STRIVING FOR PURITY
Interviews with people with malodorous exuding ulcers
and their nurses

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ABSTRACT

The overall purpose of this thesis is two-fold; to illuminate the meaning of living with ‘impurity’ in terms of malodorous exuding ulcers, and the meaning of caring for people with ‘impure’ bodies in institutions and in people’s homes. The thesis comprises four papers based on studies using qualitative methods.

To illuminate nursing care as narrated by 27 retired care providers in northern Sweden, seven audio recorded group dialogues were performed (I). The transcribed group dialogues were analysed using a hermeneutic approach. The findings formulated as cleanliness, order and clear conscience point to purity. By cleaning patients and their surroundings repeatedly, by preserving order in various ways and by keeping a clear conscience, nurses committed to preserving purity. This study opened up for questions concerning the meaning of ‘impurity’ and ‘purity’ in nursing today leading to papers II-IV. Learning about ‘purity’ is possible through studying ‘impurity’. Audio recorded narrative interviews were performed to illuminate the meaning of living with malodorous exuding ulcers (II) and the meaning of caring for people with malodorous exuding ulcers (III). A phenomenological-hermeneutic method was used to analyse the nine transcribed interviews with patients (II) and 10 transcribed interviews with nurses (III). The comprehensive understanding of living with malodorous exuding ulcers (II) was formulated as being trapped in a debilitating process that slowly strikes one down. There is a longing for wholeness and purity. When finding consolation, i.e., encountering genuineness and feeling loved, regarded and respected as fully human despite ulcers, patients feel purified. The comprehensive understanding of caring for people with malodorous exuding ulcers (III) was formulated as being exposed to, and overwhelmed by suffering that is invading. One runs the risk of experiencing desolation when one cannot make the ulcers and malodour disappear and fails to protect patients from additional suffering.

To illuminate nurses’ reflections on obstacles and possibilities providing care as desired by people with malodorous ulcers (IV), six nurses from a previous study (III) were interviewed. An illustration with findings from paper II was shown and participants were asked to reflect on obstacles and possibilities providing the care desired by patients. The 12 audio recorded transcribed interviews were analysed using qualitative content analyses. The interpretations were presented as one theme
striving to do ‘good’ and be good’. The sub-themes related to the obstacles were ‘experiencing clinical competence constraints’, ‘experiencing organisational constraints’, ‘experiencing ineffective communication’, ‘fearing failure’ and ‘experiencing powerlessness’. The sub themes related to possibilities were ‘spreading knowledge on ulcer treatments’, ‘considering wholeness’ and ‘creating clear channels of communication’.

The meaning of living with ‘impurity’ in terms of malodorous exuding ulcers, and the meaning of caring for people with ‘impure’ bodies in institutions and in patients’ homes is interpreted as striving for purity. Patients experience impurity when feeling dirty, losing hope, and not being respected and regarded as fully human. Nurses experience impurity when failing to shield patients’ vulnerability and their own defencelessness, and when facing obstacles preventing them from providing good care and being good nurses. Both patients and nurses may experience purity through consolation. For nurses, mediating consolation presupposes being consoled by being recognised for their challenging work, being respected and included in multi-professional teams supported by the health care organisation and the leaders. Then patients can become consoled, and feel restored and fully human again despite their contaminated body.

Key words: ulcers, malodour, purity, consolation, phenomenological hermeneutics, qualitative content analysis
This thesis is based on the following papers, which will be referred to by their Roman numerals, I-IV:


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INTRODUCTION

The starting point for this scholarly endeavour was a project focused on the history of nursing care in a county in northern Sweden. My part in this project was to analyse group dialogues with retired professional care providers, which resulted in a publication that is also the first paper in this thesis. For me, this meant a new field and new perspectives of nursing care. During the process of analysis I became more and more fascinated by the retired care providers talking about how their time was spent caring for patient’s bodies and how they dressed and ‘hid’ their own bodies in clean and perfect uniforms. Perusing the literature made me aware of ‘purity’ as almost a virtue, and ‘impurity’ as something that must be fought wherever it occurred during the beginning of the 20th century. The literature was explicit in connecting ‘good character’ and ‘bad character’ with purity/impurity as well as the message that the inner ‘purity/impurity’ impacted outer ‘cleanliness/dirt’ and vice versa (e.g. Abel-Smith 1960, Tallberg 1991, Thomas 1994, Andersson 2002).

The retired care providers’ reflections evoked reflections on my own previous experiences from geriatric, orthopaedic and neurological care; how we in the wards thought about and cared for patients and their bodies, how purity and impurity, cleanliness and dirt were present and coped with. To meet patients with severe and chronic diseases was always demanding and ethical challenges and practical problems were always present. The body’s malfunctioning from a chronic disease might overtake one’s life situation in such a way that is difficult to imagine when one is healthy. On the one hand, I was often surprised how patients and relatives found new ways to cope, how they solved practical problems and acquired control over their daily life. On the other hand, I also met patients who were devastated, defeated by their ill bodies and saw no options at all for the future. Their body had become their enemy and I, as a nurse, could only be there, stay with them, try to be a good listener and provide as much emotional and practical support as possible, in order to help them cope with their daily life. In light of the various experiences of nursing care, the retired care providers’ and mine, I realised that perspectives differed. For me, because purity seemed to be of great importance for the retired nurses and preserving purity equalled good care back then, the challenge was to understand what purity and impurity mean in nursing today. Exploring experiences of impurity and options for
experiencing purity for patients and nurses seemed important to increase our understanding. I had to seek out what could be considered ‘impure’ in nursing care today and what could be considered ‘dirty’. Malodorous exuding ulcers could be seen as ‘dirt’, is associated with bodies and opened up for exploring challenging perspectives on purity and impurity related to nursing care.

**BACKGROUND**

**Malodorous exuding ulcers**

In the literature on ulcer treatments, ‘wound’ and ‘ulcer’ are sometimes used to describe different types of ulcers, e.g. surgical wounds of various kinds (e.g. Dryburgh et al 2008) gastric ulcers (e.g. Sesler 2007) or pressure ulcers (e.g. Moore & Cowman 2008). When reviewing literature, the terms ‘wound’ and ‘ulcer’ seem to often be used interchangeably. For the purpose of this thesis, I will use ‘ulcer’ to refer to a physical ulcer. However, when referring to the literature I will use the same term as the literature referred to. Most ulcers heal as anticipated and most ulcers can also become chronic if complications such as infections develop. Sometimes the term ‘slow healing ulcers’ is used as it is not in the same way associated with a bad prognosis as is the term ‘chronic ulcers’ (e.g. Ebbeskog 2003). White (2008) introduced the concept of ‘delayed wound healing’ which could be understood as healing that takes longer than anticipated despite appropriate treatment. Making a judgement of delayed healing is complex and the diagnoses as well as the rated or anticipated degree of healing must be considered (Harding 2000, Cardinal et al 2008). Harding (2000) put light on the challenge and importance of clinical research in order to understand whether a wound really is chronic or difficult to heal, or if diagnoses and treatments are not optimal. ‘Hard-to-heal wounds’ is another way of describing a healing process that is prolonged or healing that is never achieved (EWMA 2008). It seems desirable to strive for consensus on definitions and terminology in order to facilitate communication and develop optimal assessment tools and treatments. However, whether we call ulcers chronic, hard-to-heal or anything else, for patients it involves a trying experience to live with these ulcers and hence, for nurses and physicians it is a challenge to provide the best treatments and care.
Normally there is a variable flow of exudate from an ulcer until it is closed and finally healed. If an ulcer is not healing as anticipated, the production of exudate might continue or even be excessive, perhaps because of an infection or inflammation. This may lead to leakage, further skin complications and prolonged healing if appropriate measures are not taken. Several authors underline the importance of understanding the role of exudate and having the skills and tools to assess and manage wounds and exudates in order to provide the best conditions for healing (White & Cutting 2006, Benton et al 2007, Thompson & Stephen-Haynes 2007, WUWHS 2007). In the consensus document from WUWHS (2007), the authors stressed the importance of examining exudates regularly: colour, consistency, amount and odour. Changes in the characteristics of exudates might indicate a change in wound status or the disease process. Exudate odour is described as “unpleasant” (WUWHS 2007, p3) and underlying causes could be bacterial growth, necrotic tissue or a fistula. Some dressings or other wound care products may also produce or cause a characteristic odour. Wound odour can be difficult to avoid even with appropriate dressings and hence something patients might have to live with. Malodour can be distressful for patients and a significant reminder of a restricted life (Neil & Munjas 2000, Piggin 2003, Morris 2008). According to the literature referred to above, some authors write about odour while the term malodour is used by other authors. Malodour seems to be considered a stronger term that indicates serious ulcers affecting both patients and the people around them.

Fungating wounds could be described as tissue death caused by loss of vascularity related to cancer cells infiltrating the skin along with lymph and blood vessels (e.g. Grocott 1999). Of importance, is that it is essential to diagnose the underlying causes of symptoms of fungating wounds, in the same way as of other non-healing wounds, in order to optimise treatments (Grocott 2007). Exudate and malodour are two major symptoms, along with bleeding and pain, causing distress for patients with fungating wounds and those around them according to studies reviewed by Naylor (2002). In a review on managing malodour and exudate in wounds, Draper (2005) emphasised that malodour might lead to involuntary gagging and could even trigger the vomit reflex causing the patients tremendous stress and discomfort. The malodour from a fungating wound is challenging because it is a constant reminder of the cancer
disease. Both researchers and experienced nurses agree that malodour is pervasive and very distressful for patients. Due to a cancer diagnosis, the wounds rarely heal and they have a significant impact on the patient, the family and the nurses (Dowsett 2002, Naylor 2002, Nazarko 2006, Grocott 2007, Morris 2008). Relatives might avoid visiting because the malodour is hard to endure and hence difficult to be near, and patients may lose their sense of self gradually distancing themselves from their bodies as a way to handle an unbearable situation (Lawton 2000). Being the person, who has to live with these ulcers and put up with all the symptoms, seems like facing tremendous suffering.

**Living with malodorous exuding ulcers**

To be ill means, for most people, that their bodies somehow are affected. It can be in such a subtle way that no one else notices or understands what is going on. It might be difficult for people to understand and make sense of their condition and the situation at hand. Even more so if they feel well, they still have control over their bodily functions and their condition is ‘invisible’. If they become or already are fully aware of their bodily condition, and find ways to cope when not feeling well, it is still possible to maintain healthy appearances as symptoms and conditions may be invisible to others. This changes when one gets a malodorous exuding ulcer.

Living with a sick body; experiencing ulcers, leakage, exudate and malodour can be distressful and painful. Exudate and malodour are difficult to be near for anyone and when patients experience nurses reactions and see their facial expressions (which the nurses might be unaware of), that adds to the suffering (cf Lawler 1991, Yearley 1995, Lawton 2000). Several studies highlight difficulties of patients living with chronic ulcers of various origins. Studies focusing on chronic ulcers (Neil & Munjas 2000), leg ulcers (Krasner 1998, Hyde et al 1999, Ebbeskog & Ekman 2001, Nemeth et al 2004) and pressure ulcers (Langemo et al 2000, Hopkins et al 2006, Spilsbury et al 2007) emphasised pain, leakage, and smell as overwhelming experiences for patients. Price et al (2008) showed, in a study including 2018 patients with various chronic wounds, that chronic wound pain is common and often related to dressing procedures. The pain was experienced as hard to deal with and 64% of the patients took pain killers to cope with it.
A review by Briggs and Flemming (2007) exploring patients’ experiences of living with a leg ulcer showed that patients described their experiences like a journey, in stages: the main experiences were physical effects like pain, odour, itch, leakage and infection. Patients’ experiences with professionals were positive when nurses seemed to work in “the chronic care route” (p 323); were aware that healing would take time and patients in the mean time would need emotional support and help to manage daily life. Then patients were listened to and could be helped to gain control over their lives again. Experiences with negative outcomes seemed to occur when patients’ desires to get help to gain control over their lives conflicted with “the specialist healing route” (p 324) where nurses mainly focused on dressing changes and the wound healing process. Patients had to pay costs of the leg ulcer in terms of problems with personal hygiene, clothes, mobility, work, hobbies and travelling. The psychological impact on patients was described as managing difficult emotions and threats to identity. Across the studies, the authors found feelings of embarrassment associated with having a leg ulcer as well as feelings of fear, anger and depression with potential for suicidal thoughts. Threats to identity were found related to loss of confidence and self-esteem (Briggs & Flemming 2007). Women living with breast cancer described how malodorous and oozing wounds triggered anxiety about seepage and limited their options to dress as they desired, and also suppressed their sexual needs (Lund-Nielsen et al 2005). Piggin (2003) discussed the risk for social isolation when having a malodorous fungating wound and called for an understanding of the factors important for patients, and a recognition of the value of social support among clinicians.

Having a non-healing or chronic ulcer might lead to an altered body image significantly affecting patients (Langemo et al 2000, Douglas 2001, Young 2005, Spilsbury et al 2007), and it seems reasonable to believe that people living with any malodorous exuding ulcers share such experiences. The altered body image and the trying circumstances related to ulcers and care significantly impact patients’ quality of life as shown and discussed in several studies (Lindholm et al 1993, Hyland et al 1994, Franks et al 2002, Kinmond et al 2002, Persoon et al 2004, Young 2005, Spilsbury et al 2007). Neil & Munjas (2000) emphasised that having a chronic wound is a different way of ‘being in the world’ rather than being wound-free, and patients
need support and encouragement to cope with significant life-changes following their conditions. It seems that living with malodorous exuding ulcers could be a devastating experience and patients’ trying situations call for highly qualified nurses prepared to meet the challenges of caring.

Having an ulcer means having skin breakdown. Rudge (1998) discussed skin as cover and how ulcers might render the body’s boarders unstable and, hence, threatens one’s clean and proper body as well as one’s integrity. Neil & Munjas (2000) discussed how a patient living with a chronic, non-healing wound also has a symbolic breakdown of the embodied self. Hopkins (2004) presented similar findings from interviews with people living with non healing venous ulcers. When everything worsens despite therapy and much time passes, maybe years, hope and compliance may fade. The trying life situations, including painful time consuming treatments, can make patients “become the wound” (p 36). One might say that the person can be reduced to an object.

**Caring for people with malodorous exuding ulcers**

Physical proximity in nursing care may be experienced as frightening and even threatening. Söderberg et al (1997) described ethical difficulties in intensive care where the risk for dehumanizing care must be counteracted by respecting dignity. Rasmussen et al (1997) discussed how encountering suffering and despair in hospice care created uneasy feelings and how nurses needed ‘an outlet’ in order to endure. Talking about uneasy feelings with colleagues or taking a sauna for cleansing the body as well as the mind was mentioned by the nurses. Caring for a person who acts provokingly and experiencing e.g. being spit at in psychiatric care was illuminated by Hellzén et al (2004). Being close and respecting patients’ dignity became impossible for these care providers and that broke them down. Being exposed to violence, when working with people with learning disabilities, is threatening and can raise feelings of e.g. fear and powerlessness according to Lundström et al (2007). Similar reactions and feelings among staff managing violent incidents in elderly care were described by Åström et al (2002). Physical proximity is one of the realities that nurses as well as patients have to face and deal with in nursing care and the proximity causes difficulties even in absence of malodorous exuding ulcers.
Caring for people with leaking bodies means being close in such a way that would be inappropriate anywhere else. For nurses, it means having to stand by the patient and take care of what ever is, however bad smelling or disgusting it might be. It means having to stay, and change dressings without violating the exposed patient (cf Lawler 1991). This can be frightening or even threatening to nurses, especially if the patient is contagious and there is a risk of catching an infection or a disease. Wilkes et al (2003) showed that nurses caring for patients with fungating wounds found it difficult to cope with patients’ malodorous ulcers and bodily conditions. The nurses struggled with the desire to make a difference and see positive effects from their efforts even if patients still suffered and the wounds did not heal. Trying to consider the whole person facilitated making a difference even if the wounds remained.

In the discussion section in the review on living with leg ulceration mentioned earlier (Briggs & Flemming 2007) in this thesis, the authors highlight the risk for initiating a spiral of hopelessness as the focus seemed to be on the wound healing process. They stressed that focusing on wound healing is entirely appropriate, but if it is the only focus and an outcome might never be achieved, patients are at risk of being treated as wounds and forgotten as persons when efforts towards healing are intensified. The authors of the position document from EWMA (2008) discussed recent research on health care professionals in wound care and pointed out the risk of feeling helpless when treatments fail and patients’ suffering cannot be controlled. This feeling of helplessness might lead to social defences such as avoiding patients or avoiding providing continuity of care, blaming or not responding to patients’ suffering. While this can occur to protect oneself as a professional, the effect on the patient can be devastating. Rudge (1998) claimed that nurses who treat patients with burn wounds protect themselves from being emotionally affected by patients suffering. Nurses might objectify patients as wounds even in their efforts to treat and re-establish boundaries by applying dressings while wounds heal. By using metaphors for skin and dressings’, like ‘cover’, they distance themselves from the emotional impacts of witnessing skin damage. Caring for people with malodorous exuding ulcers seems to be demanding in various ways and nurses seem to need updating on various aspects of ulcer treatment as well as aspects on living with hard-to-heal ulcers in order to be able to intervene efficiently (Beitz & Goldberg 2005).
A nurse is a part of a unit and a part of an organization. Fagerström (2006) pointed out the importance of organizing and administrating the daily care in a way that supports the ethical demand to provide good care as interpreted by the nurses. Finnish nurses who participated in focus groups were struggling for administrative and organizational support to provide the care they knew was good for the patient. Talseth et al (1997) described how nurses working with suicidal psychiatric patients talked as if they were totally alone with their patients. They talked as if there was no support team which made the work even more demanding and almost unbearable. Udén et al (1992) described how nurses in an oncological unit in medical care had valuable support from their colleagues, but physicians’ attitudes made it difficult for nurses to carry out good work. The importance of supportive care settings for health care staff was highlighted by Edvardsson et al (2005). The authors concluded that sensing an atmosphere of ease where both patients and staff could feel welcomed, seen, acknowledged and be able to locate themselves in familiar and safe surroundings, contributed to supportive care settings.

When treating ulcers, nurses and physicians treat patients’ bodies. Marcel (1982) discusses the significance of the body. ‘I’ as a ‘person’ exist through my body. The body constitutes my presence in the world and is inseparable from the ‘I’. The body cannot exist on its own and there is no ‘I’ without a body; it provides identity and also the possibilities of relations to others. Existing means, that I can be seen and identified by another person but also by myself. The body is the ultimate boarder between existence and non-existence. ‘My body’ is, according to Marcel, the ‘lived body’ and means something greater and deeper than the body as an object, an instrument. It is only through the incarnated body that I can participate in the world and be in communion with others. Svenaeus (2000) develops a phenomenological view by using a clinical example about a woman suffering from a severe stroke. She had totally lost control over her body and her life, and the illness was an uncanny and unhomelike experience. The acute treatments and the rehabilitation involving many people of various professions aimed to help her find the way to a regained homelikeness in her being-in-the-body and being-in-the-world, guided in dialogue and action, even if her embodiment would never again be the same. Nurses encountering patients always means bodies encountering bodies. Patients have no
choice but to expose themselves and become vulnerable and dependent. The outcome of these encounters is, to a great extent, dependant on how nurses respect and treat patients’ bodies.

**Purity**
The English vocabulary reflects to some extent two different meanings of the Swedish word ‘ren’; ‘clean’ means absence of dirt, and ‘pure’ means homogeneity understood as one substance that is not mixed with any other substance. The distinctions between the opposites, clean – dirty, and pure – mixed, indicate that striving for cleanliness does not necessarily include striving for homogeneity (Lagerspetz 2006). However, a review of the literature showed lack of consensus on how to use the words ‘clean’ and ‘pure’. In the following the words are used according to the literature referred to. When translating into English, I have interpreted the meaning expressed in the Swedish text according to the above-mentioned distinctions.

Purity as a phenomenon is complex and can be understood from various perspectives. The vocabulary of the pure and the impure, which we owe to classic Greek, expresses the ambiguity of purity that fluctuates between the physical and the ethical. “Dread of the impure and rites of purification are in the background of all our feelings and all our behaviour relating to fault” (Ricoeur 1969, p 25). According to Ricoeur (1976) a phenomenon can be revealed through its opposite, so by learning about impurity we can gain a deeper understanding about purity. Impurity is symbolic of a stain, a blemish, and as defilement something that infects by contact experienced subjectively in a feeling of fear, the dread of danger. “In fearing defilement, man fears the negativity of the transcendent” (Ricoeur 1969, p 33). Furthermore impurity symbolizes evil. Hence, purity is about goodness and the sacred. Symbols are signs expressed through communication of meaning and it is important to look deeper beyond the surface of our rituals, routines and procedures to examine their meanings and usefulness in a deeper sense (Ricoeur 1969).

According to Douglas (1978) studying purity means studying systems of symbols within a cultural context. Purity is about social and personal order. It is about accepting and staying within the boundaries set in and by society. Douglas asserts
that purity is apparent in the order of rituals that create and maintain a certain culture and also visualise patterns for social relations. Disorder, such as matters out of place or crossing boundaries, symbolises threats, as disorder is boundless and there is no way to control or foresee developments of patterns. Dirt means matters out of place and, hence, impurity, a threat to the existing order, which must be controlled. Douglas’s concept of purity was used in nursing research by Sidenvall (1999) who observed meal times in institutions for elderly. She found that, according to Douglas’s theories (1975, 1978), meals could be considered a sensitive area connected to handling food and objects on the table, as well as connected to conduct. For all of us each meal is ordered and organized in a pre-coded pattern, recognized by the people belonging to the same family or group. The patterns limit the number of plausible structures as they organize the meal as a procedure, and hence set boundaries for what could be considered normal. Elderly people in the institutions studied strove towards civilized manners based on their individual meal customs and the nurses strove towards manners based on the organized meal culture developed in the institution. Their striving for fulfilling demands and norms could be seen as striving for purity and order as interpreted by Sidenvall (1999). Her study puts light on the difficulties to reach mutual understandings of what is to be considered normal as well as desirable, and the different perspectives of nurses and patients.

Lagerspetz (2006) criticized Douglas’s view which he calls anthropological reductionism. He called for a philosophical approach in the contemporary discussion and shed light on the practical, not the symbolic dirt. He criticised Douglas for reducing dirt to symbols and claiming that ‘dirt’ was something real only if it meant something other than material dirt. Dirt concerns, according to Lagerspetz, material matters and can also be seen as a shortcoming. Dirt is always related to something and arises from contacts between whatever contaminates and becomes contaminated. Dirt is a function of the identity of the host object and in order to understand the dirt one has to understand the host object. Hence, cleanliness and dirt are qualities related to the host object. Concepts of dirt are teleological, which means that the purpose and the aim must be considered when understanding if something is dirty or not. One must further consider the situation at hand. The direct question whether something is dirty or not is according to Lagerspetz (2006) meaningless. To raise this
question one must consider the basis for forming a judgement, which implicates a perception of the role of the host object in the situation.

**Consolation**

The terms 'comfort', 'solace', 'consolation', 'soothing' and 'religious coping' denote aspects of a phenomenon. The terms are sometimes distinct and sometimes overlapping and they are used in research in various contexts. 'Comfort' has been used in studies such as Bucholtz (1994), Kolecaba and Steiner (2000), Tutton and Seers (2004) and Ångström-Brännström et al (2008), and 'solace' in studies by e.g. Horton et al (1988) and Pearson (1994). 'Consolation' has been used in studies on various groups of patients in Scandinavia in the contexts of intensive care (Söderberg et al 1997, 1999), hospice care (Rasmussen et al 2000), dementia care (Norberg 2001), psychiatric care (Gilje & Talseth 2007, Talseth et al 1997, 2003, Talseth & Gilje 2007), home care for older people (Roxberg et al 2008), among very old people (Santamäki Fischer 2007) and among women who had breast cancer and were mothers with dependant children (Öhlén & Holm 2006). 'Soothing' is used, and associated with comfort, mainly in care for small children (e.g. Drummond et al 1993, Harrison 2001), and 'religious coping', associated to consolation, is used by e.g. Maynard et al (2001). When translated into Swedish the various terms are covered by the same word: 'tröst'. The concept of 'tröst' in nursing care and the significance of 'tröst' for patients who suffer is discussed by Roxberg (2005) and as a way to handle stress of conscience in nursing by Dahlqvist (2008).

**Rationale for the study**
The study reported in paper I with the formulated themes cleanliness, order and clear conscience pointing to purity opened up for papers II-IV. The retired nurses fought
dirt, disorder and troubled conscience in their efforts to preserve purity. We wanted to understand more about purity and impurity in nursing care today, as that seemed so important for the retired nurses and not that important today. This opened up for the question whether we lack something in nursing today that was considered important when the retired nurses strove to preserve purity in their daily work. Lagerspetz (2006) has put light on the concepts of dirt, cleanliness, purity and impurity, and his research opened up for further reflections and questions on the subject. Research on purity and impurity in nursing care, as interpreted in paper I, was sparse and the significance today was, according to our knowledge, not explored.

According to Ricoeur (1976), a phenomenon could be revealed through its opposite. In order to understand purity in nursing today we could learn about impurity. In light of the findings from paper I, where care of patients’ bodies was high priority, we looked for bodily impurity today and decided for malodorous exuding ulcers. Malodorous exuding ulcers could be considered impure and they are also apparent and difficult to conceal because of the malodour and the exudate. Learning about what it means to live with bodily impurity, to be near and care for these people, becomes possible by getting access to people’s life worlds. We can not live another person’s life or understand another person’s lived experience as such, but we can get access to the meaning of the lived experience as narrated. By interpreting narrated lived experience meanings of the narrated event can be transferred. Living with malodorous exuding ulcers, caring for people with such ulcers and experiencing physical proximity, could be considered demanding and also threatening. Interviewing people with severe ulcers and nurses caring for people with such ulcers, and interpreting the transcribed interviews would fulfil our purposes to understand purity and impurity in nursing today.

Few studies were found that focus on the meaning of living with hard-to-heal or malodorous exuding ulcers, or caring for people with such ulcers. Most studies focus on diagnoses and symptoms rather than lived experiences. To provide good care for people living with malodorous exuding ulcers, we need to gain a deeper understanding of the meaning of living with such ulcers. We also need to gain a
deeper understanding of the meaning of caring for these people in order to grasp the
difficulties and challenges for nurses and other professionals providing care.

The purpose and aims of the study
The overall purpose of this thesis was twofold, to illuminate the meaning of living
with ‘impurity’ in terms of malodorous exuding ulcers, and to illuminate the meaning
of caring for people who experience themselves as having ‘impure’ bodies in
institutions and in people’s homes. The first paper opened up for purity and the
purpose of this study, and was hence during the process included in the overall
purpose.

The specific aims of the studies were
Paper I - to illuminate nursing care as narrated by retired care providers in northern
Sweden.
Paper II - to illuminate the meaning of living with malodorous exuding ulcers.
Paper III – to illuminate the meaning of caring for people with malodorous exuding
ulcers.
Paper IV – to illuminate nurses’ reflections on obstacles and possibilities providing
care as desired by people with malodorous exuding ulcers.

PARTICIPANTS AND METHODS
To fulfil the purpose and the specific aims audio-recorded group dialogues were
performed with retired nurses for paper I. The transcribed group dialogues were
interpreted using a hermeneutic approach. For paper II personal interviews were
performed with people with malodorous exuding ulcers, and for paper III with
nurses. The texts were interpreted with a phenomenological-hermeneutic method.
For paper IV nurses who were interviewed for paper III were asked to reflect upon
the findings presented in paper II. The transcribed interviews were interpreted using
qualitative content analysis.

Participants
It is complicated to reach retired nurses in Sweden because not all nurses are
registered in official records. Therefore we asked two retired nurses with good
knowledge about retired colleagues to help us find other retired nurses with various backgrounds for paper I. It was important that they had the ability and desire to participate in the study. This snowball selection is an often-used method in research on hard-to-reach populations. The method offers convenience but could be time-consuming, as you have to wait for so many to act and respond (Faugier & Sargeant 1997, Offredy 2000). Through this process 27 participants were reached, all with various backgrounds. They were all women between 65 and 90 years old, the average work experience was 45 years, and they represented various professions; registered nurses (RNs), enrolled nurses (ENs) and nurses’ assistants (NAs).

For paper II, people with malodorous exuding ulcers were selected. In order to illuminate the meaning of living with malodorous exuding ulcers from as many perspectives as possible, we wanted to include people with various diagnoses and with ulcers on various parts of the body. Head nurses at two university-hospital clinics selected patients with malodorous exuding ulcers who needed regular dressing changes during a longer period. They asked the patients about participating when they came to get their dressings changed. Seven patients were recruited this way and two were recruited through nurses who knew about the ongoing study and suggested patients for participation. All patients were given written information about the study and I contacted them by phone. Seven women and two men, aged 41–95 participated in the study. One had an infection after abdominal surgery, one had cutaneous tumours, one a complicated infectious ulcer involving dental problems and six patients had leg ulcers of various origins.

For paper III, a convenience sampling of 10 nurses working in both hospital care and primary care was made. The head nurses and also colleagues of mine suggested persons they thought should be interviewed because of their experiences from caring for patients with malodorous, exuding ulcers. The participants represented various kinds of working experiences, were all women, one EN and nine RNs and their working experience in nursing ranged 2.5 – 35 years. Four participants worked in primary care, three worked in a hospital ward where patients with hard-to-heal ulcers could receive specialist care and three worked in outpatient clinics.
For paper IV, six nurses who had participated in a previous study (III) were asked to participate in additional interviews. The remaining four participants were not asked because we failed to get in touch with one nurse, another one did not work directly with patients any more, and two nurses worked in a health centre where far-reaching organizational changes were at hand, and hence the work situation very complicated at the time. Six women, one EN and five RNs aged 29-50 participated in the study. They worked in primary care, hospital wards and outpatient clinics.
### Table 1. Overview of the studies

<table>
<thead>
<tr>
<th>Paper</th>
<th>Aim</th>
<th>Participants</th>
<th>Collection of data</th>
<th>Year</th>
<th>Interpretations</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>To illuminate nursing care as narrated by retired care providers in northern Sweden.</td>
<td>27 retired registered nurses, enrolled nurses and nurses’ assistants.</td>
<td>7 Group dialogues</td>
<td>1997-1998</td>
<td>Hermenutic</td>
<td>Published</td>
</tr>
<tr>
<td>II</td>
<td>To illuminate the meaning of living with malodorous exuding ulcers.</td>
<td>9 patients with various diagnoses.</td>
<td>9 Narrative interviews</td>
<td>2002-2003</td>
<td>Phenomenological-hermeneutic</td>
<td>Published</td>
</tr>
<tr>
<td>III</td>
<td>To illuminate the meaning of caring for people with malodorous ulcers.</td>
<td>9 registered nurses, 1 enrolled nurse.</td>
<td>10 Narrative interviews</td>
<td>2003-2005</td>
<td>Phenomenological-hermeneutic</td>
<td>Published</td>
</tr>
<tr>
<td>IV</td>
<td>To illuminate nurses’ reflections on obstacles and possibilities providing care as desired by people with malodorous exuding ulcers.</td>
<td>5 registered nurses, 1 enrolled nurse.</td>
<td>12 Reflective interviews</td>
<td>2006</td>
<td>Qualitative content analyses</td>
<td>Submitted</td>
</tr>
</tbody>
</table>

### Data collection

Group dialogues and personal interviews were performed.

**Group dialogues**

For paper I, the plan was to perform personal interviews but the participants found it difficult to remember what happened such a long time ago. Therefore small informal groups were formed and participants were asked to narrate about nursing care (cf Polkinghorne 1988). In the paper (I) the informal groups are called group dialogues. Five groups were formed based on the participants’ experiences of working in medical wards, surgical wards and various cottage hospitals in northern Sweden. Fifteen of
the 27 participants participated in more than one group because they had professional experiences from more than one care field. The dialogues took place in the university department or in public settings arranged by the participants. Four retired nurse teachers, familiar with nursing care around 1950 led and participated in the group dialogues and two researchers also participated. The gathering always started with coffee and informal small talk to create a relaxed and supporting atmosphere. The participants were asked to narrate and reflect on their memories of nursing care around 1950 based on the assumption that this would be as far back that they would remember. To narrate as a group helps one remember things that might be hidden deep down in one’s memory. One person’s recollection stimulates the recall of others, and the participants could help each other to remember persons, events and situations. Three groups met once, and two groups met twice because they had so much to tell and wanted to meet a second time to be sure they had the option to share what they had on their mind. The dialogues were audio-recorded, 15 hours and 31 minutes altogether.

**Interviews**

For papers II-III, personal narrative interviews were performed to reveal the meaning of the participants’ lived experience (Mishler 1986, Lindseth & Norberg 2004). Interviews were performed with people with malodorous exuding ulcers (II) and with nurses (III). The participants received information about the aim and the main question. They decided when and where the interviews took place; in participants’ home, at the university or in the hospital (II), in participants’ home, working site or at the university (III). The first question for people with malodorous exuding ulcers was ‘Please, tell me about your ulcer’(II), and the first question for nurses was ‘Please, tell me about a patient with malodorous exuding ulcers who needed to have dressings changed regularly during a longer period’(III). No other specific question was asked, the participants were asked to narrate their lived experience and follow-up questions were asked only in order to stimulate the participants to delve deeper. The interviews were audio-recorded, lasted seven hours (II) and seven hours and 50 minutes (III), and transcribed.

For paper IV, personal interviews were performed where participants were asked to reflect upon the findings presented in paper II. The participants received information
about the aim and the main question we intended to ask. An illustration with the themes and sub-themes was shown (Figure 1) while the interpretations were orally presented during 13-14 minutes before the interview started. As I saw, during the presentation, how strong the participants were affected I first asked for a spontaneous reaction on what had just been presented. The participants were then asked to reflect upon obstacles and difficulties providing the care desired by the people with malodorous exuding ulcers and various possibilities to make changes. As critique was expressed (II), the interviews formed a dialogue between the interviewer and participants in order to encourage reflections and help participants overcome feelings of being blamed. The interviews were audio-recorded and lasted five hours and eight minutes altogether. Two or three weeks later depending on their working schedule, a second personal interview was performed with each participant. During the period between the interviews the participants were encouraged to reflect on requirements and possibilities to improve the conditions for providing the care desired by people with malodorous exuding ulcers (II) and what possibilities they had to contribute. During this second interview, the illustration with themes and sub-themes was presented again and participants were asked to reflect on the findings, asked if they wanted to add something from the last session, or had reflected some more on their possibilities to contribute to changes. These interviews were audio-recorded as well and lasted three hours and 29 minutes.
Feeling dirty  
-Feeling ashamed  
-Having a troubled conscience

Being trapped  
-Being restrained  
-Being torn between incompatible choices  
-Feeling powerless

Losing confidence  
-Feeling violated  
-Feeling mistrust  
-Feeling betrayed  
-Being alienated

Losing hope  
-Being ruled by pain  
-Feeling fear

Becoming frustrated  
-Becoming impatient  
-Being deprived of one’s time

Protecting oneself

**BEING STRUCK DOWN**

**FINDING CONSOLATION**

Experiencing kinship  
-Not being left alone  
-Being embraced  
-Sharing

Encountering genuineness  
-Experiencing devotion  
-Experiencing relief  
-Shifting perspective

Gaining control  
-Being regarded as more than one’s body  
-Anticipating an end to one’s suffering

**Figure 1.** Findings from paper II as presented to participants in paper IV.
Interpretations
The audio-recorded group dialogues and interviews were transcribed verbatim, with pauses, sighs, sobs and laughs into text (I-IV).

Hermeneutics
We found the text to be fragmented. We also found that the content of the text included not only the retired nurses’ descriptions of nursing care, but also their reflections (I). The text had to be interpreted in order to fulfil the aim and a hermeneutic approach was used, inspired by Gadamer (1960/1996) and used as Kasén (2002). This offered a structured approach that helped understanding how to proceed with interpreting the text and what to consider providing meaning to the questions posed. According to Gadamer (1960/1996) hermeneutics is not about developing a method for understanding; it is about clarifying the circumstances where understanding occurs. ‘The horizon of understanding’ and the formulated understanding of the moment provides directions for seeking new understanding with an open mind. When interpreting a text, everything that can possibly provide meaning to the questions posed in the text is considered. New understanding is created through integration of the horizon of understanding and the answers to the questions posed in the text (Kasén 2002).

The interpretation was performed in three phases and each phase created understanding that provided ideas for the next phase (I). First, the text was read through with an awareness of the participants’ social and cultural background of having been nurses working in northern Sweden around 1950, and with the purpose to understand what the text was about. Text not related to the aim, such as intimate personal remarks about people or reflections on events with no concern for the study, was excluded. The text was found rich and fragmented and cleanliness stood out as a tentative theme. When reading and reflecting on literature about cleanliness it became apparent that in the past century, cleanliness could not be understood without considering order and morality (Abel-Smith 1960, Thomas 1994). After going through the literature thoroughly and reflecting on the text several times order and clear conscience also stood out as tentative themes. It became apparent that understanding the environmental conditions in hospitals, both rural and in towns, was a precondition for understanding nursing care in northern Sweden around 1950.
The second phase of interpretation therefore aimed to gain an understanding of the conditions for nursing care. Because the authors (I) had not had the experiences and preunderstanding of the participants, it was difficult to understand what was shared in the group dialogues and the nursing care talked about. The retired nurses were very helpful providing explanations and descriptions and literature about local conditions for nursing care (e.g. Olofsson 1985, Emanuelsson 1990), in various contexts, was read and reflected on. After further reading and reflecting on the text descriptions on work conditions were identified. After further reflection on the text in relation to the literature, a horizon of understanding that included the local context of care, as described in the literature as well as in the text, was formulated. The third phase of interpretation focused on expanding the understanding of the text. The text was again read through aiming to identify meaning units related to the tentative themes: cleanliness, order and clear conscience. The text was divided into meaning units and the few meaning units not related to the aim of the study were excluded. The meaning units were reflected on and compared, and the content of each meaning unit was condensed and then reformulated. When appropriate, the formulated condensations were abstracted and sub themes formulated as a further interpretation. The back and forth movement between interpretations and the whole text validated the tentative themes.

*Phenomenological hermeneutics*

For papers II-III, the participants narrated the meaning of their lived experiences. The texts were rich and complex and provided various perspectives on the phenomena. To understand the meanings the texts had to be interpreted. The texts (II, III) were interpreted by a phenomenological-hermeneutic method inspired by Ricoeur (1976) and developed at the University of Tromsø and Umeå University (Lindseth & Norberg 2004). The lived experience is personal and can never be shared or lived by another person. We acquire access to the meanings of people’s lived experience when they narrate it. By interpreting the meaning of the narrated lived experience, the meaning of the phenomenon narrated can be revealed. The interpretation is a dialectic movement between the whole and the parts of the text, understanding and explanation, closeness and distance. The first phase, the *naïve reading*, aims to bring the researcher emotionally close to the text, to give a sense of the whole. The naïve understanding provides directions, ideas and suggestions for
further analyses. In the structural analyses, the researcher distances him/herself from the subject and the context, and analyses the decontextualised text, in order to validate or invalidate the naïve understanding. The critical reading based on the researchers’ preunderstanding, the naïve understanding, the results of the structural analyses (themes and sub themes) and relevant literature means a recontextualisation (Ricoeur 1976, Lindseth & Norberg 2004). The comprehensive understanding opens up for possibilities in the world in front of the text (Ricoeur 1976).

The interviews for papers II- III were listened through to check and correct the transcriptions. Then, naïve readings were performed where the texts were read several times, with an open mind, to obtain a sense of the whole, and naïve understandings were formulated (II, III). The structural analyses were performed in three phases. For paper II the text was analysed related to the naïve understanding being interpreted as living with malodorous exuding ulcers means being struck down in a debilitating process, and longing for consolation providing hope and restoring the self. First, the whole text was systematically read several times and meaning units relating to how the process of ‘being struck down’ was revealed in the text, were identified. Second, the entire text was read again and meaning units related to how ‘consolation’ was revealed in the text, were identified. For paper III, the whole text was divided into meaning units related to the naïve understanding being interpreted as caring for people with malodorous exuding ulcers means facing the demands and challenges of remaining close to contamination and suffering and struggling to act in the best interest of patients. The meaning units were condensed and abstracted (II, III). Further reflection on the meaning units, the condensations, the abstractions and how they were related to each other led to formulations of sub themes and themes (II). Third, the remaining text was read several times and reflected on and an additional theme was formulated. The sub themes were interrelated and difficult to distinguish as the text was very complex (II). For paper III reflections on the meaning units, the condensations, the abstractions and the relations between them, led to formulations of themes. Further reflections on themes, abstractions, condensations and meaning units led to formulations of sub themes. Finally comprehensive
understandings were formulated, based on our preunderstandings, the naïve understandings, the themes, sub themes and relevant literature (II, III).

Qualitative content analysis
Because nurses’ descriptions and reflections on ‘obstacles’ and ‘possibilities’ providing care as desired by people with malodorous exuding ulcers was in focus, the content of the interviews had to be analysed in order to fulfil the aim for paper IV. Qualitative content analysis focuses on the subject and context, and differences and similarities between and within parts of the text. The interview text for paper IV was interpreted according to Graneheim and Lundman (2004). Several content analyses were performed. Each participant was interviewed twice and all 12 interviews were seen as one text. The audio-recorded interviews were listened to and the text read to get a sense of the content. Ideas for further analyses were developed together with the co-authors. The text was broken down into meaning units, words, sentences or phrases related to obstacles and possibilities as described and reflected on by the nurses. Each meaning unit was condensed and abstracted, the content units compared and sorted into sub themes related to ‘obstacles’ and ‘possibilities’. The sub themes were reflected on and finally one theme was formulated. The findings presented should be understood in light of the findings from the study that aimed to illuminate the meaning of living with malodorous exuding ulcers (II).

Ethical considerations
The participants in paper I shared many experiences in nursing care and many had also worked together in the past. Some of the memories emerging during the dialogues were painful and evoked strong feelings. However, the participants encouraged each other to recognize that when these situations happened they did not possess the experiences and skills of today and they had made the most of difficult situations. In telling their stories and sharing memories it seems that participants opened up for mutual closures and healing of memories.

For the people living with malodorous exuding ulcers (II), it might have been painful to talk about their experiences and to expose their suffering to a stranger, but it seemed to be a relief to be able to narrate to someone who had time and interest to listen. There were no dependency between researchers and participants and that
might have facilitated openness and the willingness for participants to narrate without fear.

For the nurses (III-IV), the interviews might have evoked strong emotions and feelings of threat. However the interviewer stressed the purpose to learn from the nurses and that there were no intentions to assess or judge their work or them as professionals. The nurses shared their experiences and reflections with openness and sincere concerns about patients. Because interviews might evoke strong emotions time for reflection was allowed after each interview (II-IV) and I was also available for further contact at the participants’ request. They were all invited to call if they had any questions or thoughts to share. None of the participants asked for further contacts, however, I phoned one of the participants a few days after the interview to inquire if everything was all right. Because very little is known about the meaning of living with malodorous exuding ulcers and caring for such patients, it is important to learn and obtain knowledge in order to develop routines and approaches in the best interest of patients. Performing interviews is one way of obtaining knowledge. There are great benefits from performing interviews and, hence, very important to follow proper procedures, be open for participants’ needs and offer support.

For paper I approval was obtained from the Ethics Committee, Medical Faculty, Umeå University (280/97). For papers II-IV, approval was obtained from the Ethics Committee, Medical and Odontological Faculty, Umeå University (section 451/01, Reg.No. 01-386). All participants received written information describing the studies, informing them that participating was voluntary and that they could leave the study without giving any explanation. Confidentiality was also assured. Participants gave their consent to participate. On the occasion of the interview (II-IV), I further underlined the voluntary participation and the option to discontinue their participation in the study without giving any explanation. For papers II-IV, the chief physicians also received written information about the studies and gave their consent.
FINDINGS

Paper I

Based on interviews with retired nurses (I) the interpretation presented was that cleanliness, order and clear conscience were important in nursing care in northern Sweden around 1950. The theme cleanliness concerned the importance of cleaning, a work that was of high priority. As the participants narrated, everyone and everything that was dirty was cleaned, patients as well as equipment and facilities. What was clean had to stay clean and therefore it was an issue to preserve cleanliness even if there was no apparent threat. Nurses would strive to preserve cleanliness at all times, as they as well as the environment were expected to stay clean regardless of the circumstances. Infections posed dangerous threats and nurses’ knowledge about hygiene was essential to protect patients from diseases both in hospitals and in patients’ homes. Because of the primitive conditions and no antibiotics, it was essential to protect patients and staff from contamination. According to participants, special routines for blood letting, surgery, bed making and keeping infected patients separated from non infected, were followed. The theme order was, as interpreted in this study, an important issue for nurses. By addressing people in a proper way and letting the social structure in the community also be present in the hospital, the social order was maintained. Participants narrated how they accepted and obeyed superiors and the formal decisions made without questioning anything, and hence, as interpreted in this study, nurses adapted to the organisational hierarchy. This also meant that RNs never took part in work “beneath their position” and that they always knew whom to turn to, who was in charge. Physicians were always put first and protected from seeing nursing care performed. Participants stressed that people, patients as well as nurses and nursing students, and everything within the ward must look perfect, always. This was interpreted as the importance to maintain appearances for people, attire and environment. The RN was responsible for this and spent a lot of time preparing and controlling staff and facilities, how they looked, to assure the perfect order. The daily work adhered to standard routines, with separate routines for day and night shifts. There were routines for everything and following routines was very important regardless of one's position. Keeping a clear conscience meant, as interpreted in this study, that they had good relations with people, that they lived in the forgiveness of God, knew that they were doing their duty, did what was right and
good and tried to be good persons. Participants narrated how this was a concern for nurses themselves as well as for the patients. By cleaning patients and their surroundings over and over again, as narrated by participants in this study, by preserving order in various ways and by keeping a clear conscience, nurses committed themselves to preserving purity.

**Paper II**

Based on interviews with people with malodorous exuding ulcers (II) the meaning of living with malodorous exuding ulcers was interpreted as including two processes. The themes related to the process of ‘being struck down’ describe a dark process and the themes related to the process of ‘finding consolation’ describe a process offering the possibility of returning to ordinary life, and of feeling whole again.

The theme *feeling dirty* involves living with the smell that cannot be hidden, constantly being reminded of the ulcers and feeling ashamed of their appearances when among others. It also involves not understanding what is going on, and regretting not seeking proper help earlier. In addition, being aware that living with malodorous exuding ulcers unavoidably involves the family gives a troubled conscience. The theme *being trapped* stood out in the text and concerns all the things one has to give up and not participate in because of the ulcer. The need for moving carefully because of thick and uncomfortable dressings, economic constraints, and having to adapt to all the people one depends on for dressing changes and domestic help also contributes to the feeling of being restrained. Being trapped also means being torn between incompatible choices, having to cope with dilemmas like the importance of taking pain killers while having another disease that precludes this. Feelings of powerlessness are overwhelming in situations where nothing or nobody can provide consolation as this is like nothing ever experienced.

The theme *losing confidence* concerns feeling violated when forced to repeatedly explain about the dressings, listen to comments about their appearance and not being taken seriously by professionals in health care. This also evokes feelings of mistrust because the professionals one is dependant on, and is expected to have confidence in, do not seem to earn that. One feels betrayed when nurses and physicians do not
console and confirm one as desired and expected. Bodily changes, affecting the image of oneself as interpreted in this study, in addition to feeling violated, betrayed and mistrust contribute to the breaking-down process and the feeling of being alienated. The theme *losing hope* is about the pain tormenting and attacking in various situations and sometimes turning nights to nightmares. This leads to exhaustion and when the pain becomes nearly unbearable the feeling of being somewhere else and caring about nothing arises. Thoughts about the future can make one fearful because no one can tell what to expect and nothing can be done to avoid whatever will happen. Feelings of fear that others can smell the ulcer or that the odour will return are constantly plaguing. Because of all the suffering, both living and dying can be feared, adding to the feeling of losing hope.

* Becoming frustrated is the only theme that includes a sparkle of power. It implies the potential for action and deep down the hope for improvements. Waiting for help and for the ulcer to heal and being able to do nothing to speed up the process can make one impatient. Important aspects of life are impossible to keep up because of travelling and dressing changes and having one’s time scheduled by all the professionals one depends on. Being deprived of time is a definite source of frustration. The theme *protecting oneself* stood out and concerns trying to avoid additional pain and suffering by withdrawing from threatening situations and also from other people. By protecting others, one is protected from the pain of seeing others facial expressions and avoidance behaviour.

The theme *experiencing kinship* concerns the strong desire to belong somewhere, to be part of a greater context where one can feel wanted and can make a difference. Having people around, being embraced by God and feeling God’s unconditional love, or being embraced by nature with animals and everything that grows contributes to the experience of kinship. Sharing experiences, worries, jokes, daily activities and special events also contribute to that experience. *Encountering genuineness* stood out as a theme and, as interpreted, concerns people who can be trusted and relied on because they are genuine. Devoted nurses with knowledge and skills encourage patients in a sincere way; they help connecting to the life going on outside the world of suffering. When getting help without having to argue and fight, and meeting the
same nurse and physician every time at the hospital it becomes possible to relax because one knows that one is recognised and that means feeling relieved. Placing oneself in the hands of those on whom one depend means relinquishing the control otherwise needed for defence against violation. When meeting genuineness, and seeing the humour in a situation and sharing that with others, it becomes possible to shift focus from the ulcerated body, and achieve consolation. This means regaining control by being regarded as more than merely a body and anticipating an end to suffering, as interpreted in this study. It means making a comeback in terms of autonomy, regaining control over the daily life, making it possible to feel safe, and that offers hope.

The meaning of living with malodorous exuding ulcers can be understood as being trapped in a debilitating process that slowly strikes one down. One is completely powerless against one’s body and suffering. There is a longing for purity and wholeness and for one’s life to improve again. One is struck even further down when the consolation longed for is not provided. One cannot do anything except endure but it becomes more and more difficult not to despair. Finally one runs the risk of affliction (cf Weil 1973). One is affected physically, socially and psychologically in a way that crushes and degrades one. Consolation is essential in counteracting this decline, it is needed to open up and start a changing process towards purity and wholeness (cf Weil 1987). One cannot do that by oneself, the people one depends on can mediate consolation but one has no right to demand it. One’s dignity demands consolation but it can only be appealed for, and when found, it certainly makes the whole difference.

**Paper III**

Based on interviews with nurses (III) the meaning of caring for people with malodorous exuding ulcers was interpreted as being exposed to and threatened by suffering that is overwhelming and invading.

The theme **facing the wound** concerns how changing dressings and providing bedside care becomes a challenging experience of closeness. It means becoming aware of and being touched by the situation for patients and their relatives. It means facing the
malodour, the appearance of the ulcer, encountering patients’ fear of smelling, and feeling exposed and watched during dressing changes. Being the person who uncovers what patients attempt to hide (the ulcer) means giving the secret away and feeling uncomfortable. Seeing patients struggle to cope with practical daily matters, seeing how they become dependant and ruled by healthcare routines and procedures, and feeling sorry for them was interpreted as perceiving patients’ vulnerability. Seeing how they are held captive by their wounded bodies gives rise to feelings of compassion. The theme facing one’s own defencelessness involves becoming aware of one’s own limitations, and how difficult it is to provide good care and feel satisfied with what is achieved. One cannot protect oneself from the malodour and one fails to do ‘good’ in front of patients, relatives, other personnel, and in one’s own eyes. The malodour, that gets under one’s skin and cannot be washed away, makes one feel invaded. Not knowing what to say or what to do when faced with challenges related to caring for people with malodorous exuding ulcers was interpreted as feeling helpless. In addition, feelings of shame arise when failing to fulfil demands, failing to keep up appearances and failing to know what is needed and wanted. Witnessing pain and suffering caused by other staff members, and not intervening, also adds to feelings of shame.

The theme struggling to shield one’s own defencelessness concerns developing strategies and finding power to face contamination and suffering. When the situation becomes too overwhelming and threatening one must find strategies to survive professionally and personally. Striving to be in control, by not revealing weaknesses, by focusing on the procedure at hand and reflecting on optional solutions is helpful. Staying and doing whatever has to be done despite malodour and contamination, not abandoning patients but enduring for their sake was interpreted as important in the struggle to shield oneself from failure. Seeking a way out was interpreted as a solution when not being able to endure malodour, contamination and suffering any more. Struggling to shield patients’ vulnerability stood out as a theme and involves a desire to see and care for the whole person, not only the ulcer. It involves demands to perform the utmost and feeling so strongly for the suffering people that shielding them becomes a priority and one is prepared to put oneself at risk for patients’ sake. The interpretations revealed struggles like pushing boundaries where finding creative
solutions becomes an issue and being a ‘jack of all trades’ becomes an art. When both patients’ and relatives’ needs are hard to satisfy and doing good for patients means painful treatments or additional suffering for relatives, uncomfortable decisions must be made. Moments of reciprocal relating beyond ulcers, dressings and roles, and sharing glimpses of human life with the person for whom one is caring was interpreted as sharing togetherness. Being present in the very moment and wanting to know the person beyond the ulcers makes mediating hope possible. Sharing togetherness also opens the way for experiencing hope and confirmation.

The physical proximity and the suffering affect nurses. One cannot make ulcers or malodour disappear and if one feels unable to provide relief and help, one runs the risk of experiencing desolation. This study shows that when nurses can see beyond ulcers and face the person with the contaminated body without despair, they can make a difference even if the malodour and ulcers still remain. Seeing the person with the contaminated body, and having support from colleagues and other personnel seems to be the precondition for making a difference and feeling satisfied and confirmed as nurse.

**Paper IV**

Based on interviews (IV), nurses’ reflections on obstacles and possibilities providing care as desired by people with malodorous exuding ulcers were illuminated. Their reflections involved patients, participants themselves as individual professionals, other nurses, physicians, the organisation and management, and the daily work. In light of the interpretations of people’s experiences of living with malodorous exuding ulcers, as presented in paper II, the interpretations of participants’ reflections were presented as one theme *striving to do ‘good’ and be good*, with the sub-themes *experiencing clinical competence constraints, experiencing organisational constraints, experiencing ineffective communication fearing failure* and *experiencing powerlessness* related to ‘obstacles’ and the sub-themes *spreading knowledge on ulcer treatments, considering wholeness and creating clear channels of communication* related to ‘possibilities’. 
Striving to do ‘good’ and be good involved participants’ understandings for patients’ situations as well as concerns about the work situation and conditions for themselves as well as other professionals. The striving to do ‘good’ for suffering patients and be good nurses were seen throughout participants’ reflections and seemed to be of major concerns for all of them.

The sub-theme experiencing clinical competence constraints involved participants’ reflections on striving to do ‘good’ by providing the best possible treatments for patients yet finding that difficult because of clinical competence constraints. Participants in hospital care expressed disappointments with nurses in primary care and vice versa. This lack of knowledge about ulcer treatments and how work is organized in other settings might lead to a lack of continuity in treatments with risks for prolonged healing of ulcers and additional suffering for patients according to participants. Organisational constraints concerned nurses’ efforts to assume responsibilities for assessments and treatments, and cooperate with other professionals and with other settings to provide good care for each patient yet finding that difficult because of no consensus on strategies and lack of professional support. Intentions to begin dialogues with patients and also efforts to make nurses’ voices heard became difficult because of the organisation’s priority: cost containment and patient numbers, instead of quality of care. Lack of common priorities and lack of cooperation complicated daily work, was time consuming and might cause patients additional suffering.

Experiencing ineffective communication concerned nurses’ striving to do ‘good’ by connecting with patients and communicating with other staff members and settings, yet finding problematic differences between care contexts and care cultures in community, primary and hospital care. Lack of discussion with colleagues and physicians, lack of documented care plans and problems adhering to a plan of care, even if they had made one were also reflected on as obstacles by participants. Fearing failure involved participants’ reflections on their desires as individual professionals to do ‘good’ and be good nurses, yet being afraid of not being able to fulfil own and others’ demands. Fear of failure and exposure of their weaknesses or vulnerability can prevent nurses from acting in patients’ best interest as nurses, on their own, have
to face patients’ anger, grief and fear. Participants talked about the risk of only focusing on the ulcer if nurses avoid becoming involved with patients because it is too much to deal with. Experiencing powerlessness involved participants’ concerns for patients as suffering human beings and the desire and striving to provide the best care, yet feeling prevented from doing ‘good’ and being good nurses by professionals who did not fulfil their obligations as they should. Hence, participants were forced to manage the consequences and take the shame. Not knowing what patients thought or how to approach patients, not knowing what to do to facilitate healing or seeing other professionals who did not seem to care about the patients, also could make participants feel powerless as all this might prolong healing and harm patients. Participants stressed that when competence, time and organisational support fail, the demands on each nurse may be overwhelming and too much to handle for one individual.

Participants reflected on possibilities providing care as desired by patients with malodorous exuding ulcers and expressed an understanding for the different working conditions in hospitals and in primary care. They stressed the importance of spreading pertinent knowledge about various dressing materials and procedures to other nurses and settings. Then it would become possible to cooperate more closely, agree on assessments, decide strategies for treatments, and limit the use of various materials and strategies leading to decreased number of dressing changes, lower health care costs and less patient suffering. The importance of providing education about ulcer treatments, basic as well as advanced levels, in nursing to ensure the effective treatment for each patient was stressed in the interviews.

Participants posed the need for a perspective where both the ulcer and the person were taken into consideration. Considering wholeness and learning about how to approach patients, how to ask appropriate but difficult questions to understand patients’ thoughts and how they experienced their situations was a concern for participants. They talked about how patients should be involved, their thoughts and personal experiences should be inquired and professionals should be true, honest and should try to be present in the situation. Hence, one should stay by patients, look them in the eyes, invite them to be open, listen to them, give them time and be
prepared to receive more than they initially express on the surface. Students must also become sensitized to needs of patients according to participants. They called for discussions in the work unit and they also called for guidance, for professional and personal support from peers as well as nurse leaders, in responding in a supportive, encouraging, and sincere way that provides hope for patients.

Clear channels of communication are essential to establish trust and good cooperation around patients, and to provide a foundation for finding new ways to share important information and provide good care according to participants in this study. They talked about how patients can read the body language and the need for being aware of and learning about how we communicate with patients. Participants reflected on involving patients in planning and decisions making, called for consensus on policies and procedures for documentation, and actually adhering to what is decided. That would help secure continuity in care and communicating with other professionals. Participants stressed that patients must feel safe, consistently obtain the same information and know the ulcer would be taken care of as planned no matter who changed the dressings.

The obstacles and possibilities reflected on in this study illuminate serious work situations that could be interpreted as leading to stress of conscience if nurses are prevented from carrying out what they assess as ‘good’ for patients. Participants described working in situations where obstacles held them back and possibilities indicated their desire to provide good care; to do ‘good’ and be good nurses. The demands on individual nurses seem high and call for extended cooperation between professionals with various competences within settings as well as between hospitals and primary care. This study points to the need for team work where each person can get professional and personal support to treat ulcers professionally and do ‘good’ for patients but also to be satisfied with what is achieved and feel good. Nurses depend on a leadership that lives up to demands to organize and manage health care in ways that make cooperation possible, convey knowledge, and provide support, confirmation and prerequisites for nurses to carry out the care they assess is needed.
The findings in paper I point to the phenomenon of purity. According to Douglas (1978), purity is apparent in the order of rituals, which creates and maintains a certain culture and also visualises patterns for social relations. People were almost ritually cleaned when admitted to the hospital (I). They were undressed, their bodies washed and then dressed as ‘patients’ in the basement before transferred to the ward. Patients’ bodies, their clothes and bed attire were then preserved clean and protected from contamination all the time. At that time antibiotics were unavailable, which meant that infectious diseases and everything that was contagious posed dangerous threats. Protecting from contamination could be a question of life and death. Clear conscience was an issue as narrated by the retired nurses, and asking for forgiveness important for getting good relations to God as well as to people. The Christian traditions provided rituals to help nurses to achieve this, both for them and for the patients they cared for. This seems to be a consequence of the culture at that time and the rituals were available and beneficial for everyone, not only for believers.

Ricoeur (1969) writes that impurity symbolizes evil outside me, and threatening me. The retired nurses narrated how contagious diseases posed threats, how they were afraid to become contaminated and how they strove to protect patients from contamination (I). The nurses were also concerned about order and maintaining the social order by keeping relations to other people as formal as was socially accepted. Good personal relations to others were also an issue and they were concerned when patients had troubled consciences. The strive for purity; for cleanliness, order and clear conscience could, in light of Ricoeur (1969), be understood as mediating consolation in terms of cleaning, and restoring relations to other people and God (I).

The distinction between clean and pure made by Lagerspetz (2006) opens up for further understandings. He claims that concepts of dirt are teleological, i.e. one must consider the purpose and the aim when understanding if something is dirty and one must understand the role of the host object as well as consider the situation at hand. The nursing care narrated in paper I was different than today, and that should consequently be considered. According to Lagerspetz (2006) impurity penetrates the whole host object, might be disgusting and cannot be cleaned away. Dirt concerns the surface, a surface that can be cleaned, and does not change the identity of the host.
object. The main issue seems to be whether the host object is ‘worth’ cleaning. According to Lagerspetz (2006), if a core of purity does not exist there is no difference between surface and substance and hence the host object could be considered impure and not worth cleaning. Purity could never be achieved by cleaning the surface. On the other hand if the host object is considered pure, if one knows that a pure core exists, and if the surface becomes dirty there is a desire to get through to the pure core or at least keep the surface free from dirt. This seemed to be what the retired nurses strove for in their daily work (I).

Malodorous exuding ulcers could be experienced as disgusting by the patients and also by the nurses who must be close and treat the ulcers (II, III). Lagerspetz (2006) claimed in his research that concepts of dirt and disgust should be separated and not seen as similar. What is disgusting is disgusting throughout the element; there is no difference between surface and substance. Miller (1997) argued that disgust is a moral and social sentiment as well as an emotion. The capacity to feel disgust comes with being human, it is a natural thing. The feeling of disgust always evokes in response to something, it is not just an unattached feeling (p 8). When something or someone is disgusting and gets too close, a person can feel threatened of becoming disgusting by attachment. Hence, disgust is related to danger, pollution, contamination and the danger of defilement. A person’s own body can be a source of disgust. Bodily excretions, odours emanating from persons’ bodies are interpreted within a social and cultural context and hence the feelings of disgust will be associated with imagined predictable social and cultural scenarios (II, III). Disgust is related to shame and both could be seen as related to self-loathing. Shame is according to Miller (1997) a person’s response to others’ disapprovals and marks a shortcoming, an understanding of not measuring up (II, III). When other people disapprove of one’s appearance one feels ashamed (II). If the nurses can see the person with malodorous exuding ulcers beyond the ulcers they see a person who is pure but with a dirty surface. Hence, they do not feel disgust and they can confirm the person with malodorous exuding ulcers so he/she may not feel ashamed (II-IV).

According to Lagerspetz (2006) we are as humans entrusted with the world and with responsibilities to maintain some kind of order where all ‘things’ live up to their
specific teleology. Dirt can fall upon people or they can be responsible for becoming dirty by themselves but in both cases their responsibilities to care for ‘things’ they have been entrusted with, forces them to act. Lagerspetz further argues that the wish to become clean, to make the body clean when being dirty, expresses an awareness of how the body is and how it should be, an awareness of an existing ideal. With those eyes people also regard other things and other people. A dirty person can awaken one’s indignation or/and compassion depending on how they judge the situation and the person (cf III, IV). According to Lagerspetz (2006) the boarder between a person and those being around depends on the situation, it is not fixed. Physical proximity, as experienced in caring, means that the distinctions between what is clean and dirty will be reconsidered. Those involved are forced to share an intimacy that could evoke feelings of becoming dirty if not a pure and dignified intimacy can be preserved. According to our studies patients are exposed and dependent (II) and hence the responsibilities to secure such an intimacy fall upon nurses and other professionals caring for patients (III, IV). Being forced to accept help from another person or being forced to help could, according to Lagerspetz (2006), be humiliating for both but it could also mean proximity and sharing, going together on the boarder of life. Hence, caring for people with malodorous exuding ulcers seems to demand skills, sensitivity and respect to make sharing and proximity possible and open up for dignified encounters (II-IV). The question to raise here is how individual nurses can manage these demanding situations, how they can find knowledge and support to develop necessary sensitivity and skills to support a dignified intimacy when caring for people with malodorous exuding ulcers. The patients with ulcers are totally dependant and also expressed how they longed for consolation in terms of experiencing kinship, encountering genuineness and gaining control. When ulcers and malodour remained despite trying treatments and patients did not experience consolation it meant threatening affliction (II). The nurses expressed many concerns about their own possibilities to provide good care (III, IV). We interpreted that they could feel threatened by overwhelming and invasive suffering and needed to shield patients’ vulnerability and their own defencelessness (III). Nurses also described and reflected on how knowledge on ulcer treatments and wholeness, and clear channels of communication was needed to provide good care (IV). It seems reasonable to believe
that nurses need tangible support to be able to create the pure intimacy that opens up for dignified encounters and mediating consolation.

In their efforts to preserve patients’ cleanliness, and a perfect order in the ward it seems that the retired nurses proclaimed every patient’s dignity and the right to be treated and met as pure. By preserving cleanliness nurses preserved goodness as they strove to keep up clean appearances and surfaces (I). In light of Lagerspetz (2006) it also seemed that they preserved purity in their efforts to keep clear conscience and help patients to get clear conscience. It seems that the nurses saw the needs for cleanliness as well as purity and also had the tools to achieve both along with knowing how to use them (I). In nursing care or any care today, we could assume that people with their bodies, as host objects, would be considered as being pure considering prevailing common values in nursing care. Swedish health care is founded on an ethical platform based on ethical principles; all human beings share the same human dignity and have the same rights, resources should be distributed or used according to needs and when deciding on interventions or treatments one should consider costs and effects in terms of increased health and quality of life. For professionals in health care, this could mean facing difficult priorities and decisions (SOU 2001:8, Prioriteringscentrum 2007:2). Whatever the bodily condition a person still has inviolable dignity. Hence, people with malodorous exuding ulcers should be treated like persons, fully human, and competent to take part in decisions on their own care (II-IV).

In light of Lagerspetz (2006) our studies show that both patients and nurses can experience impurity (II, III). People can feel dirty and experience themselves as impure related to the malodorous exuding ulcers and a situation harder and harder to endure. They are affected in a crushing and degrading way and struck further down when consolation longed for is not provided, and hence they might not feel human anymore (II). This could also be interpreted as an ‘unhomelike’ experience. The body as an object is altered; the skin breakdown with exudate and malodour has opened up the body to others. People might feel vulnerable and threatened and need help to regain their being-in-the-body and their being-in-the-world (II), (cf Marcel 1981, Svenaeus 2000). Nurses can also experience themselves as impure (III). The physical
proximity and the suffering affect nurses. The malodour that cannot be washed away can make nurses feel invaded, make them feel dirty. When, in addition, failing to fulfil external demands as well as their own intentions to provide good care and be good nurses they can experience impurity (III). Experiencing themselves being alone in demanding situations, without other professionals to discuss with or without support from others in the setting (III, IV), adds to the feeling of being impure (III).

As reported in paper II people with malodorous exuding ulcers experienced themselves as unclean, because of the ulcers, dressings and the problems e.g. to shower properly. We interpreted that they also felt impure because they did not feel respected as human beings; they did not get their dignity confirmed by other people who could not see beyond the ulcers, and according to Lagerspetz (2006) could not see the pure core under the unclean surface. Broken relations, meeting health professionals who knew not how to treat the ulcer, and sometimes even inflicted pain, who, as interpreted, were not trustworthy or genuine, contributed to the feeling of being impure (II). The kinds of rituals, as described in paper I, for providing cleanliness or purity were, according to papers II-IV, not available and the people with malodorous exuding ulcers might risk being left in their suffering (cf Ricoeur 1969). In the light of Lagerspetz (2006) it seems that the nurses recognised patients’ feelings of being dirty or unclean but not their feelings of being impure even if nurses in their narratives (III) showed that they could understand that the patients might feel that way and the significance of such feelings. When feelings of disgust occur there is a risk that nurses fail to meet a patient as pure even if it is their intention (cf Miller 1997). Caring relations can make patients feel confirmed as pure, despite the contaminated body, when they are not abandoned and people are not afraid of staying close (II, III). Confirmation communicates acceptance and when communicating relational messages like ‘I see you’ or ‘I am not afraid of coming close to you’ nurses can confirm patients (cf Cissna & Seeburg 1981). Finding consolation as longed for by people with malodorous exuding ulcers in terms of experiencing kinship, encountering genuineness and gaining control (II), and by nurses in terms of being recognised for their demanding work and receiving support (III), becomes important because being confirmed and feeling included makes one feel pure.
As reported in paper III, nurses were aware of patients’ ‘uncleanliness’. The ulcers and the dressings were unclean, and they could not clean the patients and make the ulcers go away as they would have liked to. However, the text disclosed that they saw patients as pure, i.e. they saw them as dignified human beings and felt compassion. Nurses could see and understand that patients could experience themselves as impure. By cleaning ulcers, helping patients get washed properly and making comfortable dressings, nurses not only preserved cleanliness but indirectly preserved purity because their efforts made patients feel that they deserved being cleaned. The text also disclosed that being close to contamination, malodour, exudate, and suffering, was demanding and could be scaring and even raise feelings of disgust (III). There is a risk that feelings of disgust become overwhelming in a way that makes it impossible for nurses to remain calm and composed (cf Miller 1997). The threat for nurses is the threat of failing to show patients that the nurses regard them pure, that they truly see them as pure. When failing, and giving in to the feelings of disgust, and becoming overwhelmed by the sensations, nurses also risk becoming overwhelmed by feelings of shame (III). This scenario becomes a threat to the nurses as it is regarded important to be a good nurse, and good nurses show respect and treat patients as pure despite unclean bodies and dirty conditions (cf Lagerspetz 2006).

The model of consolation based on literature and interviews with people who mediated and received consolation, as described by Norberg et al (2001), provides the framework for our further interpretations. The authors claim that both the person who suffers, the sufferer, and the person who mediates consolation, the consoler, become ready for consolation by becoming present, open and available for the other. They both become open to express suffering, which means uncovering the wound, and to listen. This presupposes time and space for both to encounter each other. The consoling dialogue, which also can occur as silence, is based on communion and leads to a shift of perspective. Communion is a miracle, founded in transcendence, and a liberating experience. Being in communion is being aware of the sacred dimension and leads to a shift of centre from the suffering to the in-between, the feeling at home. In the model of consolation ‘wound’ is used metaphorically. Living with
malodorous exuding ulcers could, reasonably, be interpreted as having that kind of ‘wound’ in terms of physical ulcers as well as the suffering related to those ulcers.

In light of the model of consolation (Norberg et al. 2001), both people with malodorous exuding ulcers and nurses become open to see the physical ulcer as well as the suffering, the wound (II, III). Both recognise the ulcer, with its malodour and exudates (II, III), and the person with the ulcer recognises the suffering and the threatening impurity experienced when not being confirmed as a pure person (II). Nurses recognise patients’ feelings of being impure, but also their own vulnerability, the threatening impurity experienced as feeling ashamed (III). The ulcers cannot be made to magically disappear, nor can the malodour. Hence, mediating consolation means, for nurses, providing cleanliness in terms of having knowledge and skills to treat ulcers as optimally as possible (III, IV). In other words it means becoming very skilled in dressing procedures and dressing materials and developing routines for ulcer treatment and dressing changes. It also means providing purity in terms of confirming patients’ dignity by seeing them, listening to and believing them, and inviting them to become involved in treatments and decision making. For nurses, mediating consolation presupposes they, themselves are consoled in terms of being seen, respected and confirmed (III, IV).

Cleaning and knowing how to treat ulcers are part of nurses’ responsibilities. When nurses lack skills and knowledge about treatments they might feel insecure and worthless and might not want to expose their weaknesses by asking questions and discussing with others. They might feel ashamed. On the other hand when they feel secure about ulcer treatments they can see patients and confirm them as persons (III). The obstacles and possibilities described and reflected on by the nurses (IV) seem to concern purity and impurity for nurses as well as patients (cf. Lagerspetz 2006). The nurses’ intentions to do ‘good’ for patients and be good nurses could be interpreted as intentions to confirm patients as pure, as whole persons and the obstacles reflected on prevent nurses from achieving that. In this struggle nurses experience impurity when they fail and feel powerless and ashamed when they see patients suffer. The possibilities reflected on would open up for nurses to experience purity again (III, IV). Nurses reflected on how structures and consensus among all
professionals on procedures as well as content was needed. Nurses expressed a need to acquire updated knowledge about ulcer treatments, to get their assessments acknowledged and respected, and to be part of a committed and skilled team of various professionals (IV). This would help nurses feel confirmed; exposing one’s vulnerability becomes nonthreatening, and hence shifting focus from themselves to the patient becomes possible (III). When feeling confirmed and respected, as a professional as well as a person, nurses can confirm people with malodorous exuding ulcers, and respect them as persons despite their contaminated bodies, and hence they can feel pure (II-IV), (cf Lagerspetz 2006). In order to achieve nurses’ goals of being good nurses, both organisation and management must live up to the demands of providing the best professional and personal support and working conditions for each nurse (cf Fagerström 2006, Swedish Nurses’ Association 2008).

**Methodological considerations**

This thesis comprises papers reporting qualitative studies aiming to illuminate the meaning of living with ‘impurity’ in terms of malodorous exuding ulcers and the meaning of caring for people who experience themselves as having ‘impure’ bodies in institutions and in people’s homes. This means striving for ‘understanding’ and calls for designs focusing on interpretations and meanings of individuals’ experiences where the researcher is involved as instrument in the research process. Hence it is important to find an appropriate sample which means to find participants who can provide rich and varying data that provide information making it possible to fulfil the aim of the study (cf Polit & Beck 2004). Another way of fulfilling the aim of this thesis would have been to include participants representing various kinds of experiences of bodily ‘impurity’ like eg incontinences. Focusing on malodorous exuding ulcers and including participants with various diagnoses and experiences, provided us a rich material to analyse and a deeper understanding of the trying conditions for people living with the ulcers as well as the nurses caring for those patients. A starting point for this thesis has been that knowledge is co- created. In the interview situation the interviewer and the participant jointly create the interview. Texts based on interviews are products of this creation and related to the prevailing contexts and values (Lincoln & Guba 1985, Mishler 1986).
For all papers (I-IV), interviews were performed with intentions to be open to what participants narrated, and to be open for their reflections. For paper I, researchers and retired nurse teachers familiar with nursing care around 1950 led the group dialogues and rendered an open, relaxed atmosphere during the interview sessions. The group dialogues were performed as one part of a project aiming to document nursing care around 1950. The aim of the study (I) was not to document what had actually happened, but to illuminate nursing care as narrated by the participants. In the group dialogues participants decided what to narrate, no specific questions were posed, and the topics emerged spontaneously. They narrated in light of their life experiences and reflected on their experiences as professional care providers in relation to experiences of being patients, relatives or visiting friends in hospitals today. In the group dialogue this brought new light to their experiences from the past and provided us a rich text to analyse. In light of the research process and the findings a different and more focused approach in the interviews might have been useful to obtain data. On the other hand, because the topics emerged spontaneously, the results are even more interesting.

I performed the interviews for paper II-IV. The people with malodorous exuding ulcers (II) were interviewed at a time and place they decided. For me, coming as a guest into participants’ homes means taking a different position compared to welcoming participants in my work place. It was difficult to avoid being interrupted by family members during the interviews in participants’ homes or by other nurses when performing interviews in the hospital (II-IV). However, we could continue the interview without feeling uncomfortable and all participants openly and willingly shared their experiences that provided rich data. It is difficult to tell how the various conditions influenced the quality of the interviews. A spouse’s presence might make one avoid telling sensitive information (II). When nurses were asked to narrate their experiences caring for people with malodorous exuding ulcers (III), they referred to recent as well as long ago experiences. Some participants seemed to welcome this opportunity to share what had been on their minds, while others were more guarded. Hence, the interviews varied in length, depth and conciseness. However, it seems important to have covered various responses and approaches as it provides more varied and rich data.
The conversational approach (IV) could be considered a disadvantage because the interviews might become less open. Participants might also become influenced in a way that affected the outcome of the interview. In the interview situation it became apparent that participants became more affected than anticipated when being confronted with the findings from paper II. In order to continue the interviews and encourage participants to further reflect, I choose to interpose supportive and confirming comments. Comments helping participants stay focused on, or turn back to, the findings presented in paper II were also made in order to fulfil the aim of the study. This might be considered influencing, but it helped participants continue reflecting that way and the interviews were rich and varied in length and content.

Criteria for quality in qualitative research are often debated. Obtaining high quality data is essential and the research process must be rigorous to fulfil criteria of trustworthiness. (Morse et al 2002, Graneheim & Lundman 2004). Throughout the research process, strategies for reliability and validity must be implemented integrally and in a self-correcting way (Morse et al 2002). To meet the criteria for reliability and validity in our studies, a systematic approach and logical methodological coherence was adopted. Notes were made after the interviews. We attempted to describe procedures for data collection, transcriptions and analyses carefully, in order to present the interpretations as clearly as possible. Quotations were also inserted to illuminate our interpretations. During the entire process of data collection and analyses each step was discussed among the authors to achieve clarity and consensus.

All interviews were transcribed into text (I-IV) and the texts were interpreted using qualitative methods. All the text was interpreted, except for paper I where parts of the text not related to the aim of the study were excluded. As a text is related to the prevailing contexts and values, it involves multiple meanings and can be interpreted in various ways (Lincoln & Guba 1985, Mischler 1986, Graneheim & Lundman 2004). Therefore, I am aware of that our interpretations are not the only possible interpretations (Ricoeur 1976).
Conclusion
Living with malodorous ulcers and caring for those patients means facing a physical proximity that is trying for both patients and nurses. According to Frank (1995, 2002) bodies need voices. People suffering from illnesses need to tell their stories and those who provide medical and nursing care need to listen because the story told is not only about illness; it is told through a wounded body. The story told is embodied in a specific person and gives voice to an experience that, according to Frank, the medical paradigm cannot describe. The story needs to be told in order to make sense of the sometimes confusing and threatening experiences, and to recreate interrelatedness in a new context. “Illness is about learning to live with lost control” (p 30) and telling stories, or turning illness into stories as Frank puts it, is meta-control, it means doing something. The situation for nurses can be very demanding. Nurses might experience threats as well as powerlessness and that means facing their own vulnerability, their shortcomings and limitations. These feelings and experiences draw near to experiences of suffering. Hence, nurses also need to turn their experiences into stories and they need listeners to their stories in order to be able to make sense and find ways to cope with patients suffering. The challenge for nurses caring for people with malodorous exuding ulcers seem to be to show patients that they are fully human, that they are whole persons and pure despite the ulcers and experiences of lost bodily control, and treat them likewise. However, individual nurses cannot carry this burden on their own, as this study shows.

Both people with malodorous exuding ulcers and the nurses can experience impurity and risk facing desolation. Both patients and nurses may experience purity through consolation. For nurses, mediating consolation presupposes being consoled by being recognised for their challenging work, being respected and included in multi-professional teams supported by the health care organisation and the leaders. Then patients can become consoled, and feel restored and fully human again despite the contaminated body.

RELEVANCE FOR PRACTICE
Even if nurses need to tell their stories and need listeners to their stories, they, in addition, need more tangible support. They need knowledge about ulcer treatments,
guidance and support to deal with suffering patients, and they need organisational support in terms of committed nurse leaders and structures for communication. According to this study that might open up for seeing patients as whole persons, providing good care, being satisfied with what is achieved and being good nurses.

Both patients and nurses in this study seem to anticipate that much more could be and should be done to improve the care of people with malodorous ulcers. The responsibilities to provide good care and to develop and evaluate treatments and care fall upon the health care system. This study’s findings are in line with the strategy for developing nursing care developed and adopted by the Swedish Nurses Association (2008). The authors stress the importance of an ethical approach in nursing care, a systematic work to uphold safety in nursing care, applying professional and organisational knowledge and exercising good leadership. When considering these aspects, implementing multi-professional teams for ulcer treatments and care of people with severe ulcers would be desirable as well as possible. It is already known that treating hard-to-heal leg ulcers is time-consuming and costly and e.g. educating nurses and re-organising care of patients with hard-to-heal venous leg ulcers decrease the time for healing and is cost-effective (Öien et al 2000, Ragnarsson Tennvall & Öien 2006, Ragnarsson Tennvall et al 2006). This thesis adds that it would be possible to make nurses feel satisfied with what is achieved, make them feel that they are doing ‘good’ and are good nurses. That seems essential when facing the challenges caring for people with malodorous exuding ulcers to provide good care with competence, perseverance and dignity, and also prevent the negative consequences of stress of conscience among nurses.

**SUMMARY IN SWEDISH – SVENSK SAMMANFATTNING**

Det övergripande syftet med avhandlingen är att belysa innebörden av att leva med ’orenhet’ i form av sår som luktar och rinner och innebörden av att vårda människor med ’orena’ kroppar på institution och i sina hem. Avhandlingen består av fyra vetenskapliga artiklar baserade på kvalitativa studier.

Syftet med studie I var att belysa omvårdnaden i norra Sverige utifrån berättelser från 27 pensionerade vårdare som hade arbetat vid sjukstugor och sjukhus i mitten av

Syftet med studie II var att belysa innebördens av att leva med sår som luktar och rinner och narrativa intervjuer genomfördes med nio personer som hade, eller hade haft, svårhänta sår som luktade och rann. Intervjupersonerna hade varierande diagnoser och sår på olika delar av kroppen. Intervjupersonerna spelades in på band, skrevs ut till text och analyserades med fenomenologisk hermeneutisk metod som gör det möjligt att tolka innebörden av ett fenomen. Innebörden av att leva med sår som luktar och rinner kan tolkas och formuleras som två processer: ’att brytas ner’ som innehåller sex teman: att känna sig smutsig, att vara fångad, att förlora tillit, att förlora hopp, att bli frustrerad och att skydda sig själv och ’att finna tröst’ som innehåller tre teman: att uppleva gemenskap, att möta äkthet och att få kontroll. Att leva med sår som luktar och rinner kan förstås som att vara fångad i en process som sakta bryter ner en. Det finns en längtan efter renhet, att få känna sig hel och efter att livet ska bli bättre och lättare. När personer med sår som luktar och rinner möter äkthet, känner sig älskade, räknade med och känner sig respekterade som hela människor trots sina sår, då upplever de sig renade. Den smutsiga kroppen smutsar inte längre ner deras självbild och självkänsla, de känner sig upprättade, som hela människor igen. Det är bara när de känner sig som hela människor som de kan återta
kontrollen och tänka på ett liv bortom såren. Även om sjuksköterskor och undersköterskor inte kan få såren och lukten att försvinna så kan de bidra till att patienternas liv förbättras. Det gör skillnad för den som har sår som luktar och rinner att få tröst i den form som uttrycks och längtas efter i den här studien. Studien visar på vikten av att se hela människan, se personen bakom såren och inte bara en kropp eller ett sår.


Innebörden av att vårda personer med sår som luktar och rinner kan förstås som att vara utsatt för och känna sig hotad av lidande som kan kännas överväldigande och till och med invaderande. Man riskerar att uppleva tröstlöshet när man inte kan ta bort lukten eller få såren att försvinna och inte kan skydda patienten från ytterligare lidande. När man misslyckas och inte kan stå ut med de svåra och utmanande situationerna blir det ytterligare en börda som ökar risken att drabbas av tröstlöshet. Att vårda personer med sår som luktar och rinner är krävande, både på ett personligt och professionellt plan och att vara nära och konfronteras med det kroppsliga lidandet påverkar vårdarna. För att vårdarna ska kunna känna att de verkligen kan göra något för patienterna och kunna känna sig nöjda och bekräftade i sitt arbete, tycks det vara en förutsättning att de ser personen under den kontaminerade ytan, och dessutom får stöd från andra. Studien pekar på behovet av utbildning och
möjligheter till reflektion kring sårbehandling och vård av personer med sår men också behovet av öppenhet i vårdorganisationen, bland dem som ansvarar för ledning och utveckling, för att kunna erbjuda möjligheter för tvärprofessionellt samarbete i form av team.

Syftet med studie IV var att belysa vårdares reflektioner kring hinder och möjligheter att ge den vård till personer med sår som luktar och rinner som dessa personer önskat. Vi gick tillbaka till sex av de vårdare som intervjuats i delstudie III och intervjuade fem sjuksköterskor och en undersköterska. Varje deltagare intervjuades vid två tillfällen. Vid första intervjuet presenterades muntligt tolkningarna av intervjuerna med personer med sår som luktar och rinner från studie II. En bild som illustrerade tolkningarna, med tolkad helhet, teman och subteman, visades samtidigt för intervjuersonerna. Först gavs de möjlighet att reagera på det som just presenterats och sedan ombads de reflektera över vad som kan hindra att man tillgodoser det patienternas frågade efter, längtade efter, enligt studie II. Intervjuersonerna ombads också reflektera över möjligheter att förändra och förbättra vården och sina egna möjligheter att bidra till detta. Inför nästa intervju ombads intervjuersonerna ytterligare reflektera över möjligheter till förändring och sina egna möjligheter att bidra till sådana förändringar. Efter ett par veckor genomfördes den andra intervjun. Illustrationen med tolkad helhet, teman och subteman visades återigen och intervjuersonerna tillfrågades om förändringsmöjligheter och sina egna möjligheter att bidra. Alla 12 intervjuerna spelades in på band, skrevs ut till text och analyserades med hjälp av kvalitativ innehållsanalys.

I intervjuerna reflekterade intervjuersonerna kring patienter, sig själva som enskilda professionella, andra sjuksköterskor och undersköterskor, läkare, organisationen och ledarskapet samt det dagliga arbetet. Tolkningen av intervjuerna presenterades som ett tema: att sträva mot att göra gott och vara duktig, med följande subteman relaterade till 'hinder': att uppleva begränsad klinisk kompetens, att uppleva organizatoriska begränsningar, att uppleva ineffektiv kommunikation, att vara rädd för att misslyckas och att känna maktlöshet. Följande subteman relaterades till
'möjligheter': att sprida kunskap om sårbehandling, att tänka på helheten och att skapa tydliga kommunikationskanaler.

Det verkar som om arbete i team skulle underlätta vården av personer med sår som luktar och rinner. Intervjupersonernas reflektioner belyser en krävande arbetssituation som skulle kunna leda till samvetsstress om de förhindras att göra gott, att ge den goda vård de bedömer att patienterna behöver. Ett väl fungerande multiprofessionellt team skulle kunna överbrygga de hinder som intervjupersonerna i den här studien reflekterar kring. Teamet skulle tillhandahålla struktur, olika kompetenser, engagemang och stöd för realistiska prioriteringar och beslut så att sjuksköterskor och undersköterskor kan göra gott för patienter och känna sig duktiga. Makten att genomföra förändringar ligger inte hos vårdpersonalen utan de är beroende av ett lyhört ledarskap som lever upp till kravet att organisera och leda vårdarbetet så att det möjliggör samarbete, förmedlande av kunskap, tillhandahållande av stöd, bekräftelse och förutsättningar att ge den vård som vårdpersonal bedömer krävs för patienten.

Innebörden av att leva med 'orenhet' i form av sår som luktar och rinner och innebörden av att vårda personer med 'orena' kroppar på institution och i sina hem tolkas, utifrån de fyra delstudierna, som att sträva efter renhet (eng. purity). Patienter upplever orenhet när de känner sig smutsiga, förlorar hoppet och inte känner sig respekterade som hela människor. Sjuksköterskor och undersköterskor upplever orenhet när de misslyckas att skydda patienters sårbarhet men också sin egen. De upplever orenhet när de ställs inför hinder som gör att de upplever sig förhindrade att ge god vård och att vara duktiga. Både patienter och sjuksköterskor/undersköterskor kan uppleva renhet genom att bli tröstade. För att sjuksköterskor/undersköterskor ska kunna förmedla tröst till patienter är det en förutsättning att de i sin tur blir tröstade genom att få erkännande för sitt svåra arbete, blir respekterade och involverade i multiprofessionella team som stöds av vårdorganisation och chefer. Då först kan patienter bli tröstade, känna sig upprättade och uppleva sig som hela människor trots sina 'smutsiga' kroppar.
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