain and other physical, mental, psychosocial and spiritual problems. This concurs with the definition provided by the Swedish National Board of Health and
Welfare which states that palliative care is health care that has the aim of alleviating suffering and improving quality of life for patients with progressive, incurable illness or injury as well as organizing support for their next-of-kin. It is also linked with a palliative approach that is characterized by a comprehensive view on the ill person. The approach involves supporting this person in order for her/him to be able to live with dignity and as much well-being as possible to the end of her/his life (The Swedish National Board of Health and Welfare, 2011). This kind of care affirms life and regards dying as a normal process and aims to neither hasten nor postpone death. Every contribution is preceded by a consideration of the pros and cons for the individual’s well-being. It also offers a support system to help the family cope during the patient’s illness and their own bereavement (WHO, 2012). The approach is based on hospice philosophy where the person is seen as a unity in interplay with her/his surroundings which means that the person has interpersonal relationships with the next-of-kin, and is a member of a society. These fundamental assumptions influence how the care is designed and what it involves (Qvarnström, 1998).

**End-of-life care**

The concepts end-of-life care and palliative end-of-life care are both commonly used and often without any real distinction. End-of-life care can sometimes be seen as a wider concept that involves care for all people at the end-of-life whether they die of old age or from an illness. Palliative end-of-life care can involve elements of the hospice philosophy. This philosophy is considered to be an important part of palliative care and is seen as the care of a person in the last part of her/his life. There is a starting point when it becomes clear that a disease is in progress and there is no hope for a cure and death is inevitable. The care has thus the aim to alleviate suffering and improve quality of life (The Swedish National Board of Health and Welfare, 2011). This kind of care can involve a complex situation for the patient and her/his next-of-kin where advanced symptoms and existential issues are present. It can be a demanding period for the health professionals who need to be well educated.
concerning nursing, medical, and existential matters in order to be able to meet the needs of the patient and her/his next-of-kin.

The use of the concepts of palliative care, end-of-life care, and palliative end-of-life care can be confusing since they are so closely linked together and often used alternatively in literature (Hui et al. 2012). Ternestedt maintains that there is a lack of clarity concerning the period of time that designates palliative care and end-of-life care, which also entails difficulties concerning which concept should be used (The Swedish National Board of Health and Welfare, 2007). Hui et al. (2012) demonstrate that there is a need for definitions of the different concepts since a lack of clarity can have negative implications and be confusing administratively, clinically, and academically.

The choice has been made to generally use the concept end-of-life care in the thesis. However the concept palliative care is used on a few occasions where it is deemed to be relevant in relation to the specific context.

**Next-of-kin**

There are several term to designate a person who has a close relationship with someone suffering from ill health or from an illness and who is involved in the care for that person. This person can be a blood relative, someone who is married into the family, a cohabiter or a close friend. It is someone that the person who is ill considers s/he is closest to. To decide which term to use for this close person can be difficult being as there is a plethora of terms used in the research literature. Andershed (2006) found fifteen different ways of naming this person: caregiver, carer, informal carer, primary informal caregiver, primary caregiver, home caregiver, cancer caregiver, caring relative, relative, surviving/widowed spouse, next of kin, family caregiver, family carer, family member and family.
In this thesis a decision was made to use the term “next-of-kin” to emphasize the close nature of the person’s relationship with the ill person.

**Aspects of end-of-life care in a Swedish perspective**

In the 1960s a modern hospice movement started in Great Britain and one of the forerunners was Dame Cicely Saunders, who devoted her life to the care of dying people. She maintained that dying should be regarded as a natural part of life. In end-of-life care the caring environment should be open and accessible for the next-of-kin and friends of the dying person. This caring environment is to be characterized by freedom from pain and other physical, psychosocial and spiritual problems, and the dying person is to feel secure in communion with loved ones, where personal integrity and human dignity is maintained (Saunders, Baines & Dunlop, 1995). This has been the starting point in Sweden as well as in other countries when good end-of-life care has been discussed. Several investigations were performed with the intention of developing the Swedish end-of-life care services.

In 1979 a comprehensive report was published concerning different aspects of end-of-life care (SOU 1979:59). This report was in many ways the first link in Sweden between a strictly medical view on the end-of-life care and a more humanistic approach to caring and what it constitutes. The human science approach to research in end-of-life care created possibilities for the use of other methods than those in natural science for the study of human conditions concerning dying and death. These approaches added knowledge about how people who are dying and their next-of-kin experience their situations (The Swedish National Board of Health and Welfare, 2007). A debate about prioritizing in the Swedish health care services led to a governmental investigation (SOU 1995:5) in which it was stated that end-of-life care should be given the same priority as emergency care. This, in turn, generated an investigation into how dignity in end-of-life care should be performed (SOU 2001:6), where an
ethical basis and standards for good quality care in end-of-life derived from hospice philosophy were proposed. The patient’s right to choose whether s/he wants her/his care in an institution or in her/his own home with help from the health services was emphasized. The next-of-kin and the patient should be given opportunities to participate in the care and be offered support. The investigation also highlighted the need for collaboration between health care providers, education and supervision of staff, and research.

**Next-of-kin in end-of-life care**

To be the next-of-kin to someone who is dying entails being in a complex life situation. It can be the next-of-kin’s first real encounter with dying and death. To come face to face with the death of a loved one can result in bitterness towards losing a lot of what is seen as being important in life (Andershed, 2006; Borneman & Brown-Saltzman, 2010; Ternestedt, 1998).

Funk et al. (2010), and Stajduhar et al. (2010) maintain that in the Western world there is an increasing emphasis on home deaths. Most of the last year in life is spent at home and a majority of patients desire to be cared for and to die at home. Next-of-kin who are involved in end-of-life care for a loved one can be seen as the backbone of the delivery of health care and social care services. The motives for the involvement of the next-of-kin in the end-of-life care can vary greatly; some may have a personal desire to give back for care and support previously given by the person who is dying (Rhodes & Shaw, 1999), some may want to maintain the family autonomy (Coristine, Crooks, Grunfeld, Stonebridge & Christie, 2003), while others can wish to avoid an expected poor quality of care or uncoordinated formal services (Exley & Tyrer, 2005; Ross, MacLean, Cain, Sellick & Fisher, 2005; Stajduhar, 2003; Stajduhar & Davies, 2005; Thomas, Morris & Clark, 2004; Wennman-Larsen & Tishelman, 2002).
The reasons for shouldering the responsibility may be concerned with love, attachment and an outlook on life where an increased awareness of precious values is a strong motivation. There can also be an expectation from the health care services that the next-of-kin take on an increasing amount of care for the dying person; care that is often complex and that used to be performed by nurses (McCorkle & Pasacreta, 2001; Ward-Griffin & McKeever, 2000). These can be expectations that leave the next-of-kin in a position where they feel that they have no choice but to do what is expected of them. The responsibility brings with it both benefits and costs. There can be a need to balance feelings that concern the impending death, which can include grief, fear, and resignation, with those that are associated with life, for example efforts to retain the capacities within the loved one’s body and mind as long as possible, and to maintain hope and dignity. It is essential, according to Sand, Olsson and Strang (2010), to create and preserve meaning. However the responsibilities and expectations can lead to a considerable burden and distress (Funk et al. 2010; Stajduhar et al. 2010).

Next-of-kin’s experiences of challenges and burden in end-of-life care can involve intense, conflicting, negative and difficult emotions (Aoun, Kristjanson, Currow & Hudson, 2005; Arranda & Hayman-White, 2001; McCorkle & Pasacreta, 2001; Mok, Chan, Chan & Yeung, 2003). The experiences can also be manifested in the form of depression and mental ill health (Fromme, Drach & Toll, 2005; Redinbaugh, Baum, Tarbell & Arnold, 2003; Salmon, Kwak, Acquaviva, Brandt & Egan, 2005). In spite of these experiences there appears to be an ambition to maintain control over the situation and to be present and at hand 24 hours a day for the dying person being as time is limited (Boucher et al. 2010; Linderholm & Friedrichsen, 2010; Millberg & Strang, 2011; Munck, Fridlund & Mårtensson, 2008; Norris et al. 2007; Young, Rogers & Addington-Hall, 2008; Zapart, Kenny, Hall, Servis & Wiley, 2007).

The provision of support in order to secure that the loved one can die peacefully with dignity and respect is important (Boucher et al. 2010; Munck et al. 2008). The next-of-kin can feel a loss of control that can lead to feelings of inadequacy if professional assistance is
not obtainable when caring at home (Linderholm & Friedrichsen, 2010; Millberg & Strang, 2011; Millberg, Strang & Jakobsson, 2004; Norris et al. 2007). However the situation where the home is turned more and more into something that resembles a hospital, where health professionals are often present can be experienced as a security. On the other hand it can be experienced by both the dying person and the next-of-kin as being exposed and invaded. There can also be difficulties if the next-of-kin or the dying person and the health professionals do not agree on how the dying person should be taken care of or if they have problems communicating with each other (Borstrand & Berg, 2009; Jo, Brazil, Lohfeld & Willison, 2007).

The perspective of being next-of-kin in end-of-life care can thus be seen as a period where feelings of satisfaction and feelings of not being able to cope with the situation can be equally common (Andershed, 1998, 2004; Persson, 2008). It can be described as a balance between caregiving activities and disruptions while at the same time dealing with daily demands (Houldin, 2007). Several studies show how next-of-kin appraise the experiences of being close to and taking care of the loved one. It can be experienced as rewarding and meaningful and leave a sense of pride and selfesteem (Aoun, Kristjanson Hudson & Currow, 2005; Aranda & Hayman-White, 2001; Hudson, 2004; Jo et al. 2007; Koop & Strang, 2003; Kristjanson, Aoun & Yates, 2006; Mok, Chan, Chan & Yeung, 2002; Scott, Whyler & Grant, 2007; Stajduhar, 2003; Wolff, Dy, Frick & Kasper, 2007). Studies have also shown that the relationship between the next-of-kin and the dying person is of importance and that the dying person recognizes and appreciates the caregiving (Hudson, Aranda & McMurray, 2002; Stajduhar, Martin, Barwich & Fyles, 2008). The next-of-kin can experience closeness and trust and at the same time struggle with existential issues and suffering concerning why this is happening. Feelings of exposure and vulnerability are often present (Wallerstedt, 2012). However trusting relationships and a supportive network can contribute to security and an alleviation of vulnerability (Exley & Tyrer, 2005; Kristianson, Cousins & White, 2004; Stajduhar et al. 2008; Strang, Koop & Peden, 2002),
Grief is a part of the experience of being next-of-kin in end-of-life care and it can often be more stressful in the pre-loss period than after the death of the loved one. The preparatory grief can involve emotional stress, intense preoccupation with the loved one who is dying and a longing for her/his former personality. It can also result in loneliness, sadness, cognitive dysfunctions, irritability, anger and social withdrawal (Hudson, Thomas, Trauer, Remedios & Clarke, 2011; Johansson & Grimby, 2012). The next-of-kin often grieve in lonely isolation as s/he does not want to burden the loved one with her/his sorrow (Fisker & Strandmark, 2007). The grief can also involve a sense of helplessness and fear of what is going to happen (Gunnarsson & Öhlén, 2006). The next-of-kin can be in need of support to be able to cope with the end-of-life situation (Henriksson, 2012) and this support needs to start before the death of the loved one and continue into the bereavement period after the death. Support from members of the close family is preferable but if next-of-kin do not want to burden members of the family, support from health professionals can be required (Benkel, Wijk & Molander, 2009).

A desire to support the dying person and make the remaining time in life as comfortable as possible can create a meaningful participation. Andershed and Ternestedt (2001) describe how a meaningful participation can be facilitated if next-of-kin can have a say in how they want to be involved in the care. The choice is a freedom but at the same time a responsibility to make as good a choice as possible and if the time is limited the choice can be even harder to make. Values such as “honouring your mother and father” and “for better, for worse” as well as knowledge about goals in end-of-life care and a good death can also influence the importance of making a good choice. If the next-of-kin feels that s/he has made the wrong choice experiences of guilt and/or shame may occur.
Guilt and shame

Guilt and shame are phenomena associated with experiences of not being good enough. These experiences are inevitably linked to the self in relation to other people and are two of our most intimate and private feelings. Experiences of guilt and shame develop in our interpersonal experiences within the family and in other important relationships. From an early age and throughout life they influence our behaviour in interpersonal connections. This causes guilt and shame to be self-conscious since they involve an assessment of the self (Teroni & Deonna, 2008). Guilt and shame are also moral experiences being as they probably have a key role in the fostering of moral behavior (Tangney & Dearing, 2004). A person’s morality is linked to human conduct and the ability to separate what is right from what is wrong. The morality includes ethical principles concerning respect for the autonomy of others, refraining from doing harm to others, promoting welfare, and acting in the best interest of others (Beauchamp & Childress, 2009). Christianity has influenced the Western societies’ beliefs and attitudes towards both guilt and shame and the experiences can be referred to being under some sort of judgment (Katchadourian, 2010).

The distinction between the two concepts is complex and in many ways uncertain. Katchadourian (2010) demonstrates that there is a disagreement between researchers, some mean that guilt and shame are two aspects of the same emotion while others refer to them as being distinct from each other. Many studies have been performed into what the concepts of guilt and shame really mean and how they differ. Teroni and Deonna (2008) state that it is one of the most debated questions within literature in general and in particular in psychological literature. In everyday speech the concepts of guilt and shame are often linked together without any clear distinction. Tangney and Dearing (2004) have investigated how the two concepts differ and show that a distinction between them is not obvious. Even experts in psychological literature use the concepts inconsistently, alternating, or without making a distinction between
them (e.g. Harris, 1989; Potter-Efron, 1989; Schulman & Mekler, 1985).

Lewis (1995) maintains that both guilt and shame involve negative experiences as they evolve from an apprehension of moral sin. Guilt has a focus on behaviour and its influence on a victim and has possibilities of being more extrovert than shame. Kaufman (1996) states that there must be an ethical judgment of immorality added to a situation in order for it to produce guilt. Shame is instead more introvert since it holds a focus on the negative significance of the act and the act’s influence on the self (Lewis, 1995). Smith, Webster, Parrott and Eyre (2002) show that shame can be connected to the harm one’s reputation gets when a misdeed is made public. Shame has been described as a painful experience often followed by feelings of being belittled as well as feelings of being worthless and powerless. Shame is also connected to experiences of ignominy, discomfort, awkwardness, degradation, and humiliation (Gilbert, 2000; Hasui & Kitamura, 2004; Lehtinen, 1998; Sundström, 2004).

People who experience shame feel exposed and feel a desire to hide and disappear. In contrast guilt is seen as a less painful and devastating experience where the primary concern has to do with a special behaviour. Experiences of guilt include tenseness, regret, and remorse over what has or what has not been done. People experiencing guilt think about what they have done repeatedly and wish that they had acted differently or that they in some way could make what is done undone (Tangney & Dearing, 2004).

Since experiences of shame are attached to the self, these experiences can be deeper and more destructive than experiences of guilt. The shame makes the person ransack and doubt her/himself (Lewis, 1995). Tangney and Dearing (2004) mean that the person experiencing guilt is more focused on a specific behaviour or action while the person experiencing shame is influenced in a more destructive way when it comes to self-confidence, self image and self esteem. In comparison experiences of guilt can generate a bad conscience but not as destructive for a person’s self-confidence, self image, and self esteem. Blavier and Glenn (1995) maintain that the
difference between guilt and shame is the difference between doing and being (cf. Gilbert, 2000; Lehtinen, 1998).

Fontaine et al. (2006) list four different ways of looking at guilt and shame from a psychological perspective. The first amounts to guilt and shame being separated like an external and internal orientation. The guilt is characterized by a personal judgment that norms of behaviour have been transgressed, which is followed by remorse and brooding. Shame on the other hand is characterized by the experience of being exposed to a real or imagined public repudiation, which is followed by a tendency to want to hide or disappear. The second view is based on psychodynamic and anthropological concepts where guilt can be defined in terms of transgressed norms and obligations while shame is associated with feelings of not living up to one’s own norms and endeavours. In the third guilt and shame are separated by the focus on guilt being linked to a concrete act while shame is characterized by a negative focus on the self (cf. Blavier & Glenn, 1995; Smith et al. 2002; Tangney & Dearing, 2004; Teroni & Deonna, 2008). Furthermore guilt can be associated with a feeling of participation, to focus on the negative consequences in one’s behaviour and to try to put things right. On the other hand shame has a negative focus on the self which brings feelings of weakness and incompetence, which in turn can lead to defensive and aggressive reactions (cf. Lewis, 1995; Tangney & Dearing, 2004). The fourth view focuses solely on guilt, which is seen as a collectively oriented experience that leads to restitution of the balance with other people (Fontaine et al. 2006).

The aspect of moral behaviour in experiences of shame can be linked to Martinsen (2009) who presents a somewhat different and more positive view, based on the thoughts of Lögstrup (1956/2009). This view highlights the essential factors of being able to experience shame. Shame can be generated by transgression of social norms, both written and unwritten, and can leave a person with a sense of not being good enough. Experiences of shame are expressions of sensitivity for ethical borders or borders tied to integrity that therefore should not be transgressed. A person experiences shame when these borders are exceeded. Experiences of shame can thus be
seen as an ethical preparedness for circumstances that offend and destroy life (Martinsonen, 2009). Similar thoughts can also be found in Kaufman (1996); Lewis (1995); and Wiklund Gustin (2010). Wiklund Gustin (2010) terms this kind of shame “healthy shame”, which can be seen as a shame that is good to be able to experience since it sends out warnings that a person is about to offend someone or at risk of crossing ethical borders. She also presents the opposite; the “unhealthy shame”, a shame that does not derive from internal, genuine ethical ideals but instead is forced upon a person by other people, by false ideals or unattainable demands.

Next-of-kin’s experiences of guilt and shame in end-of-life care

As mentioned above next-of-kin in end-of-life care often have a desire to support the dying person. This desire comprises a wish to participate and make the remaining time as comfortable as possible. It can be important for the next-of-kin to create something meaningful within a situation that in many ways can be experienced as meaningless. To participate in the end-of-life care for the dying loved one means that the next-of-kin has to choose in which way this care is to be carried out (Andershed, 1998). According to Frankl (1987) anxiety can occur when having to make choices, an anxiety about whether the choice made is the wrong one. A limited amount of time, as can be the case in end-of-life care, also contributes to the choices possibly being harder to make as there might be no chance of compensating a wrongly made decision or of repairing mistakes. If a person feels that s/he has not fulfilled her/his obligations experiences of guilt and/or shame can arise.

Research about experiences of guilt and/or shame among next-of-kin in end-of-life care exists but it is difficult to find studies that focus on these experiences, being as they are often generally presented as instead being part of an overall description of what it is like to be next-of-kin in end-of-life care. The aspects of next-of-kin wanting to do good and to alleviate the loved one’s suffering and then feeling
that they have not succeeded can result in experiences of guilt (Millberg, Olsson, Jakobsson, Olsson & Friedrichsen, 2008). McGrath, Vun and McLeod (2001) describe how next-of-kin experience guilt for behaving negatively or angrily towards their loved one due to stress associated with the caregiving situation. Sand et al. (2010) show how next-of-kin can experience guilt and shame when they withdraw from things they consider being their responsibility. Similar findings can be seen in Bäckström and Sundin (2009), while in Morita et al. (2004); Namba et al. (2007); and Yamagishi et al. (2010) the next-of-kin spoke of their experiences of guilt when they id not know enough about treatment or did not understand the needs of the loved one. Greaves, Vojkovic, Nikoletti, White and Yuen (2008) show how next-of-kin to cancer patients with delirium experience a considerable burden in caring and in decision making which lead to experiences of guilt. The guilt has to do with a fear that the loved one may die with unresolved issues that have been impossible to discuss due to the delirium.

The literature review shows that there are difficulties finding studies that focus on experiences of guilt and shame and in particular the aspects concerning shame are difficult to find. The reason for this being the case may have something to do with shame being an experience that is linked to the self. This makes the person ransack her/himself in a destructive way (Lewis, 2000), and might lead to difficulties talking about and sharing these experiences.
RATIONALE FOR THE THESIS

Being a next-of-kin in end-of-life care can be a complex life situation. Standing face to face with dying and death can entail a sorrow that is difficult to cope with. Being aware that the time available is limited and that feelings of helplessness about how to be able to cope with the situation can be experienced. A desire to be present, supportive, and participatory in the care is common. Research shows how this situation can be experienced as rewarding and meaningful where the next-of-kin feels that s/he fulfills a duty and takes on responsibility. At the same time this responsibility can lead to the next-of-kin having to carry out an increasing amount of often complex care that s/he might not have been prepared for. To deal with physical and medical tasks, to be an emotional support for the loved one, to coordinate care, and to make decisions can be a challenge that is difficult to manage. If the next-of-kin has the possibility of choosing in what way s/he wants to be involved in the end-of-life care then this can facilitate her/his participation. However being able to make choices always entails the risk of making the wrong one. Experiences of guilt and/or shame may be the result of a wrongly made choice.

The next-of-kin’s experiences of guilt and shame have, to some extent, been described in the research concerning end-of-life care. It emerges that these experiences can lead to a considerable burden and distress. There appears, however, to be a lack of empirical studies that focus specifically on these experiences, and that elucidate what these experiences imply for the next-of-kin. Against
this background it is important that a more profound knowledge and understanding of the next-of-kin’s experiences of guilt and shame in end-of-life care is gained.
AIMS

The overall aim of the thesis was to explore and describe the concepts of guilt and shame and gain a greater understanding of the next-of-kin’s experiences of guilt and shame in end-of-life care.

Specific aims for the four studies

I. To explore and describe next-of-kin’s feelings of guilt and shame related to the dying person’s situation in end-of-life care.

II. To elucidate the meaning of and the distinction between the concepts of guilt and shame.

III. To gain a greater understanding of the experiences of guilt of the next-of-kin in end-of-life care.

IV. To gain a greater understanding of the experiences of shame of the next-of-kin in end-of-life care.
THEORETICAL PERSPECTIVES

This thesis has a theoretical perspective that emanates from caring science, which is an autonomous science that is not tied specifically to one profession. It has its foundation in the human needs derived from being a patient or a next-of-kin in a caring relationship. The aim is to strengthen and support health, a condition that can be characterized by well-being and the ability to fulfill projects in life (Dahlberg & Segesten, 2010). The human being is seen as a unit consisting of body, soul and spirit and the caring context is built on this holistic perspective. This perspective entails viewing a human being in her/his total context that also comprises the social network that surrounds her/him. It also presupposes an access and an understanding of the human being’s life world (Dahlberg & Segesten, 2010). In end-of-life care the next-of-kin is in a complex life situation and time is often limited, which can lead to the next-of-kin having difficulties fulfilling her/his obligations. Experiences of not having fulfilled obligations and of making wrong decisions are described as a possible cause of experiences of guilt and/or shame (Kaufman, 1996; Katchadourian, 2010; Lewis, 1995; Tangney & Dearing, 2004) A caring relationship is of importance here in order to be able to support the next-of-kin in her/his situation.

The holistic perspective of caring science entails an ethical demand (Dahlberg & Segesten, 2010). This demand is derived from the thoughts of the Danish philosopher Knud Lögstrup. Lögstrup (1956/2009) who maintains that trust is a fundamental conduct between people. Under normal circumstances we meet other people
with trust and it is only deceit that can suppress this trust. In the encounter one person can contribute to making the other person’s world safe by an attitude of open heartedness without judgment, protest or belittling her/him. The demand of taking care of the other person is a silent, unspoken demand that implies that you shall not violate the other’s dignity. The ethical demand is also radical which entails that no matter where it comes from, if it is a loved one, a stranger, or an enemy, the demand should still be followed. Lögstrup (1956/2009) furthermore poses that the ethical demand is unconditional, which in some way can be seen as limitless. There can be a danger in the limitlessness that might force the other person into doing something that s/he actually does not want to do by insisting that it is for her/his own good. This is something that is important to be aware of because the ethical demand thus empower and this power has to be handled in a proper way so that it does not harm the other who puts her/his trust in the person’s hands. Lögstrup (1956/2009) calls it interdependence, where we are each other’s world, and which makes us dependent on each other. It is important to be perceptive as to what is happening in the encounter, a perceptiveness that demands openness towards the other and towards the situation. If a person is guided by an ethical approach in accordance with Lögstrup (1956/2009) it entails being open but also at the same time respecting the other’s untouchable zone, i.e. integrity. This is in accordance with the ethical demand that the other silently expresses.

The thoughts of the Lithuanian philosopher Emmanuel Levinas have been a help in visualizing how the responsibility for the Other can be experienced. Levinas (1969/2011, 1985/2006) holds that the Other’s face, is the ethical demand to respond to and be responsible for. The Other’s face represents exposure, nakedness, and that which is the utmost vulnerable. Standing in front of the Other’s face creates a responsibility for the Other, a responsibility that is beyond will and consciousness. The Other creates this feeling of responsibility by her/his mere presence. According to Levinas (1969/2011) the Other in her/his otherness is someone who is to be respected. In the encounter the Other person exposes her/himself to the risk of being hurt or rejected. Levinas (1969/2011, 1998/2006) poses that ethics
lies in the encounter with the Other and we are responsible for each other in a timeless perspective. This ethic is founded on respect for the Other and for her/his otherness without attempts to reduce her/him. It also represents openness towards the Other, a courage to look into the Other’s face and stay close to her/him. The openness towards the Other as another person also involves making room for the Other and gives her/him space (Levinas, 1969/2011; 1998/2006).

Neither Lögstrup nor Levinas wrote specifically with caring science in mind but their thoughts about the responsibility for the other in an encounter can help explain and visualize the responsibility that the next-of-kin experience in end-of-life care for the dying loved one. The next-of-kin is exposed to the silent ethical demand when s/he stands in front of the Other. If the next-of-kin is in some way unable to fulfill the demand and the responsibility, then experiences of guilt and/or shame may occur.

Lögstrup’s ethical demand, and Levinas’ thoughts about the face, which actually represents the person and what that person is, can also be applicable in the encounter between the next-of-kin and the health professionals. The next-of-kin can be vulnerable in the end-of-life care. How s/he is treated in the encounter with the health professionals can have significance for how s/he copes with the situation of being next-of-kin in end-of-life care.
MATERIAL AND METHODS

In this section of the thesis the design of the studies and the pre-understanding of the researcher are presented as well as each study’s sampling procedure, data collection, and data analysis. The section also comprises ethical considerations. The text is presented under six headings:

- Design
- Pre-understanding
- Study I
- Study II
- Studies III and IV
- Ethical considerations

Design

In order to achieve the aims of the thesis a descriptive and interpretive design was used to both semantically examine the concepts of guilt and shame and to examine the experiences of guilt and shame from the perspective of the next-of-kin (see table 1). The objectives were to create an ontological understanding of the concepts and provide a basis for a theoretical, contextual and clinical understanding and development of them. Furthermore the objective was to gain a greater understanding of the next-of-kin’s experiences in order to provide knowledge of how and why these experiences occur. The starting point for the exploration of the phenomena of
guilt and shame from different angles was a qualitative secondary analysis of interviews with next-of-kin in end-of-life care following Thorne’s (1994) method. This was followed by a semantic analysis of the concepts of guilt and shame where Koort’s (1975) method, further developed by Eriksson (2010) was used. The result of these analyses formed a guide for the two subsequent empirical studies where the variations of the phenomena were further explored using hermeneutic analysis (Flemming, Gaidys & Robb, 2003; Gadamer, 1960/2006). A hermeneutic approach has been applied in the research and has guided the procedure throughout all the four studies.
Table 1. Overview of the four studies underpinning this thesis: main content, sample, method, data collection, and analysis.

<table>
<thead>
<tr>
<th>Study</th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main content</td>
<td>Next-of-kin’s feelings of guilt and shame in end of life care</td>
<td>Elucidation of meaning of and distinction between guilt and shame</td>
<td>Next-of-kin’s experiences of guilt in end-of-life care</td>
<td>Next-of-kin’s experiences of shame in end-of-life care</td>
</tr>
<tr>
<td>Sample (n=)</td>
<td>47 next-of-kin</td>
<td>10 Swedish dictionaries</td>
<td>17 next-of-kin</td>
<td>17 next-of-kin</td>
</tr>
<tr>
<td>Method</td>
<td>Secondary analysis</td>
<td>Semantic concept analysis</td>
<td>Hermeneutics</td>
<td>Hermeneutics</td>
</tr>
<tr>
<td>Data collection</td>
<td>Narrative interviews</td>
<td>Systematic search in dictionaries</td>
<td>Narrative interviews</td>
<td>Narrative interviews</td>
</tr>
<tr>
<td>Analysis</td>
<td>Secondary analysis with inductive interpretation</td>
<td>Etymological analysis and discrimination analysis</td>
<td>Hermeneutic analysis</td>
<td>Hermeneutic analysis</td>
</tr>
</tbody>
</table>

Pre-understanding

In studies involving a hermeneutic approach it is important to present the researcher’s pre-understanding. This can be seen as a historically affected awareness where history and culture shapes a person and how s/he understands the world (Gadamer 1960/2006, Ödman, 2007). My background is that I have worked as a registered nurse specialized in oncology and pain management for many years. I have encountered severely ill and dying persons and their next-of-kin in this setting. And I have met pain and sorrow but also happiness and hope. These situations have included talking to,
comforting, and crying with patients and their next-of-kin. These experiences have provided me with an understanding of what it is like to be severely ill and dying and what it is like to be next-of-kin to a severely ill or dying person. In the research group three of the four members have personal experience of working as nurses and researchers in palliative care.

**Study I**

Approximately 200 qualitative interviews were carried out in research programme “Caring in the end-of-life and other critical events” at Örebro University, Sweden, in collaboration with Ersta Sköndal University College, Sweden. The interviews were performed with next-of-kin of dying patients and with next-of-kin who had lost a loved one with the aim of exploring and describing the next-of-kin’s situation and involvement in end-of-life care. Many interviews contain rich narratives where the next-of-kin have shared her/his experiences in depth and can thus serve as data material for more studies than were initially intended. Approximately one fourth of these interviews were chosen (47) and included in the study. Of the informants 19 were males (7 husbands, 10 sons, 1 brother, 1 nephew) and 30 females (12 wives, 16 daughters, 1 sister, 1 friend). In two of the interviews two persons participated at the same time.

The 47 qualitative interviews were “auto-data”, which means material that exists within a research group. This can thus provide a deeper knowledge about and understanding of the context where the data was collected (Heaton, 2004). The interviews were characterized by an open attitude towards the next-of-kin who were encouraged to talk about their, and the loved one’s situation in end-of-life care. This open attitude created possibilities to search for experiences of guilt and/or shame which had not been the focus of the original studies.

A secondary analysis of qualitative interviews is used when researchers want to further investigate data material that has already
been used in previous studies. This is done in order to provide a new perspective of the original research question or to raise and explore new assumptions (Heaton, 2004; Hinds, Vogel & Clarke-Steffen, 1997; Thorne, 1994, 1998). The secondary analysis was carried out in order to achieve descriptions of phenomena that were related to next-of-kin’s experiences of guilt and shame and it provided opportunities to use parts of the interviews regarding the next-of-kin’s experiences that had not previously been analyzed. The previously transcribed interviews were reanalyzed using the secondary analysis method described by Thorne (1994). This approach consists of five sequences. The interview transcripts were re-read in order to gain an overall impression of the reasoning behind the next-of-kin’s experiences of guilt and shame. The whole interviews were used as a primary source. An open coding then took place, which involved reading the transcripts carefully and extracting contents and meaning related to the aim of the study. Situations describing next-of-kin’s experiences of guilt and shame were thus systematically searched for. Each incident and quotation that described experiences which could be interpreted as containing next-of-kin’s feelings of guilt and shame were written in to a matrix for each interview and interpreted and coded in relation to the entire interview. The codes were analyzed and compared for each interview as well as between the different interviews. Patterns concerning the next-of-kin’s experiences of guilt and shame were continuously searched for by going back and forth between the different sequences described above.

**Study II**

Study II is a semantic concept analysis of the concepts of guilt and shame and is based on a sample of dictionaries. These dictionaries are to cover as long a period as possible. A literature search was thus performed to try and cover the development of Swedish dictionaries from as far back in time as possible until the present time. The literature search provided 13 dictionaries in the initial phase. It was then important to distinguish between original dictionaries and
copies in order not to generate an incorrect calculation of the degree of synonymy. This was carried out with the assistance of a lexicologist. Ten dictionaries covering a period from 19th to 21st century, where the oldest dictionary includes data as far back as the 16th century, were subsequently included in the study.

In the analysis synonyms for the concepts of guilt and shame were collected from synonym dictionaries. Data about the concepts and their synonyms were then collected from the ten chosen Swedish dictionaries.

A semantic concept analysis according to Koort (1975) and further developed by Eriksson (2010) was performed. It entailed an analysis of the meaning of the linguistic expressions of the concepts guilt and shame taken from dictionaries. There are three main purposes in this kind of concept analysis: 1. To investigate and understand conceptual contents of meaning, 2. To discriminate between two close concepts. 3. To investigate how concepts in a family of concepts are related to each other. The semantic concept analysis helps to establish a concept’s ontological and contextual essence and further it can create a deeper understanding for and shaping of the concept which can contribute to caring science (Eriksson, 2010; Sivonen, Kasén & Eriksson 2010). The concept analysis consisted of two parts: an etymological analysis and a discrimination analysis. In the first analysis information about the concept was sought etymologically. In the discrimination analysis an investigation of how the concepts were related to their respective synonyms was carried out. The latter analysis comprises three phases: the matrix phase, where the synonyms of the concept were summarized using the chosen dictionaries, the paradigm phase, where a discrimination paradigm was created using the concepts and their respective synonyms and finally the interpretation phase, where an interpretation of the findings were performed and presented.
Studies III and IV

The data material in Studies III and IV derive from the same group of interviews where the participants were recruited from an oncological ward at a hospital in eastern Sweden. The inclusion criteria were that the presumed participant was noted as the closest next-of-kin to a patient who had died of cancer at the oncological ward, in their own home, or at an old people’s home during a three months period. The participant should also understand and speak the Swedish language. Seventeen next-of-kin to 15 patients agreed to participate, twelve were married/cohabiter and five were sons/daughters. In one interview the wife wanted her daughter to also participate and in another two daughters decided that they both wanted to participate. All the next-of-kin were Swedish citizens, three were males and 14 were females, age 21-86 (mean 58 years).

The data collection consisted of individual qualitative interviews with next-of-kin approximately three months after they had lost their loved one. The next-of-kin decided where the interview should take place and twelve took place in the homes of the next-of-kin and five at the office of the interviewer. The interviewer tried to maintain an openness and sensibility towards the next-of-kin’s narrative in order to follow her/his story. Questions that were used were open-ended in order to encourage the next-of-kin to further explore the issue of being next-of-kin in end-of-life care.

The interviewer began with the question: “Can you please tell me about your experiences of being next-of-kin in end-of-life care”. This was a way to allow the next-of-kin to talk about their general experiences of being next-of-kin in end-of-life care before a greater focus was put on experiences of guilt and shame. By maintaining an open mind towards the research phenomena a number of follow up questions were used in order to explore and gain a greater depth of the experiences of guilt and shame. The qualitative interview is, according to Kvale (2009), a suitable method for gathering data in hermeneutic research as it allows people to freely describe their world, actions, and opinions in their own words. Allowing the next-
of-kin to be part of the interview creates possibilities for her/him to emphasize what s/he finds important to talk about. The interviewer tried to be adaptable to the next-of-kin and conduct the interview in order to allow her/him to narrate her/his story in her/his own way. The interviews lasted between 50 minutes and two hours and were recorded and transcribed verbatim. The transcriptions of the interviews were made by the interviewer and took place as soon as possible after the interview. Non-verbal expressions, such as if the next-of-kin cried, laughed, raised her/his voice, or whispered were noted in the transcription.

The analysis of the data material in Studies III and IV was inspired by Gadamer’s thoughts on hermeneutic understanding (Gadamer 1960/2006). It is important to be flexible in the approach to the data material and what it says and also to have possibilities for incorporating one’s own experiences and knowledge. Gadamer (1960/2006) claims that it is only through one’s pre-understanding that understanding is possible. When using a hermeneutic approach it is important to be conscious of this pre-understanding when interpreting data material so that the pre-understanding does not take over and lead the researcher in a direction away from the data material. Instead the pre-understanding must work together with the data material to create a more profound understanding. Gadamer (1960/2006) speaks about a fusion of horizons, the history of the transcribed texts can be seen as one horizon and the pre-understanding of the researcher can be seen as another horizon. These two collaborate in order to gain a deeper understanding of the subject. In the analysis it was therefore important to acknowledge the pre-understanding of the researchers. One way was to encourage an open attitude towards data as well as to each other. The research group discussed and confirmed each other’s understanding.

The hermeneutics that Gadamer (1960/2006) has developed derives from his philosophical thoughts concerning how understanding is created. He describes a way to think derived from his philosophy of how hermeneutic thoughts develop. The analyses in Studies III and IV followed a Gadamerian-based approach further developed by Fleming et al. (2003) where gaining understanding through dialogue
with the text includes four phases and a movement between them. The analysis which is presented below was performed separately for experiences of guilt (Study III) and experiences of shame (Study IV).

First the whole data material was examined in order to gain a fundamental understanding of the meaning of the text as a whole. The text was read several times, sometimes separately and sometimes whilst listening to the recorded interviews. This is in accordance with what Gadamer (1960/2006) calls hermeneutic listening. It was seen as a starting point of the analysis and the understanding of the whole then influenced the understanding of the parts.

In the second phase every single sentence or section of the text was investigated in order to expose meaning of the experiences of guilt (Study III) and shame (Study IV). This investigation led to a more detailed understanding of the phenomenon in question. The interpretation of the experiences was then challenged by and in turn challenged the researchers’ pre-understanding. An example of ways to increase the understanding was using the semantic concept analysis (Study II) that helped capture the linguistic view and the meaning of the concepts of guilt and shame. This semantic understanding was helpful when it sometimes was difficult to interpret what guilt/shame was and what it was not. By allowing the meanings of guilt/shame to step forward in an interaction with the pre-understanding and the text it created a movement between the data and the semantic concept analysis back and forth. The semantic concept analysis thus worked as a magnifying glass that expanded the understanding.

The third phase consisted of allowing the parts of the text to be related back to the whole of the text and vice versa, which helped expanding the understanding of the phenomenon. This way of gaining new understanding and widening the horizons of understanding was performed several times. Ödman (2007) describes this movement as first having a vague idea about the whole of the text, this idea then undergoes a gradual change. When
the parts are given a clearer meaning, the understanding of the whole also becomes clearer. It is a difficult and time-consuming process where thoughts and interpretations need time to mature. Digressions, such as different interpretations, historical explanations, and comparisons are often needed in order to broaden the views and the understanding of the whole can thus become clearer. Gadamer (1960/2006) refers to this way of constructing meaning as the hermeneutic circle, a movement between the parts and the whole. This fusion of horizons creates new understanding. Ödman (2007) in agreement with Radnitzky (1970) maintain that the circle symbol might be a bit static and suggests that the process of pre-understanding and of interpretation instead should be compared to a spiral, the hermeneutic spiral.

The fourth phase involved efforts to ensure that the perspectives of the next-of-kin were seen as clearly as possible by allowing the voice of the next-of-kin to be heard in the presentation of the results.

**Ethical considerations**

The aim has been to perform the research in this thesis in accordance with the ethical principles of autonomy, beneficence, non-maleficence, and justice (Beauchamp & Childress, 2009). The thesis followed the Swedish Ethical Review Act’s regulations of ethics in research involving humans (SFS 2003:460) and the changes to this act (Regeringens proposition 2007/08:44). The principles for human clinical research in the guidelines of World Medical Association Declaration of Helsinki (2008) have also been considered. In three of the four studies in this thesis the next-of-kin to persons who had died from a cancer disease were asked to narrate their experiences of how they experienced the situation in end-of-life care. This situation was in many aspects both demanding and difficult. To interview persons under such circumstances can be difficult. It is therefore of utmost importance to show sensitivity and perceptiveness towards the next-of-kin’s reactions during the interview. Respect for the informant’s choices to tell or exclude parts of their experiences had
to be shown. It was thus important that the interviewer had professional experience of dialogues concerning personal and sensitive subjects, was well acquainted with crisis reactions, and was able to assess an individual’s defense system and personal strength. Being as the interviewer has had several years of experience in meeting next-of-kin in end-of-life care this pre-requisite can be said to have been fulfilled.

In an attempt to avoid harm being afflicted on the next-of-kin participating in the interviews safety measures were taken. All participating next-of-kin gave their consent to be interviewed. They were also informed that they could withdraw from being interviewed, take a break in the interview, or withdraw the recording when the interview was finished if they so wished. The next-of-kin also had, to some extent, influence on which issues were addressed in the interviews being as they narrated freely around the question of what it was like to be next-of-kin in end-of-life care. The next-of-kin were also informed that they could contact a social worker if they had questions they would like to discuss or if they experienced the interview as emotionally difficult. The next-of-kin were informed about this possibility during the first contact with the researcher; however none of the interviewed next-of-kin requested this contact.

There is an ethical dilemma when interviewing people about something difficult that they have experienced. It was thus important to consider what could generate the greatest good, i.e. not interviewing next-of-kin about their experiences or interviewing them. There is a risk in the interview situation that the informant can feel uncomfortable when s/he relives the experience. At the same time the research might have the potential to do good by adding knowledge about how next-of-kin experience their situation, in this case guilt and shame. This knowledge can be valuable in teaching and clinical settings within the caring context. After the interview was finished the interviewer was often told by the informants that s/he was nervous and a bit afraid of what the interview might bring forward. When the interview was finished, however, s/he felt good talking about her/his situation and how feelings of guilt and/or shame were experienced. S/he also felt good about sharing the
experiences and hopefully contributing to help and support others going through similar situations. Some informants also felt that telling their story was a way of processing what they had been through.

Ethical approval for Study I was obtained from the Research Ethic Committee at Örebro hospital, Sweden and from the Regional Ethical Review Board in Uppsala, Sweden (Dnr: 854/91, 793/01, 208/03). Ethical approval for Studies III and IV were obtained from Regional Ethical Review Board in Stockholm, Sweden (Dnr: 2008/1223-31).

In Study II the aim has been to follow the method of Koort’s (1975) semantic concept analysis and also give consideration to the further development of the method by Eriksson (2010). In accordance with Sivonen et al. (2010) thoughts about ethics in semantic concept analysis the following considerations have been taken: in the analysis conscious efforts have been made to enter a reflective process, to argue the pros and cons and show what the choices made are based upon. In the selection of dictionaries the objective has been to try and reach as broad a source of material as possible in order to avoid a perspective that is too narrow and that might influence the findings.
FINDINGS

In this section of the thesis the results from the studies are presented. The text is presented under two headings:

- Next-of-kin’s experiences of guilt in end-of-life care (Studies I, II, and III)
- Next-of-kin’s experiences of shame in end-of-life care (Studies I, II, and IV)

Next-of-kin’s experiences of guilt in end-of-life care (Studies I, II, and III)

The results in the three studies (I, II, and III) have contributed to a more profound understanding of the next-of-kin’s experiences of guilt in end-of-life care. The knowledge has developed from an open and broad search for experiences of guilt in Study I, via the semantic concept analysis that provided tools for recognizing and gaining a greater understanding of the concept guilt. Finally the knowledge from Studies I and II can be seen as part of a pre-understanding that has been useful in the hermeneutic analysis in Study III. The knowledge presented possibilities for challenging and being challenged in the interpretation of the data material with the aim of seeing what experiences of guilt can be.

It is evident both in earlier research and in Studies I and III that the next-of-kin consider it to be important to be there for the loved one
and support her/him during end-of-life care. There is a commitment and a desire to make the remaining time for the loved one as good as possible. This commitment can be seen as a moral responsibility and/or as an act of love. These are two aspects that can coincide in the commitment and take varying amount of space. There appears to be a core theme in that there is no alternative way than to follow the dying person on her/his last journey. The moral responsibility and/or act of love appear to be the foundation from which the situation evolves. The responsibility seems to involve a varying degree of voluntariness for the next-of-kin whose actions can be seen as either being closer to or further from an act of love. Even when there appears to be no act of love in what the next-of-kin does, the moral responsibility still demands that the next-of-kin acts in a certain way. If the next-of-kin feels that s/he has acted in a correct way under the given circumstances then s/he can find strength in that feeling. It can be of help to know that “I did the best I could”. It thus appears that it is the situation, how it evolves, and how the next-of-kin copes with that situation that forms the experience and determines whether or not experiences of guilt arise.

When, for some reason or other, the commitment cannot be accomplished there is a risk that the next-of-kin experience guilt. In Study I it is shown that having several commitments can lead to a bad conscience whatever the next-of-kin do. Another aspect of guilt can arise when the next-of-kin and the loved one have not talked sufficiently to each other about important things. Furthermore the analysis shows that not having been together during important events can generate guilt. In this situation the next-of-kin can have a bad conscience for not being with the loved one during these events, such as when the loved one is given a prognosis or when s/he dies. Not having done the right things is also an aspect of guilt where the next-of-kin grieve afterwards and feel worried that perhaps they have not acted correctly when they tried to support the ill and dying loved one. These four aspects are interpreted as contributors to experiences of guilt and are presented in figure 1.
It has been shown in research that it can be difficult to separate the two concepts of guilt and shame (Katchadourian, 2010; Tangney & Dearing, 2004; Teroni & Deonna, 2008), a way to establish the differences has thus been to perform a semantic concept analysis (Study II). This analysis reveals dimensions of meaning for guilt to be: *loan*, *being the cause of*, and *sin*. The meaning *loan* has in the further analysis been excluded based on the aim of the study and the perspective of next-of-kin in end-of-life care being as *loan* is connected with guilt in a monetary context. The two remaining dimensions of meaning, *being the cause of* and *sin*, have contributed to a general view of what the concept guilt means. Furthermore it was found that they were difficult to distinguish from each other. Based on a lexical description, the synonyms for the concept guilt can be applicable to both these meanings. This means that *being the cause of* and *sin* are closely connected with each other even though they do not mean the same. The synonyms of the concept contributed to a further development of the understanding of what
guilt means. In the analysis the synonyms with at least a 50 % degree of synonymy were used to form a discrimination paradigm. These synonyms are: Guilty (Skyldig), Fault (noun) /Wrong (adjective) (Fel), Blame (noun) (Förskyllan), Liability (Förbindelse), Being the cause of (Förvållande), and Blame (verb) (Skylla). The synonyms are also more or less related to each other, which can explain why the two dimensions of meaning of the concept, being the cause of and sin, are difficult to separate. In figure 2 a discrimination paradigm of the concept of guilt is presented. In the figure there are links in the form of arrows that show how some of the synonyms are connected to each other and also if these connections go both ways or in just one direction.
Figure 2. Discrimination paradigm for the concept of guilt. The numbers present degrees of synonymy in per cent. Links are illustrated by arrows and show if the link goes both ways or just in one direction. Bold arrows: link concept – synonym, broken arrows link synonym – synonym.
A further step in the analysis was to investigate the explanations of the synonyms in the chosen dictionaries. This was carried out in order to increase the understanding of the concept of guilt. The concept, its synonyms and the explanations of the synonyms have provided a foundation that has been of use in understanding what experiences of guilt can concern. This is something that has been of great value in the analysis of the data material in Study III. It has not always been the case that the next-of-kin use the actual word guilt in their narratives. The more profound understanding of what the concept guilt implies has thus been useful in the interpretation. It is also demonstrated in Study III that experiences of guilt concern what a person has done and how this influences the other.

In Study III experiences of guilt are interpreted as emanating from *not having fulfilled a commitment*, from *an omission*, and *being the cause of something*. It can be difficult to make distinctions between these experiences, as they sometimes exist independently from each other and sometimes they appear to depend on each other. For example the next-of-kin can experience that s/he does not fulfill a commitment due to neglecting the dying person or that s/he can be the cause of something that in turn is experienced as an omission. How committed the next-of-kin is also influences how s/he feels when s/he does not fulfill her/his commitments. However the experience of guilt concerns an act that the next-of-kin carefully looks at and assesses. S/he then experiences a burden of guilt and the weight of that burden is a consequence of the verdict.

Figure 3 is an attempt to illustrate how the aspects found in Studies I, II, and III can contribute to how next-of-kin experience guilt in end-of-life care. The situation involves a commitment and this commitment can be based on a moral responsibility and/or an act of love. What is or what is not done in the situation can then give rise to guilt. The different experiences of guilt in study III; *not fulfilling a commitment, omission, and being the cause of* can all be found in the four aspects of guilt in study I. For example *not having done enough* can involve experiences of *not fulfilling a commitment*, of an *omission*, as well as *being the cause of*. The same can be said for the
other three aspects. In Study III the quotes from next-of-kin can also be seen as a further elucidation and clarification of the aspects in Study I. The results in Studies I, II, and III can thus be linked together as a way of increasing our understanding of what experiences of guilt can really mean.
Figure 3. An illustration of aspects contributing to next-of-kin’s experiences of guilt in end-of-life care.
Next-of-kin’s experiences of shame in end-of-life care (Studies I, II, and IV)

In order to make the understanding of the experiences of shame of the next-of-kin in the context of end-of-life care more profound the results from the three Studies (I, II, and IV) have been processed together. A broad open search for experiences of shame in Study I was combined with the semantic analysis of the concept of shame in Study II where synonyms and dimensions of meaning of the concept were presented. Both these results were then useful in the interpretation of the interviews in Study IV as a way of expanding the understanding.

It is evident that a desire to make the remaining time as good as possible for the loved one is a starting point for the next-of-kin in end-of-life care, as was seen for the experiences of guilt. This desire can be linked to a perception of how the remaining time together with the dying person should be, a perception that is guided by morality and human conduct about what is right and wrong. When a next-of-kin for some reason is unable to live up to that perception it leaves her/him with feelings of not being good enough. The experience seems to concern being exposed in the next-of-kin’s own eyes or in front of someone else who sees her/his shortcomings. Experiences of shame can evolve in these situations.

In Study I it is shown that feelings of inferiority and powerlessness developed from experiences of not being taken seriously, of not being listened to, or of not being respected, can lead to experiences of shame. The next-of-kin can also experience shame on behalf of the dying person if the latter is exposed to humiliation or degrading situations. Another aspect of shame is when family conflicts are elucidated. These three aspects are interpreted as contributors to experiences of shame and are presented in figure 4.
Figure 4. Aspects contributing to next-of-kin’s experiences of shame in end-of-life care in study 1.

A semantic concept analysis (Study II) was performed in order to gain greater knowledge of the concept of shame. This analysis showed that dimensions of meaning for the concept shame are *something that gives rise to shame, ability to experience shame*, and *the devil*. In the further analysis the meaning *the devil* has been excluded based on the study’s perspective of next-of-kin in end-of-life care and being as shame in this meaning is a direct paraphrasing of the word devil and therefore not applicable. The two remaining dimensions of meaning: *something that gives rise to shame,* and *ability to experience shame* provide an insight into in which way the concept can be considered. The synonyms for the concept of shame with at least a 50% degree of synonymy can also be distinguished with these dimensions of meaning. The synonyms for *something that gives rise to shame* are Ignominy/Disgrace (Nesa), Dishonour/Disrepute (Vanheder), Disgrace (vanära), Ignominy/Humiliation (Smälek), and Shamefulness (Skamlighet).
The synonyms for *ability to experience shame* are *Shame* (Blygsel), and *Sense of shame* (Hut). The synonyms are also more or less related to each other for each of the dimensions of meaning. In figure 5 a discrimination paradigm of the concept shame is presented. In the figure there are links in the form of arrows that show how synonyms for each dimension of meaning are connected and also if these connections go both ways or in just one direction.
**Figure 5.** Discrimination paradigm for the concept shame. The numbers present degrees of synonymy in per cent. Links are illustrated by arrows and show if the link goes both ways or just in one direction. Bold arrows: link concept – synonym, broken arrows: link synonym – synonym.
In order to further the understanding of the concept of shame the next step in the analysis was to examine how the synonyms are explained in the chosen dictionaries. This way of gathering information by investigating the concept, its synonyms and the explanations of the synonyms has generated knowledge that provides a greater understanding of what the concept of shame implies. This has been of great importance in Study IV in terms of the analysis of the data material. As previously mentioned where the experiences of guilt were concerned, it is not always that the next-of-kin actually use the word shame in their narratives. Having synonyms and explanations of these synonyms has thus been of great help in the analysis of the narratives. In a shameful situation the interpretation of the findings shows that shame is focused on the person’s self and the influence that what has happened has had on the person.

Experiences of shame can develop both in situations that the next-of-kin actually has caused her/himself but also in situations that are beyond the control of the next-of-kin. It is shown in Study IV that many of the experiences that the next-of-kin speak of concern themselves being put in difficult situations where experiences of shame occur. At the same time they are unable to do anything about these situations because it is other people who have put them there. The experiences appear to be unjust and interpreted as some kind of unfair treatment, and consequently the experience of shame also appears to be unfair. One example is when health professionals or other relatives ignore the next-of-kin, do not listen to her/him, do not answer questions, or promise one thing and then do something else. This kind of shame leaves a feeling that there is no way to justify what has been done as the judgment has already been given.

Experiences of shame are interpreted as *ignominy, humiliation, disgrace*, and second order shame in Study IV. Ignominy for the next-of-kin entails them feeling ashamed, worthless and powerless, and not worth listening to. The ignominy can be seen both in situations that are caused by the next-of-kin her/himself but also in situations where someone else has put the next-of-kin in a shameful situation. This kind of shame can be seen as a somewhat milder form
of humiliation, based on the results from Study II. Experiences of humiliation can include scorn and indignity emanating from other persons. Ignominy might occur without any intention to do harm but humiliation, however, can be caused by a deliberate desire to hurt. If the humiliation is an intentional act the next-of-kin has problems justifying what has happened and cannot expect to be listened to. Humiliation also puts the next-of-kin in a shameful situation that is often seen by others.

Another aspect of shame that is found in Study IV is disgrace, where the next-of-kin find themselves in situations where they feel inferior, where they feel that other persons are looking down on them and do not consider them to be worth listening to. Situations concerning shame on behalf of the dying person can be seen both in Studies I and IV. The dying person can be in degrading situations where her/his dignity is violated and s/he can be more exposed than necessary. S/he might not be conscious of the situation and the next-of-kin can instead experience shame, a so called second order shame. This aspect of shame can also occur when health professionals act in a shameful way without being aware of it, and instead the next-of-kin takes over their shame as being her/his own. The experiences of shame in the examples referred to above concern the reactions of the next-of-kin within her/himself to the situations that they are exposed to and do not concern what has actually happened.

Figure 6 is an attempt to illustrate how the aspects found in Studies I, II, and IV can contribute to how next-of-kin experience shame in end-of-life care. Something occurs that gives rise to the shame and the next-of-kin can be contributors to this, while it can also be another person who contributes to the experience. Examples of what this shame can involve are demonstrated in Studies I and IV. The findings provide an insight into how the next-of-kin her/himself experiences the situation. The aspect of Feelings of shame on behalf of the dying person from Study I have developed into second order shame in Study IV being as health professionals and the way they perform their work can also cause the next-of-kin to take over their shame as being her/his own. The aspect: Family conflicts being
elucidated is only found in Study I but is also an important aspect of the shame experiences of next-of-kin. The quotations used in Studies I and IV are a way to make the next-of-kin’s experiences even more visible.
In study I

**Inferiority and powerlessness**  
**Shame on behalf of the dying person**  
**Family conflicts being elucidated**

In study IV

**Ignominy**  
**Humiliation**  
**Disgrace**  
**Second order shame**

**Figure 6.** An illustration of aspects contributing to next-of-kin’s experiences of shame in end-of-life care.
DISCUSSION

In this section of the thesis a discussion of the methods and the findings in the different studies are presented as well as a conclusion of the thesis. The text is presented under three headings:

- Methodological considerations
- Discussion of findings
- Conclusion

Methodological considerations

Secondary analysis

The starting point in this thesis was a secondary analysis of interviews with next-of-kin who had narrated their experiences of being with their loved ones in end-of-life care. In Study I the research group used these existing data that had been collected for previous studies in order to learn more about experiences of guilt and shame in end-of-life care. This means that the data constitute so called auto-data, i.e. data that have been gathered within a research group that the researchers in Study I are involved in. The analysis is performed by the same researcher or research group that originally collected the data. The use of auto-data can be seen as less problematic than if data is derived from another researcher or research group. Heaton (2004), and West and Oldfather (1995)
maintain that researchers have an advantage when analyzing their own data. They have a more profound knowledge of the context in which the data are gathered, and they also have a level of understanding of the background that is not available for those who use data collected by others. On the other hand different members of a research team can have different knowledge of the data. It can thus be argued that if a researcher is involved in the primary research it does not automatically mean that s/he has an advantage when carrying out a secondary analysis (Heaton, 1998, 2004). It was considered in Study I that there was an advantage in having a deeper knowledge about the gathered data and the end-of-life context as a way to gain a deeper grasp the meaning.

There are some key issues that are important to consider when considering principles of conducting a secondary analysis (Heaton, 1998, 2004, Thorne, 1994). Two of these issues are particularly relevant for the present study. The first concerns compatibility of the data for a secondary analysis and involves whether or not the primary data are suitable for a secondary analysis. The data material on which Study I is based has been well suited for a secondary analysis being as the interviews have been about experiences of being next-of-kin in end-of-life care. The move from that broad perspective to a narrower one where the focus is put on specific experiences of guilt and/or shame was thus not difficult to carry out.

The second concerns the ethical issue of how consent was obtained in the primary study as it is generally not feasible to seek additional consent from the participants. The aim in the primary studies was to learn about next-of-kin’s experiences of being next-of-kin in end-of-life care. This aim has not been altered in the secondary analysis even though a specific focus has been applied in order to seek knowledge about guilt and shame.
Semantic concept analysis

The second step in this thesis was to establish the semantic meanings of the two concepts of guilt and shame, in order to gain a deeper understanding of the concepts and create a deeper insight into how to encounter the experiences of guilt and shame. The semantic concept analysis was also a way of helping to distinguish between the two concepts and avoid confusion or conflict of ideas.

When performing a semantic concept analysis the degree of synonymy illustrates in figures the relationship between the concept and its synonyms. An important consideration in this type of analysis concerns where the cut-off point for the degree of synonymy is to be made. Two aspects need to be considered: using synonyms with a degree of synonymy lower than 50% can be questionable in terms of their relevance. If all the synonyms were to be included (35 for guilt and 31 for shame) the meaning of each concept would risk becoming too vague and diffuse, and the distinction between different dimensions of meaning could be lost. On the other hand synonyms with a degree of synonymy lower than 50% can constitute a nuance of meaning that can be of importance for the understanding of the concept. The decision was made, however, in Study II to follow Koort’s (1975) outlines and only use synonyms with a degree of synonymy of at least 50%, in order to maintain the meaning of the concept as distinct as possible. This choice was also a help in the coming interpretation of interviews in Studies III and IV.

The dictionaries used in the analysis were sought with the ambition of providing dictionaries with as wide a scope as possible. According to Koort (1975) the dictionaries should be published with approximately ten year intervals in order to provide a picture of the concept’s development over time. It has not been possible to fully comply with this aim. For example, no dictionaries from the time around the First and Second World Wars have been found. There were also some difficulties in distinguishing which dictionaries were original works and which were copies. The content of a dictionary which is a copy of a previously released one has not been subjected
to the same accurate process of definition as is the case for an original work. In the latter the authors work independently with a definition of each concept that reflects the contemporary use of language. There is a risk that the number of bindings between the concept and the synonyms will be incorrect, when including dictionaries that are copies together with original dictionaries. An incorrect calculation of the degrees of synonymy can thus be generated and the connections between the concept and its synonyms will then be incorrect as a consequence. Help was requested, as previously mentioned, from a linguistic researcher and lexicologist in order to apply a critical view to the sources of data and to distinguish the original dictionaries from copies.

A semantic concept analysis presents an understanding of a concept’s meaning and should preferably be carried out in the native language of the researcher (Sivonen et al. 2010). The concepts of guilt and shame are, however, seen as feelings that are part of being human in a global perspective. Experiences of guilt and shame are present in palliative care and as the palliative philosophy is global, the knowledge deriving from the analysis was considered to be of wider common interest. The decision was therefore made to present the results in the English language in order to reach as many readers as possible. It was a difficult task to translate the conceptual meaning into English and great efforts have been made to find the English words that correspond closest to the meaning contents of the original Swedish words. This procedure sometimes resulted in translations containing more than one word being as there was no one specific word in English that corresponded directly with the Swedish word.

The hermeneutic understanding

In Studies III and IV the analysis was inspired by Gadamer’s thoughts on hermeneutic understanding (Gadamer 1960/2006). It is thus important to discuss the pre-understanding of the researcher being as the pre-understanding in many ways influences how a person understands and sees the world (Gadamer 1960/2006,
Ödman, 2007). The research group’s insights into palliative care and research concerning palliative care have been of importance being as it has provided a profound insight into the situation of the next-of-kin. This knowledge has also been something to be aware of in the interpretation of the data material as there is a potential threat that the pre-understanding dominates the understanding and diverts the researcher away from the data material. The pre-understanding has been tempered by maintaining a conscious and open-minded attitude towards the data material and analysis. Having only a few expectations about the exact findings and instead maintaining an open mind and curiosity towards the experiences of guilt and/or shame has been a way, as Dahlberg and Dahlberg (2003, p. 45) express it: “to not make definite what is indefinite” until a reflective view of experiences of guilt and/or shame emerge. During the analysis the research group also has had profound discussions about the emerging findings in order to challenge and reflect upon the pre-understanding. The aim has been to follow Gadamer’s (1960/2006) thoughts and create a fusion of horizons where the data material and the pre-understanding of the researcher’s work together to create a deeper understanding of the phenomenon of guilt and shame.

**Trustworthiness**

This thesis is mainly built on qualitative studies (Studies I, III, and IV), which has been considered the best way to capture human experiences being as qualitative research is based on the assumption that knowledge about humans cannot be accomplished without describing human experience as it is lived and defined by people themselves (Polit & Tatano Beck, 2009). It was therefore important to encourage the next-of-kin to narrate their stories about what it was like to be in the end-of-life care situation so that possible experiences of guilt and shame could emerge. Listening to the whole narratives also provided possibilities to see these experiences in their context and pose questions when considered necessary. In order to discuss the trustworthiness of the findings, Lincoln and Guba’s (1985) four actions: credibility, transferability, dependability, and conformability, have been used.
A way to establish *credibility* is to use suitable methods to achieve the declared aims of the research (Lincoln & Guba, 1985; Shenton, 2004). The choice was thus made to interview the next-of-kin being as the research in this thesis concerns the next-of-kin’s experiences of guilt and shame in end-of-life care. Open-ended questions were used in the interviews where the next-of-kin were encouraged to talk freely about their experiences as a way to try and capture the true experiences (Studies III, and IV). There can, however, be questions about differences in the next-of-kin’s experiences of guilt and/or shame and the stories they tell about the meaning they attach to these experiences. On the other hand Polkinghorne (2007) argues that “The storied descriptions people give about the meaning they attribute to life events is, I believe, the best evidence available to research about the realm of people’s experiences” (Polkinghorne, 2007 p. 479). An attempt has therefore been made to return to the next-of-kin’s experiences during the interviews several times in order to let them talk about them from different angles. It is, however, impossible as a researcher to ensure that the experiences have been fully grasped. It is always the next-of-kin’s choice to what extent they want to share their experiences. Inspired by Gadamer’s (1960/2006) views on hermeneutics it has been important to show how the researcher relates to the pre-understanding as part of the interpretation of the data material. The pre-understanding has been recognized by letting the whole research team take part, discuss and question the analysis and results through the whole process. This has included going back and forth between the different phases of the analysis. Furthermore the studies have been critically examined during seminars with researchers within the palliative research field. It has also been important for the trustworthiness to let the next-of-kin’s real voices be heard. The recorded interviews were transcribed verbatim and listened to several times with the aim of grasping the “spirit of the original words” (Gadamer, 1960/2006, p. 386). The use of quotations has also been a way to allow the voice of the next-of-kin to be heard.

In Study I the results are built on data material that is derived from an earlier study where the purpose was to capture the next-of-kin’s experiences of being next-of-kin in end-of-life care. The data
material consisted of transcribed interviews where the next-of-kin willingly shared their own personal experiences. Specific questions regarding experiences of guilt and/or shame were not asked in these interviews. It can thus be questioned if the data material can generate results that can be interpreted as experiences of guilt and/or shame. However, by describing the process of the analysis as carefully as possible the aim has been to make it transparent to the reader in order to increase trustworthiness.

One assumption is that the experiences of guilt and shame can be transferable to other difficult caring situations where next-of-kin are involved. Transferability is, however, difficult to accomplish in a qualitative study being as the results must be viewed and understood within the context and geographical area in which the study has been carried out (Shenton, 2004). It has therefore been important to describe the informants in each study, the inclusion criteria, the data collection methods, the number and length of data collection sessions, and the time period over which the data was collected. This information provides the readers with the possibility of determining themselves how far they can be confident in transferring the results of the studies to other situations.

Dependability is closely tied to credibility (Lincoln & Guba, 1985), and giving an accurate presentation of the credibility has been a way to partly ensure the dependability. Furthermore dependability has been sought by using the same open ended initial question in Studies III and IV in the interviews. It has also been the same interviewer who has performed and transcribed all the interviews.

Measures were taken in the research group with the aim of being open-minded and trying to set aside possible preconceived notions about the data material. This included being aware of, discussing and seeing the potential in each research group member’s pre-understanding. This was a way of attempting to ensure confirmability and to show that the findings in the research were as far as possible results of the experiences and ideas of the informants and not the characteristics and preferences of the researchers. Furthermore attempting to ensure confirmability also included using
quotations from the informants as a way of visualizing the experiences of guilt and shame, and to return to the next-of-kin and their stories in order to confirm the findings.

In Study II the aim has been to as accurately as possible describe the semantic analysis with the choices made concerning dictionaries, synonyms, numbers of bindings to the concept, dimensions of meaning, and degree of synonymy. This has been a way to provide the reader with possibilities of developing a profound understanding of the method used in the study and how this method works.

**Discussion of findings**

The overall aim of this thesis has been to explore, and describe the concepts of guilt and shame and gain a greater understanding of next-of-kin’s experiences of guilt and shame in end-of-life care. It has been possible to achieve this aim by studying these experiences with qualitative methodological approaches that involve allowing the next-of-kin to narrate their experiences in their own words.

The results show that next-of-kin experience both guilt and shame in end-of-life care and how these experiences can leave the next-of-kin in a vulnerable state. The experiences have a starting point for the next-of-kin in a perception of how the remaining time together with the loved one should be. This perception can be linked to how the next-of-kin in end-of-life care often take on an increasing amount of care for the dying loved one. The findings in the thesis show how this responsibility can be something that the next-of-kin accept being as there is a wish to be present for the dying loved one and to make good use of the time that is left together. Earlier research also shows how this commitment can bring satisfaction where the next-of-kin appreciate the experiences of being able to be close to and take care of the loved one (Andershed, 2006). The perception seems to create a commitment that is guided by the next-of-kin’s morality, a morality that refers to human conduct and what is right or wrong to do. A way of understanding this sense of morality is by considering
the ethical principles that Beauchamp and Childress (2009) present. These principles involve respecting the autonomy of others and refraining from harming them, promoting welfare and acting in their best interests. The thoughts of Lögstrup’s (1956/2009) about the ethical demand and what that entails can also be brought into consideration here. These principles contribute to how the next-of-kin sees that s/he should act in the encounter with the loved one. The commitment can also involve an aspect of love and the findings in the thesis show how both the moral aspect and the aspect of love interplay in how the next-of-kin act. A question to pose is whether it is possible to feel the commitment if there is no love in the situation? It is shown in the findings of this thesis that this is possible, and that there can be a commitment built solely on moral obligations when there seems to be no affectionate feelings for the dying person. A possible way of understanding this commitment is to use the words of the Australian philosopher John Finnis (2011): “… there are things within our power either to do or not to do which (whatever we desire) we have to do (but not because we are forced to), or must do, which is our duty to do, which it is wrong not to do, or shameful not to, which one morally (or legally) ought to do …” (Finnis, 2011 p. 297).

The responsibility that the next-of-kin experience can also put them in situations where they feel that they cannot live up to what they consider being their obligations or what others expect of them in the end-of-life situation. As mentioned above the next-of-kin often have a view of how the remaining time together with the loved one should be. When this image is broken the next-of-kin is left in a vulnerable state where feelings of inadequacy and of having acted in a wrong way can contribute to experiences of guilt and/or shame.

**The concepts of guilt and shame**

The semantic concept analysis (Study II) confirms the findings of Blavier and Glenn (1995), who maintain that the synonyms for the concept of guilt, e.g. *being the cause of* according to the findings are linked with a “doing” and the synonyms for the concept shame, e.g.
disgrace according to the results are linked with a “being”. It is also evident that none of the synonyms for the two concepts overlap each other. Blavier and Glenn (1995) maintain that guilt is related to the responsibility a person feels for her/his actions and shame is related to the person’s doubt in her/himself which is demonstrated in the findings from Studies I, III, and IV. Experiences of guilt are focused on the next-of-kin’s behaviour and how this behaviour influences the dying person. It is not the person her/himself who is put in focus but what this person has done (c.f. Tangney & Dearing, 2004). The experience of guilt thus refers to something external. On the other hand the experience of shame refers to something internal being as the next-of-kin often hide such experiences deep inside.

**Experiences of guilt in end-of-life care**

In situations where experiences of guilt are generated the next-of-kin’s commitment to the dying person has for some reason not been completed to the next-of-kin’s satisfaction. When the result of this becomes evident to her/him then a sense of morality affects her/him and takes the role of being a judge. One problem appears to be that it is not always that the next-of-kin has a possibility to choose what seems to be the right choice, sometimes there appears not to be any alternatives but still the next-of-kin can consider the choice to be the wrong one thus creating experiences of guilt. It can sometimes be easy to see, when looking back and having a complete picture, that the choice made was the wrong one but in the moment the next-of-kin was forced to make a decision without all the facts available.

The results in the studies (I, II and III) show that experiences of guilt can be acts of not fulfilling a commitment, of omission, and of being the cause of. In the analysis omission and being the cause of have sometimes been difficult to separate from each other. One possible explanation is twofold: both omission and being the cause of can be linked with the synonym fault/wrong and thus have similar meanings. However, being the cause of may semantically have a greater influence on (in this case) the dying person being as it also can be tied to the synonym blame. The experiences of omission and
of *being the cause of* can also coincide in that *omission* can *be the cause of* something, and the next-of-kin through her/his decisions and actions can cause the dying person something harmful. Examples of this from Study III are when the next-of-kin causes the dying person harm by not saying no to an unsuitable transportation or by not letting the dying person stay at home even though he desires this. Singular events such as these mentioned above or missing the death of a loved one can despite having cared for the loved one leads to doubts of the value of what the next-of-kin did for the person during the whole period of illness, which Stajduhar et al. (2010) have also shown. The decisions that are made can be a burden of guilt that follows the next-of-kin even after the death of the loved one. The next-of-kin wants the remaining time to be as good as possible and when negative incidents occur it can become a double burden. On the one hand s/he has done something wrong and on the other hand this wrongdoing has caused suffering to the one s/he cares about.

In the literature search for this thesis and in the results of the studies, experiences of guilt have not been found as painful and devastating as experiences of shame. Tangney and Dearing (2004) suggest that it might have to do with the primary concern in experiences of guilt having to do with a special behaviour. The person thinks about what has happened over and over again and wish that they had acted differently.

**Experiences of shame in end of life care**

Experiences of shame have been found to be more complex than experiences of guilt both in the literature search as well as in the findings in all four studies. In experiences of shame in end-of-life care the next-of-kin feels exposed and not able to live up to perceptions of how s/he should be in her/his own eyes or in the eyes of others. When a loved one is dying there are often many actors involved in the situation. Next-of-kin and other relatives, friends, and health professionals can be part of the caring and have opinions about how it should be performed. The next-of-kin is often
vulnerable in these situations and even if s/he tries her/his best there are still doubts that it is good enough. In the exposed situation shortcomings are also revealed. If others, e.g. health professionals or relatives, question or ignore the next-of-kin this doubt can increase and the next-of-kin can feel themselves belittled and worthless. The next-of-kin ransack and doubt themselves and the shame is often painful and may lead to self condemnation. This shame might not involve public humiliation, and the next-of-kin can experience shame known only to themselves. The shame can also be public, i.e. other people can see the next-of-kin’s inadequacy in the situation that the next-of-kin is ashamed of. The experience of shame can be further complicated if the next-of-kin is put in shameful situations by others, situations where the next-of-kin is not responsible (cf. Lehtinen, 1998). Other relatives can by their actions or their unwillingness to see what is going on cause the experiences of shame to arise. Health professionals can similarly put the next-of-kin in shameful situations.

In Study IV the experiences of shame were interpreted as ignominy, humiliation, disgrace, and second order shame. In order to be able to separate the experiences of ignominy, humiliation, and disgrace from each other the semantic concept analysis (Study II) was of help. Ignominy and humiliation are synonyms that are related to each other with similar explanations of meaning. Ignominy is, however, seen as a milder form of humiliation since the situation that gives rise to humiliation can also include abuse, and scorn. These distinctions were helpful in the interpretation. Disgrace involves insulting and degrading situations which were also a help in distinguishing the different forms of shame from each other.

The results in Study I and IV provide several examples of how the next-of-kin are treated in encounters with health professionals, relatives, and friends and how these encounters can cause experiences of shame. Even though there appears to be no specific reason for the next-of-kin to experience shame it still occurs. A question to ask is why the next-of-kin sometimes do not respond to this, apparent, unfair treatment with nothing but acceptance? There can of course be many different answers to this question that have to
do with the next-of-kin’s sense of self-esteem and self-confidence. One possible way to look at it is by using what Lehtinen (1998) refers to as underdog shame. In Lehtinen’s words this kind of shame is a social emotion that arises in the encounter between people from different social levels and can thus affect different groups in society to a varying extent as it includes hierarchical connections. A socially privileged person who is put in an embarrassing situation may have greater possibilities of walking away from this situation relatively unaffected. On the other hand, if a person already feels subordinate in relation to others s/he does not have the same options to locate the shame outside her/himself and it is easier for her/him to feel shame (Lehtinen, 1998). The experience of underdog shame is evident in the following quote taken from one of the next-of-kin: “Yes we were humble ordinary people, we could only look up”. The expression underdog shame can apply to the vulnerable situation that the next-of-kin in end-of-life care experience. In this situation s/he tries to support the dying person while struggling with her/his own grief and sorrow concerning the approaching loss. The vulnerability makes it difficult to oppose what appears to be an unfair treatment. The next-of-kin is already so downhearted and might not have the strength to question the treatment s/he experiences. There appears to be a sense of resignation about what is happening and this resignation leaves the next-of-kin with experiences of not being good enough.

Shame on behalf of the dying person or someone else is a complex experience that involves situations that the next-of-kin might not have caused. This sort of shame can occur if the next-of-kin feels that the dying person is more exposed than necessary or if s/he in some way is undervalued. This sort of shame can also be experienced in situations where the dying person or someone else e.g. a health professional behaves in a shameful way. These experiences can be compared to what Lehtinen (1998) calls second order shame, which is a state of being ashamed in situations where one would normally expect someone else to experience shame. The dying person or someone else who is involved in the end-of-life situation can be humiliated or behave in an improper way without being aware of the shameful situation. Instead this shame is
transferred from that person to the next-of-kin and s/he is the person who ends up with this experience because shame can be contagious. Wiklund Gustin (2010) provides examples of how experiences of shame can be linked to external circumstances, e.g. the conduct of health professionals. If the next-of-kin is exposed to unfair treatment, her/his dignity can be worn down and experiences of shame can arise. This can happen in circumstances where the next-of-kin’s needs and feelings are not acknowledged, are not seen, or have been judged and found inadequate (cf. Andershed & Ternestedt, 2000). Wiklund Gustin (2010) refers to this as an unhealthy shame. If the next-of-kin sees her/himself to be unworthy, as when experiencing shame, it can lead to suffering, especially when the shame is inflicted by other people or generated by unattainable demands. The suffering drains the next-of-kin’s dignity. This can be compared to what Kaufman (1996) calls the shame spiral, which he describes as experiences of shame that turn inwards and enmesh the person. The experiences of shame flow in circles that endlessly trigger each other. The circumstances in which shame arose can thus be relived over and over again, which is something that may strengthen the sense of shame and also absorb other experiences, resulting in only shame being left. Kaufman (1996) also uses the concept of interpersonal bridges, which stands for bonds between people. These bonds are formed out of reciprocal interest and shared experiences of trust. When a person experiences shame it can leave her/him outside the companionship with others and s/he can withdraw and feel estranged, which according to Lögstrup (1956/2009) might be interpreted as the opposite to trust, i.e. mistrust. These circumstances can cause the interpersonal bridge to break down which can create even more shame.

**Theoretical discussion**

The ethical demand, according to Lögstrup (1956/2009), is that we are each other’s life and therefore the demand is endless. The demand implies that in the encounter between two people, and in this case between the next-of-kin and the dying loved one, the next-of-kin can contribute to making the dying person’s world as safe as
possible. This can be done by taking care of the latter and showing consideration and respect. According to Lögstrup (1956/2009) the encounter is built upon trust, which is seen as a fundamental conduct between people. In line with this the dying person meets the next-of-kin trusting that s/he will take care of her/him. This trust gives the next-of-kin power which needs to be handled properly. When the demand is experienced as being impossible to fulfill the experiences of guilt and shame are close at hand. The ethical demand is often deeply rooted and therefore the experiences of guilt and/or shame leave the next-of-kin in situations where failure is prevalent. Even if the next-of-kin have accomplished her/his very best in end-of-life care the experiences of guilt and/or shame can still be predominant and conceal everything else.

Levinas’ (1969/2011, 1985/2006) thoughts about the Other’s face, where the use of the concept face can be seen as a way to concretize the other person can also help to understand the responsibility that the next-of-kin experience in the encounter with the dying loved one. The dying person in her/his nakedness and vulnerability expresses the wish “take care of me”. The next-of-kin’s response is to stay close and take care of her/him. The responsibility also entails respect for the Other’s otherness, which may mean that the dying person is given space. Experiences of guilt and/or shame can emerge and leave the next-of-kin in a vulnerable state if s/he is not in some way able to live up to the responsibility.

The ethical demand can also be seen from another point of view. In the encounter between the next-of-kin and the health professional, the health professional can contribute to making the next-of-kin’s world as safe as possible. Andershed (1998, 2006) highlights the significance of the health professional’s approach towards the next-of-kin, an approach that includes respect and openness, sincerity and cooperation. This involves an attitude of open heartedness that Öhlén et al. (2007) describe as opening oneself towards the other as a unique person. This openheartedness does not have to include a total agreement with what the next-of-kin think and feel but the health professional must receive the next-of-kin without judging, protesting or belittling her/him. Thus health professionals need to be
sensitive towards the next-of-kin’s life situation, and be aware of existential circumstances (Andershed 1998, 2006). The thoughts of Løgstrup (1956/2009) and Levinas’ (1969/2011, 1985/2006) can be applicable in these situations being as the ethical demand concerns the responsibility we have for the other. The vulnerability that the next-of-kin might experience can then challenge this responsibility. A way to responding to this challenge is to be supportive with respect for the next-of-kin’s dignity (Gunnarsson & Öhlén, 2006). Next-of-kin need support from the health professionals and in end-of-life care this support can involve information about experiences of guilt and shame so that the next-of-kin are aware that these experiences can arise in the end-of-life situation. Knowing that other people have had similar experiences can be of help in dealing with one’s own situation. The health professionals need to be perceptive towards the next-of-kin. This perceptiveness can involve paying attention to how the next-of-kin behave and how they deal with experiences of guilt, and experiences of shame such as underdog shame or second order shame. An awareness of these experiences and an accommodating approach that does not offend the next-of-kin are thus prerequisites. If the next-of-kin have insight into experiences of guilt and shame it may contribute to being able to recognize that these experiences are “normal” and understandable under the given circumstances. This knowledge can bring alleviation.

Health professionals also need to be aware of their own attitudes and how they do and say things to the dying person and next-of-kin in end-of-life care being as the next-of-kin can be vulnerable and words and behaviour can cause suffering if they are perceived the wrong way. There are several findings in this thesis (Studies I, III, and IV) that show how the health professionals’ attitudes can cause the next-of-kin to feel bad in a situation where they are already exposed. Experiences of guilt and shame can leave the next-of-kin vulnerable and therefore it is important to encounter them as genuinely as possible and confirm their dignity as human beings. If health professionals have knowledge about how different ways of conducting themselves can influence the next-of-kin and if they
know how to communicate confirmation and support, this can help the next-of-kin rebuild their wounded dignity.

**Conclusion and implications**

The situation of being next-of-kin in end-of-life care is complex and demanding. S/he is often profoundly involved in the care and at the same time has to deal with her/his own feelings of the impending loss. Research concerning experiences of guilt and shame add knowledge to the existential dimensions of losing a loved one, which is important to address in end-of-life care.

This thesis adds knowledge about how the experiences of guilt and shame can influence the next-of-kin in an already burdensome situation. A situation that leaves them in a vulnerable state where they question all of what they have done in the end-of-life care of the loved one. By identifying the next-of-kin’s experiences of guilt and shame the result might also facilitate the bereavement process, which in turn might reduce ill health among the next-of-kin. The findings also have a potential to help next-of-kin see that experiences of guilt and shame are normal and understandable reactions when spending time with and taking care of a loved one in end-of-life care. It can help the next-of-kin in their adaptation to the end-of-life situation as a whole.

In the meeting between the next-of-kin and the health professional trust and reliance are fundamental and health professionals need to show patience towards the next-of-kin. If health professionals can understand and see the experiences of guilt and shame there is a possibility that this knowledge can help to alleviate and maybe also prevent suffering for the next-of-kin and for the loved one.

The results in this thesis can be of importance when end-of-life care is discussed. The findings can add knowledge to caring science and help develop a body of knowledge that can help nursing students and health professionals in their work supporting next-of-kin who are
facing and have faced the death of a loved one. It is important that health professionals are perceptive to the next-of-kin’s experiences of guilt and shame because it is not always natural that these experiences are presented spontaneously. Having knowledge about experiences of guilt and shame and being perceptive of these experiences can be seen as ways of making the health professionals better able to encounter the next-of-kin.

Further research is required to explore how the experiences of guilt and shame develop over time after the death of the loved one. Can next-of-kin reconcile with the experiences and if so, how? What happens if they cannot reconcile? Research is also needed to investigate how health professionals deal with experiences of guilt and shame that they meet in encounters with next-of-kin, maybe not only in end-of-life care but also in other caring contexts. Both in nursing and in nursing education this knowledge can be of help in learning about the caring relationship between next-of-kin and health professionals.
SVENSK SAMMANFATTNING

Skuld och skam i vård i livets slutskede – Närståendes perspektiv


Att vara närstående i livets slutskede kan ses som en period där både känslor av tillfredsställelse och känslor av att inte klara av situationen är närvarande. Det kan ses som en balansgång mellan vårdaktiviteter och att samtidigt klara av de krav som utgör
vardagen. Att vara närstående i livets slutskede kan också kännas meningsfullt och ge en känsla av stolthet och självförtroende. Den närstående kan känna närhet och förtroende och samtidigt kämpa med existentiella frågor om varför det hela har drabbat dem.

Sorg är ofta en del av upplevelsen och denna sorg uppstår redan innan den nära personen har avlidit. Sorgen kan inbegripa känslomässig stress och en längtan tillbaka till hur det var innan den nära och kära blev sjuk. Känslor av ensamhet, kognitiv dysfunktion, irritabilitet och ilska kan finnas med i sorgen och den närstående vill ofta inte betunga den döende med sin sorg.


Forskning som tar upp upplevelser av skuld och/eller skam hos närstående i vård i livets slutskede finns men studier som fokuserar på dessa upplevelser är svåra att hitta. Istället är de ofta mer generellt presenterade i en mer övergripande presentation av hur det är att vara närstående i vård i livets slutskede.

**Syfte:** Det övergripande syftet med avhandlingen var att undersöka och beskriva begreppen skuld och skam och att fördjupa förståelsen för närståendes upplevelser av skuld och skam i vård i livets slutskede.
Delsyften för de fyra studierna var att:

I Att undersöka och beskriva närståendes känslor av skuld och skam relaterat till en döende persons situation i vård i livets slutskede.

II Att belysa meningen med och skillnaden mellan begreppen skuld och skam.

III Att skapa en djupare förståelse för upplevelserna av skuld hos närstående i vård i livets slutskede.

IV Att skapa en djupare förståelse för upplevelserna av skam hos närstående i vård i livets slutskede.

Metod och material: För att uppnå syftet med avhandlingen har en beskrivande och tolkande design använts för att semantiskt undersöka begreppen skuld och skam och för att undersöka upplevelserna av skuld och skam i ett närståendeperspektiv. För att undersöka upplevelser av skuld och skam från olika synvinklar var utgångspunkten en kvalitativ sekundäranalys av intervjuer med närstående utifrån Thornes analysmodell. Denna följdes av en semantisk begreppsanalys av begreppen skuld och skam där Koorts metod, vidareutvecklad av Eriksson, användes. Resultaten från dessa analyser användes sedan i de två följande empiriska studierna där variationer av fenomenen skuld och skam undersöktes med hermeneutisk analys inspirerad av Gadamer.

Datamaterialet bestod i Studie I av 47 kvalitativa intervjuer där närstående berättade om sina upplevelser av att vårda en nära och kärl i vård i livets slutskede. Av dessa informanter var 19 män (7 makar, 10 söner, 1 bror, 1 systerson) och 30 kvinnor (12 makor, 16 döttrar, 1 syster, 1 vän). I två intervjuer deltog två närstående samtidigt. I Studie II användes tio svenska ordböcker vilka sträckte sig över en tidsperiod från 1800-talet fram till 2000-talet, där den äldsta ordboken inkluderade data från så långt tillbaka som 1600-talet. Studierna III och IV utgick från samma datamaterial där 17 närstående som förlorat en nära och kärl i en cancersjukdom.
intervjuades. Av dessa informanter var tolv äkta make/sambo och fem barn. Tre var män och 14 kvinnor, åldersspannet var 21-86 år (M 58 år).

Resultat: Resultaten visar att närståendes upplevser av skuld och skam i vård i livets slutfase har en utgångspunkt i hur den närstående anser att den återstående tiden tillsammans skall vara. Situationen involverar åtaganden och ansvar att försöka göra den sista tiden tillsammans så bra som möjlig. Åtagandet kan innefatta att moraliskt agera på ett sätt som följer de etiska principerna och även en kärlekshandling. Upplevelser av skuld visar sig i studierna som att inte uppfylla åtaganden, att försumma och att vara orsak till. Dessa tre aspekter av skuld kan ses i händelser som att inte ha gjort nog, att inte ha varit tillsammans med den döende vid viktiga skeenden, att inte ha talat med varandra tillräckligt och att inte ha gjort vad som uppfattades som det rätta. I upplevelsen av skuld är det själva handlingen som ligger i fokus.

Upplevelser av skam visar sig i studierna som känslor av underlägsenhet och kraftlöshet som kan ha sitt ursprung i att inte bli tagen på allvar, att inte bli lyssnad till eller att inte bli respekterad. Vidare kan skammen vara en skam i andra hand (second order shame) som handlar om att känna skam å någon annans vägnar. Det kan t.ex. vara den döende som befinner sig i förnedrande situationer utan att själv vara medveten om detta, istället tar den närstående på sig denna skam. Skammen kan också handla om att familjekonflikter kommer fram i ljuset och ses av andra utomstående. Upplevelser av skam tolkas också som en nesa, förnedring och vanära, där nesa och förnedring kan ses som snarlika upplevelser men där nesan är en något mildare form av förnedring utifrån den semantiska begreppsanalysens resultat. Skammen kan utvecklas i situationer där den närstående har orsakat något men den kan också ha att göra med att den närstående försätts i svåra situationer där någon annan, t.ex. andra närstående, vänner eller vårdpersonal placerar henne/honom. Skamupplevelsen är kopplad till jaget och kan innebära att den närstående rannskar och tivi på sig själv.

Avhandlingen kan bidra till fördjupad förståelse för den närståendes situation i vård i livets slutskede. Denna kunskap kan bidra till att i vårdutbildningar och i klinisk verksamhet visa på den komplexitet som upplevelser av skuld och skam kan innebära.
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