The ambiguous suffering body – a way to discover meaning nuances of dignity

Vibeke Bruun Lorentsen

OsloMet Avhandling 2021 nr 4

OSLO METROPOLITAN UNIVERSITY
STORBYUNIVERSITETET

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Vibeke Bruun Lorentsen

Dissertation for the degree of Philosophiae Doctor (PhD)
Institute of Nursing and Health Promotion
Faculty of Health Sciences
OsloMet - Oslo Metropolitan University

Spring 2021

OsloMet Avhandling 2021 nr 4

ISSN 2535-471X (trykket)
ISSN 2535-5454 (online)
ISBN 978-82-8364-283-4 (trykket)
ISBN 978-82-8364-293-3 (online)

OsloMet – storbyuniversitetet
Universitetsbiblioteket
Skriftserien
St. Olavs plass 4,
0130 Oslo,
Telefon (47) 64 84 90 00

Postadresse:
Postboks 4, St. Olavs plass
0130 Oslo

Trykket hos Byråservice

Trykket på Scandia 2000 white, 80 gram på materiesider/200 gram på coveret

Acknowledgements

With this thesis I place a preliminary comma in my efforts to understand the meaning of the suffering body and dignity in health and suffering. I am thankful to have been given the opportunity to immerse myself in a subject that has followed me for many years, also before this research project started.

My deepest gratitude goes to all those who have been involved in this research process and supported me in my work with the dissertation.

I am grateful to Oslo Metropolitan University (former Oslo and Akershus University College of Applied Science) and Institute of Nursing and Health Promotion, who funded my scholarship and gave me the possibility to design my own research process.

My deepest gratitude goes to the participants in the study. Without their willingness and cooperation this project would not have been possible. The patients in particular impressed me with their expressed sadness at not having the opportunity to read my finished work as they knew that they would not live that long. It was nevertheless important for them to participate in order to help others.

My greatest gratitude goes to my two supervisors, Professor Berit Sæteren and Professor Dagfinn Nåden. Thank you, Berit, for your strong belief in my project and in me as a PhD fellow and a human being. Thank you for always having an open door, your warmth and love and our many formal, but also informal, conversations about the project and the many facets of life. Thank you, Dagfinn, for your strong belief in my project throughout the research process, your kindness and openness to my thoughts and perspectives. You have both taught me about the art of guidance and especially the importance of asking the few but well considered questions that have helped me further in the research process.

Thank you to the head nurses and the nurses at the hospice inpatient units who helped me in recruiting participants to the three studies. Your patience and your commitment to finding participants with rich stories on the subject under study have been essential and the foundation of the whole study. However, due to the ethical principle of confidentiality, I cannot name the nurses or the institutions.

Being a PhD fellow might be quite lonely. Thus, I am grateful to good colleagues at the Institute of Nursing and Health Promotion, and especially Anne Storaker, Anette Winger, Elena Albertini Früh, Dag Karterud and Line Nortvedt, with whom I have discussed issues related to the project and shared experiences of being a PhD-fellow. Also a thank you to former colleague Elisabeth Gabrielsen who, with enthusiasm during the whole research process, has supported me, especially regarding the concept analysis.

I also want to thank my fellow PhD-students at our PhD seminars, thanks for discussions and valuable, shared experiences. An especially warm thank you to PhD fellow Lisebet Skeie Skarpaas for support during the whole project. Our regular lunches at our nice café where we have shared common experiences have been of great value to me and given me extra strength to carry on.

Thanks to family and friends who have been interested and asked about what I have been occupied with over the past years. Thanks for your support and cheers although it may have been difficult to understand exactly what I have been working on.

My deepest thanks go to the most important people in my life. My dear children, Mathias, Fredrik and Jakob – thank you for your great love, comfort and joy. Also, a huge thanks for the interest you have shown to my research project, for your questions and attention to what I have been working on. And last, but not least: My deepest gratitude goes to my dear husband Torleif. You have been my rock during these years. Without your comfort, support and patience this project would never have been realized. Thank you for tolerating my absence, both physically and mentally, and for taking such good care of our home.

Oslo, 24th of August, 2020

Vibeke Bruun Lorentsen

Abstract

The body is the center of human experience. The bodily changes caused by cancer disease and treatment affect physical, psychological, social and existential dimensions of life. When meaning and knowledge have their origin in embodied experiences it is appropriate to explore dignity through the nurses', relatives' and patients' stories about the vulnerable body. Thus, the overall aim of the study was to gain a deeper understanding of the meaning of the body in order to understand dignity in health and suffering. The study consists of three empirical studies and a hermeneutic concept analysis. It has a hermeneutical approach based on Gadamer's ontological hermeneutics.

Study 1 revealed that the nurses described the patients as trapped in "alien bodies", as suffering bodily in terms of disgust, shame and loathing, and that the decay of their bodies reminded them of the seriousness of death. The nurses were also concerned with supporting the patients in experiencing coherence and meaning in the midst of their suffering. Study 2, the hermeneutic concept analysis of flesh and fleshly, revealed dimensions of flesh as the corporeal, protective, temporal, sensuous, shameful and vigorous body. The study made visible some of the wordlessness and invisibility concerning the body, which is important for the human beings' feelings of dignity and health. Study 3 revealed that the relatives experienced the patients' bodies as totally changed, physically, mentally, socially and existentially, but the patients were still the same as before. The confirmation of ambivalence was understood as a strong ethical obligation and unselfish love to treat the other with dignity, which further was understood as the core of ethics and ethos. Study 4 revealed that the patients lived in interaction between suffering and health. The unpredictable, sick bodies were like unruly wrecks that threatened the patients' identity and dignity. Simultaneously, the patients had a will to life and love that aimed at keeping the unruly bodies together in order to preserve dignity. Dignity was understood as the good ambiguity.

Exploring the meaning of the suffering body opened up for nuanced understandings of dignity. The suffering body helped the human being to acknowledge and come in contact with the ambiguity, the paradoxes, the suffering and the vulnerability in life and discovered dimensions or truths that had been vague and difficult to verbalize. Being in contact with the innermost being or the health inducing rooms, filled with love and goodness, was important for being able to experience the coherence and support needed to become oneself and experience dignity. The studies reveal that dignity has breadth, depth and enough space to

contain both health and suffering. Dignity is not a narrow or dualistic concept, but needs descriptions that embrace the goodness and love in ambivalence.

Sammendrag

Kroppen er sentrum for menneskelig erfaring. De kroppslige endringene forårsaket av kreftsykdom og behandling rammer fysiske, psykiske, sosiale og eksistensielle dimensjoner ved livet. Siden mening og kunnskap har sin opprinnelse i kroppslige erfaringer, er det hensiktsmessig å utforske verdighet gjennom sykepleieres, pårørendes og pasienters fortellinger om den sårbare kroppen. Derfor var den overordnede hensikten med studien å få en dypere forståelse for meningen med kroppen for å kunne forstå verdighet i helse og lidelse. Studien består av tre empiriske studier og en hermeneutisk begrepsanalyse. Den har en hermeneutisk tilnærming inspirert av Gadamers ontologiske hermeneutikk.

Artikkel 1 viste at sykepleierne beskrev pasientene som fanget i «fremmede kropper», kroppslig lidelse i form av avsky, skam og vemmelse, og at kroppslig forfall minnet om dødens alvor. Sykepleierne var også opptatt av å støtte pasientene til å oppleve sammenheng og mening midt i lidelsen. Artikkel 2, den hermeneutiske begrepsanalysen av kjøtt og kjødelig, viste dimensjoner av kjøtt som den legemlige, beskyttende, temporale, sanselige, skamfulle og kraftfulle kroppen. Studien gjorde synlig noe av ordløsheten og usynligheten knyttet til kroppen som er viktig for menneskers følelse av verdighet og helse. Studie 3 viste at pårørende opplevde pasientenes kropper som totalt forandret fysisk, psykisk, sosialt og eksistensielt, men likevel var pasientene de samme som før. Bekreftelse av ambivalensen ble forstått som en sterk etisk forpliktelse og uselvisk kjærlighet for å behandle den andre med verdighet, som videre ble forstått som kjernen i etikk og ethos. Studie 4 viste at pasientene levde i interaksjon mellom lidelse og helse. De uforutsigbare syke kroppene var som uregjerlige vrak som truet pasientenes identitet og verdighet. Samtidig hadde pasientene en vilje til liv og kjærlighet som hadde som formål å holde de uregjerlige kroppene sammen for å bevare verdigheten. Verdighet ble forstått som den gode tvetydigheten.

Å utforske meningen med den lidende kroppen åpnet opp for nyanserte forståelser av verdighet. Den lidende kroppen hjalp mennesket til å erkjenne og komme i kontakt med tvetydigheten, paradoksene, lidelsen og sårbarheten i livet, og oppdaget dimensjoner av sannhet som hadde vært vage og vanskelige å sette ord på. Å være i kontakt med den innerste væren, eller de helsebringende rommene fylt med kjærlighet og godhet, var viktig for å kunne oppleve sammenheng og støtte for å bli seg selv og oppleve verdighet. Studien viste at verdighet har bredde, dybde og rom nok til å romme både helse og lidelse. Verdighet er ikke

et avgrenset eller dualistisk begrep, men det trenger definisjoner som favner godheten og kjærligheten i ambivalensen.

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Lorentsen, V.B., Nåden, D. & Sæteren, B. (2019). The paradoxical body: A glimpse of a deeper truth through relatives' stories. *Nursing Ethics*, 26(6), 1611-1622.
DOI: **https://doi.org/10.1177/0969733018768660**

Lorentsen, V.B., Nåden, D. & Sæteren, B. (2019). The meaning of dignity when the patients' bodies are falling apart. *Nursing Open*, 6(3), 1163-1170.
DOI: **https://doi.org/10.1002/nop2.301**

Lorentsen, V.B., Nåden, D. & Sæteren, B. (2019). Understanding the meaning of the Ambiguous Body – A hermeneutic concept analysis of flesh and fleshly. *International Journal of Caring Sciences*, 12 (2), 1-10. URL:
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1 Introduction

The importance of the body in health and suffering has received my attention for many years. It started for real when I wrote my master's dissertation on men with prostate cancer receiving hormone treatment (Lorentsen, 2004). While analyzing the results from the survey, I became curious about how it would feel to live in a body that had changed so much due to disease and treatment, and the deeper meaning of such bodily changes. I did not come up with any answers to these questions at the time, as that was not the aim of my study. However, these questions have followed me ever since, in my work as a nurse and assistant professor in nursing education and now in this research project.

This project has a hermeneutic methodology inspired of Gadamer's (2004) ontological hermeneutics. In this project, I seek to understand how patients with advanced cancer diagnosis at the end of life perceive their sick and altered bodies, and how relatives and nurses experience the patients' sick bodies. I also try to gain a deeper understanding of the meaning of the body by performing a semantic analysis of flesh and fleshly, in order to gain insight into dignity as related to health and suffering.

The body is easy to ignore when one is healthy, and it may be taken for granted simply because it is such an obviously integral part of ourselves. Frequently, the body escapes our conscious attention until we get sick (Lupton, 2012). Thus, in the search to understand the meaning of the body in health and suffering, it is worthwhile to study the body in a palliative cancer context. Research studies show that the bodily changes caused by advanced cancer disease and treatment affect physical, psychological, social and existential dimensions of life (Donovan & Glackin, 2012; S. Gibson & Green, 2013) and thereby also the person's dignity (Eriksson, 1994; Edlund, 2002; Lindwall, 2004; Eriksson, 2006; Edlund, Lindwall, von Post & Lindström, 2013).

Several influential international organizations recognize dignity as an essential need, a fundamental right and an inherent quality of every human. The concept of dignity has been used to articulate values, define goals, promote policies and defend services (Brennan, 2014). The United Nations (1948) emphasizes that all human beings have an inherent dignity. This understanding is an important foundation for the *Declaration of Human Rights*. In

Declaration on the Promotion of Patients' Rights in Europe, the World Health Organization (WHO, 1994) underscores the importance of protecting the integrity and dignity of the person. The *ethical guidelines for nurses* (NSF, 2014) and the *ICN Code of Ethics for Nurses* (ICN, 2012), emphasize how the preservation of dignity is an important part of caring.

Dignity was also a fundamental theme and an underlying philosophy when the pioneers of palliative medicine began to articulate a coherent science and practice of symptom control and psychosocial support. That patients should experience symptoms like pain and nausea was considered undignified. Restoring comfort and symptom control was to restore dignity. Palliative care was a care that honored and protected the dying (Brennan, 2014). Dignity was, in this setting, described as an individual concept, an inherent property, rather than an item that could be damaged or lost (Radbruch & Payne, 2009).

Thus, the concept of dignity is important in healthcare because it might say something profound about the status, the sacredness and uniqueness of the human being (Tranvåg, Synnes & McSherry, 2016). Loss of dignity has been reported by 46 % of individuals with advanced cancer. Such loss has consequences for patients' quality of life, and causes hopelessness and depression, and dependency on others for personal care (Hack et al., 2004). Maintaining dignity has been identified as one of the core needs of those with life threatening illnesses (Meier et al., 2016). As dignity is a central concept in palliative care both historically and presently, and bodily changes become so obvious to the patients and the people around them at this stage of the disease, I found it relevant to go to this setting when seeking to gain a deeper understanding of the meaning of the body in order to understand dignity in health and suffering.

Gaining a deeper understanding of dignity is also an important subject for nursing research. Although nurses may have an intuitive understanding of dignity, and a common attitude or intention that one shall not violate the human being's dignity (ICN, 2012; NSF, 2014), circumstances can lead to violations of patients' dignity if nurses lack the in-depth understanding required to manifest dignity in practical care situations. Thus, professional caregivers should seek to obtain a deeper understanding of the underlying components of dignity (Tranvåg & McSherry, 2016). This was also an important motivation when I started working on this PhD-project.

My PhD-work is carried out at the PhD-programme of Health Sciences at Oslo Metropolitan University. The PhD-programme has an interdisciplinary profile and understanding, and promoting health is a common focus in the programme. In the curriculum, health is described as a complex and comprehensive phenomenon that involves interaction between physical, psychological, and social dimensions. Care is also a key element in the programme (PhD programme in Health Sciences). There is no articulated common ontology for health science in the programme. However, as a nurse researcher, I have my scientific foundation in nursing science and caring science.

1.1 The historical understanding of the body

In order to understand the meaning of the body today, it is useful to take a brief look at the historical development and changes in notions of the body over the years, as our view of the body is based on centuries of history. The division between body and mind has lasted from the ancient philosophers, such as Plato (427-347), and until today. Plato described the human being in a dualistic way as consisting of two parts or two realities, body and soul. The body was material and controlled by time while the soul was eternal and infinite. As the body was material and mortal, several human problems arose in the body. Likewise, the soul was considered of greater value and was viewed as immortal and eternal (Lindwall, 2004). This dualism also influenced the Christian view of the body as the seat of unreason and immorality (B. S. Turner, 2008).

The modern western understanding of the dualism of mind and body has its origin in Descartes’ (1596-1650) division between body and mind. Descartes defined the soul, or mind, as the thinking and controlling element of the human being, seeing the body as an object, a machine, that could be repaired if something was broken (Engelsrud, 2006). The Cartesian dualism which opens for the body being studied scientifically as an object has been dominant in medicine until today.

Thus, up until the past few decades the body has not attracted much attention in social or cultural theories (Lupton, 2012). However, the turn towards theorizing the body and the increased attention to the importance of the body in representing thought (Lakoff & Johnson, 1999), may be explained with reference to modern social movements such as feminism, the growth of consumer culture and the influence of poststructuralist and postmodernist theories.

These movements, and the fact that Foucault's writings about the body (Lupton, 2012) and Merleau-Ponty's philosophy of the body have become better known, have focused new attention on the body and its role in human subjectivity (Merleau-Ponty, 1968, 2002; Lupton, 2012). Merleau-Ponty's (1908-1961) project was to break down the dualistic view of the body, and he did not see body and consciousness as two separate units. He stated that humans exist, and are in touch with the world, in and through their bodies. It is thus imperative, according to Merleau-Ponty that humans return to their bodies in order to understand the world and their place in it (Merleau-Ponty, 1968, 2002).

Lupton (2012) claimed, more specifically, that the emergence of HIV and Aids, drug use in sports, the relationship between diet and health, and the genetic dimension of ill health and disease have incited recent research on the body.

Since Descartes' mind-body split, questions have been asked about the nature of the relationship between the physical and the non-physical, between mind and body and between meaning and material (Bullington, 2009). The objective body represents only one way of viewing the body. More recent times have witnessed an increased interest in understanding the body in a broader perspective, viewing the body as something more than the physical or objective body (Sakalys, 2006; J. Draper, 2014; Mason, 2014; Marchetti, Piredda & Marinis, 2016).

1.2 The bodily changes in a palliative care context

Research emphasizes the many bodily changes caused by cancer disease and/or treatment. These changes, which affect the patients in different ways, are, among others, emaciation, scars, hair loss, fatigue, ulcers, loss of limb(s), but also invisible changes in bowel, urinary and sexual function (Price, 2009; Yarbro, Wujcik & Gobel, 2014).

To understand the extent and the meaning of the bodily changes, I searched for the occurrence and severity of the symptoms patients, and especially cancer patients, experience in a palliative phase. Chang (2019) finds that the most common symptoms that occur in patients in a palliative phase are pain, depression, anxiety, confusion, fatigue, breathlessness, insomnia, nausea, constipation, diarrhea and anorexia. Stark, Tofthagen, Visovsky and McMillan (2012) state that the most reported occurring symptoms in the cancer patient population are fatigue, feeling drowsy, difficulty sleeping and worrying. Further, the symptoms reported of greatest severity were hair loss and impaired sexual activity. Pain, fatigue and difficulty sleeping were reported as the most distressing problems (Stark et al., 2012). Teunissen et al. (2007) report fatigue, pain, lack of energy, feeling weak and weight loss as the symptoms that occur most frequently in patients with incurable cancer. Likewise, Oechsle, Goerth, Bokemeyer and Mehnert (2013) state that lack of energy, tiredness and pain are the most frequent symptoms in cancer patients in palliative care.

Research studies also explore how patients experience living with advanced stage cancer. S. Gibson and Green (2013) examine patients' experiences with fungating wounds and find many devastating consequences of the wounds, physically, socially, psychologically and existentially, such as malodor, pain, uncontrollable exudate, social isolation, loss of identity, disfigurement and shame. Lo et al. (2012) also study patients' experiences with malignant fungating wounds and find that age, malodor, pain issues and psychological issues have negative impact on quality of life. Donovan and Glackin (2012) describe a lot of physical, social, and psychological difficulties encountered by patients with head and neck cancer receiving radiotherapy, as a result of their treatment.

The bodily changes do not only affect the patients, but also their relatives. Several studies show that relatives worry and have a difficult time when their dear ones experience advanced cancer disease. Relatives have higher levels of anxiety and lower quality of life throughout the period of illness, but also after the patients' death (Grov, Dahl, Fosså & Moum, 2005; Persson & Sundin, 2008; Pusa, Sundin & Persson, 2012). The relatives are in touch with the sick bodies of their dear ones physically, socially, existentially and/or mentally. However, few studies have explored the relatives' emotional experiences when their dear ones' bodies change so radically (McClement, 2005; Alexander, 2010).

Few studies have delved deeply into how nurses experience the physical changes of the cancer patients from a psychosocial perspective, and how nurses can help the patients to become reconciled with their altered bodies. Several studies report that healthcare professionals do not address bodily problems with the patients because they experience this as taboo and consider it to possibly cause more harm than good. Moreover, the nurses believe that there are few relief measures to initiate and therefore do not take the initiative to invite the patients to such conversations (Hopkinson, Wright & Corner, 2006; Dewey & Dean, 2007; Konradsen, Kirkevold & Zoffmann, 2009). However, the bodily changes may be distressing and affect the nurses' lives and their interaction with the patients they care for.

Thus, to gain a deeper understanding of how the patients' physical changes affect the nurses, I performed a literature search where I specifically searched for various visible bodily changes, finding that malignant cancer wounds are among the most difficult issues to deal with for both patients and nurses (Alexander, 2010; Hawthorn, 2010; Taylor, 2011; Cornish, 2019).

1.3 Understanding dignity through the body

Dignity and body are two of the main phenomena in the project. To gain a greater understanding of dignity in health and suffering, I wanted to develop the understanding of dignity in a bodily context.

The body often serves as a symbol of dignity by presenting attributes that show the status and position in the society (Edlund, 2002; Edlund et al., 2013). Human beings become more aware of their bodies when they get sick and the bodies do not act the way they used to. This affects the natural relationship between human beings and their bodies. Thus, the dignity of the human body is violated or offended by illness and treatment (Lindwall, 2004), when the body no longer behaves as expected.

Dignity is understood as subjective and objective dignity, or as absolute and relative dignity (Eriksson, 1994; Edlund, 2002; Gallagher, 2004; Eriksson, 2006; Edlund et al., 2013; Lindström, Nyström & Zetterlund, 2014). Edlund (2002) describes the body as the bearer of relative dignity, but also as a source of violation. In her study, conversations with elderly people revealed that they felt their dignity was threatened when their body did not function like it did when healthy, or that they could not perform actions that were in accordance with the culture's or the body's rules and norms of dignity. The sick body was described as an obstacle to freedom. Freedom is an important dimension in human dignity (Edlund, 2002; Edlund et al., 2013). Edlund (2002) states further in her study that the body generates feelings of pride and shame, vulnerability, violation, strength and powerlessness. Thus, the body is both a source and a threat to dignity. According to Eriksson's (1987b) caring science, the body is an important part in the unity of the human being as body, soul and spirit, a unit that must be whole to experience dignity (Edlund, 2002; Edlund et al., 2013).

Lindwall (2004) also describes how bodily dignity is violated when the body becomes sick and the body's wholeness is threatened. The body is described as an entity that carries the soul and spirit, but also health, illness, and feelings of well-being and suffering. When illness afflicts the body, the balance or the unity in the body is disturbed and dignity is threatened (Lindwall, 2004).

Thus, the body is the human being’s access to life, and is the center of human experience. The body and bodily experience is therefore valuable sources in the search for a deeper understanding of dignity in health and suffering. Merleau-Ponty (2002) states that as long as we live, the body is the hub of our existence. Any change in the body causes a change in the access to life and the world, which again will have consequences for the experience of dignity in health and suffering.

Understanding dignity through the body might provide a way to better understand the richness and depth of the concept, and thus a way to meet some of the criticisms concerning dignity research (Macklin, 2003; Barclay, 2016). Barclay (2016) claims that research concerning dignity often results in lists or categories of what informants identify as dignity or not, and that the definition of dignity often ends up as synonymous with quality of life. Further, he claims that dignity in many ways seems to be only a fashionable new term for existing values and thus a useless concept (Barclay, 2016).

However, K. M. Gibson (2017) states that in order to avoid reductive theories about human dignity, one should consider the richness and diversity of the empirical life. A discourse on dignity is not founded in rationality but in emotions. Dignity is a relational good that exists in the interrelatedness of human beings (K. M. Gibson, 2017). Thus, in line with K. M. Gibson (2017), turning the understanding of dignity into a bodily perspective might be a way of understanding more of the richness and deepness of the concept.

According to Nåden, Råholm, Lohne and Eriksson (2013), there is a need for research on the nature of dignity. There is already much research on dignity, but most of it is on dignity in relation to other contexts, and only a small portion concerns the ontology of dignity. Thus, this present attempt to understand dignity through the body is an attempt at gaining more insight into the nature of dignity.

1.4 Palliative care in Norway

Palliative care has developed rapidly since the late 1960s. The modern hospice movement emerged as a protest against the growing medication of the National Health Service. The founder Dame Cicely Saunders and her colleagues opened the world's first modern hospice in London in 1967, St Christopher's hospice, where clinical care, teaching and research were combined within a holistic philosophy. The aim of the philosophy was to improve the quality of life for patients with life-threatening illnesses, meet individual needs, prevent and provide relief of physical, psychosocial and spiritual suffering, and care for the patients' families (WHO, 2002; Sandsdalen, 2016; Birkelund, 2017).

The establishment of hospices for seriously ill and dying patients has not had the same impact in Norway, but the philosophy of comprehensive/holistic care has been prominent in the planning of palliative care health services for the severely ill patients (NOU, 1984:30, 1997:20, 1999:2, 2017:16). However, the official Norwegian Report *På liv og død (On life and death)* (NOU, 2017:16) still emphasizes the importance of implementing the patient perspective into all areas of health and care services. The report (NOU, 2017:16) states that a one-sided, disease-centered approach has had too much power up until now, despite patient-centered care being one of the corner stones in palliative care internationally.

The concept of palliative care has changed and gained new meaning over time. Previously, the term 'palliative care' was primarily associated with the care of dying patients with cancer. However, the demographic and technological changes in the community due to an ageing population, longer life expectancies, changing illness trajectories and advances in pharmacological and surgical techniques have resulted in that palliative care now also include patients that may not be dying, but for whom relief of suffering and improvement of quality of life are important (Meghani, 2004; NOU, 2017:16).

World Health Organization defines palliative care as:

> Palliative care is an approach that improves the quality of life for patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 2019).

There is also different terminology concerning the term 'palliative care' across Europe. Healthcare providers often use the term palliative care interchangeably with 'hospice care', 'end-of-life-care' or 'terminal care' (Radbruch & Payne, 2009).

The subject of this thesis will keep increasing in relevance as the global burden of cancer increases from 10 to 24 million patients during the next 50 years (Clark, 2007). In 2018, in Norway 34 190 individuals received cancer diagnosis and among 237 000 lived with prior cancer diagnosis. Eleven thousand died from cancer disease in 2017. The number of patients who suffer from cancer disease is expected to increase in the years to come. An estimated 42 % increase in men and 27 % increase in women with a cancer diagnosis are expected within 2030, compared to today (*Kreftregisteret*, 2019). Improvements in diagnostic and treatment entail that more people survive cancer disease or live longer with the illness. The treatment is also more complex and intensive than earlier, and lasts longer (NOU, 2017:16). This means that people live much longer with hidden bodily disorders. However, even though the treatment of patients in a palliative phase has been intensified and strongly improved, approximately 30 % will die within a period of five years from their diagnosis (*Kreftregisteret*, 2018).

1.5 Disposition of the thesis

In the next chapter, I will present previous research studies about the body in illness and palliative care, research studies about dignity in palliative care and research studies about dignity in a bodily perspective. In the third chapter, I present the rationale of the study, being 1) presentation of the aim and the research questions, 2) the relationship between the research questions and the sub studies, and 3) the relationship between ontology, epistemology and methodology. Chapter four presents the theoretical framework, being 1) Eriksson’s caring science theory about the human being, health and suffering (Eriksson, 1987a, 1994, 2006; Lindström et al., 2014; Eriksson, 2018), 2) the body as a unit, and 3) theory about dignity. The body as a unit is understood from Eriksson’s perspective of caring science (Eriksson, 1987b, 1987a, 1994, 2006, 2018) and Merleau-Ponty’s (1968, 2002) philosophy of the body. Theories about dignity are mainly Eriksson’s and Edlund’s view on dignity as absolute and relative dignity (Eriksson, 1988, 1994; Edlund, 2002; Eriksson, 2006; Edlund et al., 2013; Lindström et al., 2014; Eriksson, 2018). Chapter five presents the study’s methodology. In chapter six the results from the four sub-studies are presented and a further interpretation of the studies. The further interpretation results in a deeper understanding of the meaning of the body and dignity formulated as three new themes. The new themes are further discussed in chapter seven. Chapter seven is the discussion, which ends with reflections on the more nuanced understanding of dignity in a bodily perspective. In chapter eight, I discuss methodological considerations and limitations, and the final chapter presents the conclusion and future perspectives.

2 Previous research

In order to investigate the existing knowledge base and identify any questions still in need of answers in accordance with the aim of the study, I conducted frequent systematic literature searches. The searches were performed several times, starting with the planning of the study in 2014 and then frequently throughout the study period, up until 2019, in the following databases: Medline, Cinahl, Psych Info and Amed.

Initially, I searched for research studies on which bodily changes are most common as a result of advanced cancer disease in a palliative phase. I also looked at which symptoms occur most frequently, and which symptoms are most stressful for the patients and the relatives in this stage of the disease. The search terms were, among others: ‘symptom, symptom burden/symptom prevalence, body change’. Several research studies had studied the effect of cancer treatment. Inserting the search term ‘life experiences’ showed that there were far fewer research studies regarding the bodily experience of being ill.

Further, considering the aim of the study, I searched for research studies that would help me explore and gain a deeper understanding of the body and its importance in order to promote dignity in health and suffering. The search terms used were ‘human body, body image/body awareness, embodiment, body, dignity and neoplasm/cancer’. Since the study is in a palliative context, the database search was combined with ‘palliative care’ with different combinations of ‘hospice care/palliative nursing/terminally ill patients’.

The review of the literature discloses that there is a great deal of research studies concerning dignity in a palliative context, or more precisely, dignity at the end of life and death. Combining the literature search with ‘neoplasm OR cancer’ reveals fewer research studies. Further, combining the search with synonyms of the term ‘body’ uncovers only a handful or fewer research studies, and these studies mainly investigate couples’ experiences of sexuality and life-threatening illness. As far as I can see, no studies explore in-depth dignity in a bodily perspective. Lindwall (2004) describes the body as the bearer of health and suffering. However, she also found that it is difficult to preserve bodily dignity when the body is tormented by severe disease.

Finally, ‘philosophies OR Merleau-Ponty’ was used as a search term as Merleau-Ponty’s philosophy of the flesh is a central theoretical foundation for the study. However, combining this search term with various forms of ‘body AND palliative’ gave few relevant results.

I also picked up current studies from reference lists and performed a related article search. Some studies overlapped, as they were included in two or more databases.

In general, the search terms have been key words, but also text words. I present a summary of the main results of the literature review below. The literature review contains empirical studies as well as a few philosophical studies. I will point out, in the text, which studies are philosophical studies.

2.1 The body in illness and palliative care

Both ‘body’ and ‘embodiment’ are concepts that are used to describe the meaning of the body. However, there is a distinction in meaning between the two concepts as the ‘body’ implies a thing, an object or some kind of concrete material entity, while ‘embodiment’, or the lived body, is a state, a presence, and a way of being (J. Draper, 2014).

There has been an expansion of literature across several disciplines during the last 20 years concerning the body and embodiment, that is, what it means to live in and through the body (Sakalys, 2006; J. Draper, 2014; Mason, 2014; Marchetti et al., 2016). In scientific research, the body has become the subject of detailed clinical studies due to the dominance of the biomedical model with its objectively measurable knowledge (Marchetti et al., 2016). The experience of the lived body (embodiment) has primarily been a topic for philosophical inquiry, where matters of the intellect and consciousness have been central. Embodiment as something beyond the intellect has remained a relatively silent and ignored matter, unlike the object body (J. Draper, 2014).

There has been lack of theoretical and empirical investigations of the body and embodiment in nursing research. Nursing knowledge and much of its practice have been tacit and relatively invisible despite that bodily function and dysfunction represent the dominant focus for the nurse-patient relationship (Shakespeare, 2003; Wolf, 2014). In nursing education the human body is based on the dominant perspective of science and medicine. The scientific and medical understanding of the body has tended to emphasize the ‘object’ body and ignore the ‘subject’ body (J. Draper, 2014; Marchetti et al., 2016).

According to Madjar (1997) the disease affects the anatomical body, but it is the person who experiences the illness, who suffers and whose embodiment is affected by bodily changes, which go beyond an organic level. Objectification, through diagnostic labelling, categorisation and classification, makes nurses focus on the observable and measurable aspects of illness, and may lead them to ignore its subjective and embodied nature (Madjar, 1997). Thus, several studies state (Gadow, 1980; Reed, 2000; Sakalys, 2006; J. Draper, 2014; Tyreman, 2015) that there is a need to rediscover the importance of embodiment in nursing in order to ‘rehumanize’ care and promote and protect a high standard of person centered nursing practice. Tyreman (2015) claims that we have the most certain knowledge in our bodies, not, however, in the sense of the abstract biological knowledge that a doctor has about our bodies, but a knowledge that enables us to act in a taken-for-granted and largely unconscious way and have confidence in our bodies. This certain knowledge is threatened by illness. Reed (2000) states that embodiment is the core concept in understanding health experiences. Gadow (1980) claims that to promote healing and wholeness, nursing must achieve reconciliation of the dichotomy between lived body and object body, not as an either/or phenomenon, but as a dialectic in which neither aspect is meaningful without the other.

In palliative care, research studies concerning how patients experience their altered bodies have been scarce. This is confirmed by two recent studies by Vas, Povey and Clark-Carter (2019) and Hilário (2016). Vas et al. (2019) state that many studies have focused on body image of individuals affected by cancer. However, only few studies have investigated altered body image and adjustment among palliative care patients or how people with progressive cancer experience living in a changed body and what the body tells and expresses. Hilário (2016) has investigated, in a gendered perspective, how men and women at the end of life perceive and experience their visibly altered bodies. She finds that physical matters were more of concern for women than for men. The women consider their appearance important for their self-identity.

Rasmussen, Tishelman and Lindqvist (2010) also confirm that knowledge about peoples’ experiences living with bodily changes as death approaches remain limited. Morgan, Currow, Denehy and Aranda (2017) state that embodied experiences of physically active living while dying are under-represented in palliative care literature.

However, some research studies study the experiences of living in a sick body (Lindwall, 2004; Lundgren & Bolund, 2007; Lindwall & Bergbom, 2009; Sekse, Gjengedal & Råheim, 2013). Lundgren and Bolund (2007) find that patients with cancer develop a new sensitivity to bodily signals, a sensitivity that is related to insecurity associated with the disease and treatment. The body is transformed into a messenger in a wide sense and expresses the inexpressible, and the lack of reliance on the body may be a manifestation of a lack of trust in life. The studies of Lindwall (2004), Lindwall and Bergbom (2009) and Sekse et al. (2013) do not directly relate to bodily experiences in a palliative setting, but I have included the studies as I find the knowledge they have gained to be transferable to a palliative setting.

Lindwall (2004) states that the body is the carrier of language and power, fears and feelings of powerlessness. When illness afflicts the body the balance between health and suffering is disturbed and the body becomes an adversary to the human being and to life. She describes the adversarial relationship as a battle that is being fought between the illness that breaks down the body and the human being striving to preserve the body as a whole. The defenselessness of the body, its ethos, appears because the unity of the body is afflicted by illness (Lindwall, 2004). Lindwall and Bergbom (2009) also use the battle metaphor in the study of women with breast cancer. The women say they feel like they live in a prison after breast cancer surgery. The body has failed them and they experience their sick body as a home where a struggle is taking place. The body after surgery becomes a stranger that is forever altered (Lindwall & Bergbom, 2009). Sekse et al. (2013) state that the sick body is a bearer of existential issues. They find that when women with gynecological cancer lose control over their bodies, this challenges them existentially and they become more vulnerable. The women describe an unhomelike being-in-the-body from which they cannot escape (Sekse et al., 2013).

2.2 Dignity and palliative care

K. Turner et al. (1996) attempted to measure dignity for patients during the last three days of life. However, the study revealed that the measurement of dignity was defined and measured by health professionals who were not always sure of what they were measuring. During the last 15-20 years, quite a lot of knowledge has evolved on how patients approaching death understand the concept of dignity. The research of Chochinov and his team (Chochinov, Hack, McClement, Kristjanson & Harlos, 2002; Chochinov, 2008, 2012) in particular has received much attention. Based on the experiences of terminal cancer patients, Chochinov et al. (2002) developed a ‘Dignity conserving model’, specifying factors that either supported or undermined a dying patient’s sense of dignity. Three major categories emerged from the qualitative analysis, including illness-related concerns; dignity conserving repertoire; and social dignity inventory. The concept of dignity and the dignity model offered a way of understanding how patients faced advancing terminal illness.

The ‘Dignity conserving model’ served as a basis for ‘dignity therapy’, giving health providers a psychotherapeutic instrument to measure the psychosocial and existential stress and to bolster a sense of meaning, purpose and dignity for people reaching the end of life (Chochinov et al., 2002; Chochinov, 2008, 2012). This ‘dignity therapy’-model is described and further developed in different populations, not only for dying cancer patients (Hall, Goddard, Opio, Speck & Higginson, 2012; Dose et al., 2016), and is also used as a framework to appraise the literature in review studies about dignity and palliative care (Werkander Harstäde, Roxberg, Andershed & Brunt, 2012; Johnston et al., 2015; Martínez et al., 2017).

Barclay (2016) is, from a philosophical point of view, critical to parts of dignity research and states that a trend is to analyze dignity in terms of the broader notion of a good health care or a good death, rather than addressing dignity more specifically. The study refers, among others, to Pringle, Johnston and Buchanan’s (2015) systematic review of dignity and patient-centered care, in which half of the existing literature cited addressed the quality of health care, or of patients’ experiences of health care, rather than addressing dignity more specifically. Barclay (2016) also refers to Chochinov’s Dignity Model (Chochinov et al., 2002), which often reverts to broader discussions of patient distress or patient satisfaction rather than dignity, which is the foundation for the model. The point that respecting patients’ dignity is a part of good quality health care, but not synonymous with it, is reasonable. Barclay also claims that dignity is a part of, but not synonymous with, a good death. Dignity is a unique value like safety, compassion and autonomy. It refers to “upholding the patient’s standing as an equal, especially by respecting her capacity to live in accordance with her standards and values” (Barclay, 2016).

As described in this thesis, dignity has a special place in nursing and medical ethics with respect to end-of-life care (Hemati et al., 2016). Li, Richardson, Speck and Armes (2014) were concerned with the dynamic relationship between the intrinsic and extrinsic factors regarding dignity at the end of life. They found that ‘being valuable’ was the core meaning of patients' dignity and this comprised both intrinsic and extrinsic factors. Hemati et al. (2016) state that despite that dignity is an important structure in providing care for dying patients and their families, and many research studies have emphasized this, dignity at the end of life is poorly defined, and there is a lack of definitions of the concept of dying with dignity and its applications. Consequently they performed a concept analysis which revealed key attributes such as respect for privacy, respect, spiritual peace and hope (Hemati et al., 2016).

However, research on palliative care and dignity has focused mainly on the final stages of life and death (Enes, 2003; Hack et al., 2004; van Gennip, Pasman, Oosterveld-Vlug, Willems & Onwuteaka-Philipsen, 2013; Hemati et al., 2016). This is in contrast to the World Health Organization, who states that palliative care should be initiated as early as possible in the trajectory of any chronic, ultimately fatal, illness (WHO, 2019). van Gennip et al. (2013) are concerned with this issue and describe the development of a conceptual model of dignity that shows how serious illness can undermine patients' dignity, not only when patients approach death, but during the whole illness trajectory. They claim that living a life with dignity is as important as dying with dignity, and that this should be the focus throughout the illness trajectory. van Gennip et al. (2013) suggest that it is not the illness itself, but rather its consequences that pose a threat to dignity because of the stigma it generates, and also, interestingly, state that dignity is a construct apart from the concept of 'quality of life', which is more directly determined by the symptoms of illness.

2.3 Dignity in a bodily perspective

In nursing and caring science the literature is sparse regarding the body or the embodied being and dignity. Few research studies (Street & Kissane, 2001; Edlund, 2002; Edlund et al., 2013) have studied in any depth the body and the body's importance when searching for what strengthen the patients' dignity.

Franklin, Ternestedt and Nordenfelt (2006) have studied elderly cancer patients at the end of life and found that their dignity was threatened because the body was unrecognizable. The patients felt ashamed of how their bodies looked, how they smelled, how they appeared and that their bodies were no longer controllable. Other research studies reveal that protecting the body's privacy and strengthening the patients' body images were important issues regarding dignity (Webster & Bryan, 2009; Lin, Watson & Tsai, 2013). However, these nursing research studies did not explore to any extent, the importance of the bodily changes for the human being's experience of dignity.

Ijzerman and Cohen (2011) have examined the links between body comportment and honor from a psychological perspective. They claim that the body is a carrier of complex cultural values and found that body posture can be connected to honor.

The philosopher Nussbaum (2006) defines the body and reason in functional, rather than metaphysical, terms. She lists ten human capabilities that describe a bare minimum of what respect for human dignity requires (Nussbaum, 2006). Nussbaum (2006) defines the body in terms of the capability to move or use the senses. She has a functionalist understanding of dignity. Only the sum of the body's needs and capabilities is worthy of respect. Thus, Bernardini (2010) states that Nussbaum has a limited understanding of human dignity when identifying worthiness only with one's capabilities (Bernardini, 2010).

The former studies described dignity mainly from an external bodily perspective or suggested that dignity was experienced dependent on how the body functioned or could perform actions that were in accordance with the cultural rules and norms of dignity.

The next studies (Street & Kissane, 2001; Edlund, 2002; Bullington, 2009; Edlund et al., 2013; Galvin & Todres, 2015) examine dignity from an inner bodily perspective in which there is no mind-body dualism and people exist as body and consciousness in a unity (Merleau-Ponty, 1968; Eriksson, 1987b; Merleau-Ponty, 2002). Street and Kissane (2001) describe dignity as embodied. They refer to the conceptual work on body image and claim that such categorizing of body image might sanitize and disguise the embodied experience of dying. In order to understand the patient's experience, they state that it is better to turn to work on abjection. The boundaries of the human being's body are never completely drawn. People know themselves and others through their bodies. By watching the body, how it functions, people might experience that the perimeter of the body is constantly broken by 'flows of urine, tears, shit, vomit, blood (especially menstrual blood) and sweat'. This ambiguous state of ruptured boundaries of skin and orifices is a rejection of the body that cannot be known as 'clean and proper' (Street & Kissane, 2001). Street and Kissane (2001) claim that in palliative care dignity becomes a romanticized, paramount to 'the right way to die'. They ask rather that health practitioners be more aware of the hidden dimensions, of the kinds of dignified death that matter to patients and their families (Street & Kissane, 2001).

Bullington (2009) states, from a psycho-somatic perspective, that the body constitutes dignity for the human being as the body is a living source of meaning and experience. Humans are embodied selves, unique in space and time, and this constitutes the dignity of the human being (Bullington, 2009). However, there is no in-depth description of how the body constitutes dignity.

Edlund (2002) has, in her PhD-work and in a later study based on this work (Edlund et al., 2013), developed a concept model of dignity from a caring science perspective where the body is one of the three dimensions. Edlund (2002) found that the body strengthens the human being's dignity, but also destroys it. The body serves as a symbol of dignity by presenting attributes that show status and position in society. The body performs actions that conform to the cultural rules and norms of dignity, but is also a source of violation when it can no longer accomplish what is expected of it. The body enables, restricts and interferes with human dignity. It is the human being's tool for freedom, but also an obstacle. The body makes independence possible, but also limits this same independence. The body is a source of pride as well as shame and opens up for vulnerability and violation. The body is power, but also powerlessness, and the body is a vital part of the unity of a human being, a unity that must be upheld for dignity to be experienced. When the body fails and dignity is destroyed, the human being suffers (Edlund, 2002; Edlund et al., 2013).

Galvin and Todres (2015) wanted to clarify the meaning of dignity as a coherent phenomenon. They describe seven kinds of dignity, among them embodied dignity. When one's sense of such bodily dignity is grounded, they suggest, the person is affirming the value of their carnal nature. They state that the body screams out when one's bodily privacy is invaded or when one's bodily presence in the face of others is shamed. When we see another who carries herself with embodied dignity, they continue: "....we may notice a comportment in which the person carries or bears both a sign of self-accepted vulnerability and a certain honor in this; the body in dignity pre-reflectively knows itself as 'honor-wound'" (Galvin & Todres, 2015, p. 2014). Dignity lies in valuing the conjunction of the limits of being human with the immensity of being. Dignity here encompasses both honor and wound. Wound describes both existential and literal vulnerability. Honor describes uprightness, worth and value. Dignity transcends either/or categories (Galvin & Todres, 2015).

Galvin and Todres (2015) wish to ground the human phenomenon of dignity ontologically in Being. The perspective of dignity provides the possibility of a respectful caring behavior, which could otherwise easily become instrumental without such perceptual-intuitive attitude. Dignity is both relational and experiential. It is neither objective nor subjective, but a conjunction of both (Galvin & Todres, 2015).

2.4 Summary of the literature review

The literature review reveals that theoretical and empirical investigations of the body and embodiment in nursing research are relatively scarce. Nursing knowledge and much of its practice have been tacit and relatively invisible despite the focus on bodily function and dysfunction that dominate the nurse-patient relationship (Shakespeare, 2003; Wolf, 2014). Several studies state (Gadow, 1980; Reed, 2000; Sakalys, 2006; J. Draper, 2014; Tyreman, 2015) that nurses need to rediscover the importance of embodiment in nursing care to give the patients person-centered or integrated care. This means that nurses should care for the whole patient's body, not only the body as a physical object, but as a unity of body, soul and spirit.

However, the literature review reveals that there are few empirical studies that have investigated how patients experience living with a changed body. Lindwall (2004), Lindwall and Bergbom (2009), Lundgren and Bolund (2007) and Sekse et al. (2013) found that the body was described as a stranger and an alien. Further, the body set boundaries and limits for existence, and it does not feel like a home anymore, but rather like a prison where battles were being fought.

There is quite a lot of knowledge on how patients approaching death understand the concept of dignity due to the work of Chochinov et al. (2002) and his team. They have developed a 'Dignity conserving model', specifying factors that either support or undermine a dying patient's sense of dignity. The 'Dignity conserving model' serves as a basis for 'dignity therapy', giving health providers a psychotherapeutic instrument to measure psychosocial and existential stress and to bolster a sense of meaning, purpose and dignity for people reaching the end of life (Chochinov et al., 2002; Chochinov, 2008, 2012). However, there is some criticism of some of this dignity research (Chochinov et al., 2002; Pringle et al., 2015), stating that the discussion and literature address quality of health care, patient distress or satisfaction, rather than attempt to understand dignity more specifically (Barclay, 2016).

The literature review also reveals that there is sparse literature regarding the body or the embodied being and dignity (Street & Kissane, 2001; Edlund, 2002; Edlund et al., 2013).

However, some studies have described dignity from an external perspective (Franklin et al., 2006; Nussbaum, 2006; Webster & Bryan, 2009; Ijzerman & Cohen, 2011; Lin et al., 2013) or state that dignity is experienced dependent on how the body functions or is able to perform actions that are in accordance with cultural rules and norms of dignity.

There are also a few studies (Edlund, 2002; Edlund et al., 2013; Galvin & Todres, 2015) that have examined dignity from a mind-body perspective, in which people are described as existing as body and consciousness simultaneously and not as an either or. Galvin and Todres (2015) state that dignity in a bodily perspective may be understood as neither objective nor subjective, but as a unity of both or as honor and wound.

Thus, this literature review shows that the research that attempts to understand dignity from a bodily perspective is relatively scarce. My research may therefore contribute with more knowledge on the meaning of the body in health and suffering and help understand dignity in a broader perspective.

3 Study rationale

Based on the descriptions in the introduction and the literature review, the overall aim of the project is to gain a deeper understanding of the meaning of the body in order to understand dignity in health and suffering. To answer this aim, I have developed four research questions. Each research question has been the subject of one paper.

The research questions are as follows:

- What are the nurses' experiences of the significance of bodily changes of patients in palliative care? How might the nurses help the patients to become reconciled with their changed bodies, if possible?
- What is the meaning and content of the concepts flesh and fleshly, and how can this knowledge enrich the understanding of the ambiguous body and what the body means to the suffering human being?
- What are the relatives' experiences of the patients' bodily changes, and how do these experiences give insight into the phenomenon of dignity in a bodily perspective?
- What are the patients' experiences of bodily changes and how do these experiences give insight into the phenomenon of dignity?

The project uses a hermeneutic methodology (Gadamer, 2004), as understanding and meaning are the central issues in the overall aim of the study. To answer the research questions, I conducted individual qualitative interviews with nurses, relatives and patients with advanced cancer disease in a palliative perspective. I also performed participant observations with the patients to give more knowledge about the suffering body and the patient's situation. In addition, I have carried out a hermeneutic concept analysis of flesh and fleshly.

The nursing study (Lorentsen, Nåden & Sæteren, 2016) was the first study in the project. With this study, together with the literature review (chapter 2), I wanted to explore if the topic was relevant for further research. The nursing study gave me a growing understanding of the meaning of the body and a beginning understanding of the relative dignity in health and suffering. This gave me confidence to continue to develop the study to gain an even deeper understanding of the meaning of the body and thus dignity in health and suffering. On this background I found it relevant to develop the relative study (Lorentsen, Nåden & Sæteren, 2019b) and the patient study (Lorentsen, Nåden & Sæteren, 2019a).

Since the aim of the study is to understand dignity from a bodily perspective, the relative study (Lorentsen et al., 2019b) provided knowledge about dignity from a relative perspective (Edlund, 2002; Edlund et al., 2013), where dignity is influenced by external factors like culture and society, or, as in this study, by how the relatives experienced the patient's body or bodily changes. This legitimized the relative study (Lorentsen et al., 2019b) (article 3).

The attempt at understanding the meaning of the body from the patient's perspective provided knowledge on dignity as embodied (Street & Kissane, 2001; Edlund, 2002; Edlund et al., 2013; Galvin & Todres, 2015). This legitimized the patient study (Lorentsen et al., 2019a) (article 4), which examined the patients' experiences of bodily changes and how these experiences yielded insight into the phenomenon of dignity.

In my attempt to gain a deeper understanding of the meaning of the body, I found that Merleau-Ponty's (1968) philosophy of flesh enabled a view of the body as inhabiting a dimension of the body as the individual's body, and that, simultaneously, flesh described the inner reality of being. This legitimized study 2 (Lorentsen, Nåden & Sæteren, 2019c) where I performed a hermeneutic concept analysis of flesh and fleshly (article 2).

3.1 The relationship between ontology, epistemology and methodology

The PhD programme of Health Sciences at Oslo Metropolitan University (PhD programme in Health Sciences) has no common, articulated ontology. Thus, I found Eriksson's caring science valuable as a theoretical perspective as it is in its nature ethical and has clearly formulated ontological basic assumptions about the human being, health, suffering and dignity (Eriksson, 1987b, 1987a, 1994, 2006; Lindström et al., 2014; Eriksson, 2018). These are all important basic assumptions for this study and will be further described in chapter four.

Even though the body is one of the dimensions in the entity of the human being, Eriksson (1987b) has not developed an in depth understanding of this dimension of the human being. However, with background in Eriksson's caring science (Eriksson, 1987b, 1987a, 1994, 2006; Lindström et al., 2014; Eriksson, 2018), the meaning of the body is further developed by Sivonen and Kasén (2003) and Lindwall (2004), which is described in chapter four; theoretical perspective.

There is a clear relationship between ontology, epistemology and methodology in Eriksson's caring science (Eriksson, 1987b, 1987a, 1994, 2006; Lindström et al., 2014; Eriksson, 2018). The search to understand the deeper meaning of the body in order to understand dignity in health and suffering requires an open view of knowledge and endeavoring to understand what is unknown and difficult to capture. The epistemology of caring science has this open view of knowledge, a humility and an archeological approach to gaining an inner understanding of meaning and formation of ideas (Nyström, 2015), and is a good framework for this project of gaining a deeper understanding of the meaning of the body and more knowledge about dignity. I have chosen a hermeneutic approach in this study (Gadamer, 2004), as hermeneutic ontology and epistemology open up for thinking and interpreting beyond the prevailing boundaries of knowledge, and for an understanding of the complexities of reality that are not immediately given to us.

In addition to Eriksson's caring science (Eriksson, 1987b, 1987a, 1994, 2006; Lindström et al., 2014; Eriksson, 2018), I found it useful to include Merleau-Ponty's (1968, 2002) philosophy of the body as a part of the theoretical perspective. His philosophy further elaborates on the meaning of the body and understands the body, not as something isolated, but as part of a whole (see chapter 4). However, using Merleau-Ponty's theory of people existing and having contact with and knowledge about the world through their bodies, may look like a misconception with regard to the relative and nursing studies. This is because it would be difficult for others to ascribe meaning to what is perceived in and by another's body. The experiences the nurses and relatives describe are their own experiences of the patients' bodily changes and not the patients' subjective bodily experiences. However, the knowledge gained from the nurses and relatives is relevant with regard to understanding more about the meaning of dignity or, more concretely, the meaning of the relative (Edlund, 2002; Edlund et al., 2013) or subjective dignity (Gallagher, 2004) in health and suffering, which is further described in the introduction to this chapter.

Likewise, Merleau-Ponty's (1968, 2002) philosophy helps to understand the body as a mind-body unity, as something more than the physical body. Understanding the body as 'something more' may affect the nurses' and relatives' understanding of the patients' vulnerability, suffering (Lindwall, 2004) and dignity. Not only is the patient's physical body hurt, but the whole entity of body, soul and spirit. People exist as both body and consciousness, but the two do not exist as separate units. It is in and through their bodies that people exist and have contact with and knowledge about the world. The body is both something we have, and something we are (Merleau-Ponty, 2002).

Since the aim of the project is to gain understanding, using Gadamer’s (2004) hermeneutic methodology is reasonable, and this methodology is closely related to the ontology and epistemology of this project. Even though Merleau-Ponty (1968, 2002) represents the phenomenological tradition, I find his philosophy of the body useful as there are few others who have explored on the meaning about the body. The body is not an isolated unit (chapter 1), but is influenced by the body’s constant interaction with society.

4 Theoretical perspective

Science is based on theoretical perspectives, which consist of assumptions and theories on which research questions are based and constitute ways of looking at the world (Bowling, 2014). Theoretical perspectives direct attention and provide frameworks for interpretation. According to Bowling (2014), Kuhn (1970) pointed out that what we see depends on what we look at and on what ‘previous conceptual experiences’ have taught us to see. Thus, it is important to be aware of and describe the theoretical perspectives thoroughly as these perspectives influence the whole research process, from the formulation of the aim and research questions to the collection and interpretation of the results and discussion. The theoretical perspective in this study is an elaboration of the ontological assumptions health and suffering, the body as a unit and dignity.

4.1 The human being, health and suffering in Eriksson’s caring science theory

No science is value-neutral, and Eriksson’s (1987a, 1994, 2006, 2018) caring science is clearly articulated. Ethos is the underlying foundation of value, which the caring science considers as true. Ethos consists of the idea of love and charity or caritas, and the respect for human holiness and dignity. Ethos and ethics belong together and in the caring culture they belong as one. Ethos is the sounding board of all caring and refers to home or to the place where the person can rest and feels at home. Caritas constitutes the motive of caring and consists of the two forms of love, eros and agape. Combining these two forms of love makes generosity the human being’s attitude towards life, and joy is its form of expression (Eriksson, 1987a; Eriksson, 2003; Lindström et al., 2014; Eriksson, 2018).

Eriksson’s caring science theory view health and suffering as inseparable parts of the human life, and the human being as an entity of body, soul and spirit (Eriksson, 1987b). At an ontological level, all dimensions are perceived as equally important and the entity is understood to be indivisible. Eriksson (1994, 2006) emphasizes the importance of understanding the ontological context of the human being or the dual tendencies that exist within him or her. The human being is constantly becoming, constantly changing and therefore never reaches a state of completion. He is engaged in a constant struggle and live in a tension between being and nonbeing. The struggle is between good and evil, between life and annihilation, and between being unique and simultaneously longing to belong in a larger communion. The human being seeks a communion where he can give and receive love, experience faith and hope, and be aware of the meaning of existence (Eriksson, 1994, 2006). Eriksson (1987b) describes the human being as a religious being, even if not all human beings have recognized this dimension yet. The human being's power of transcendence is the foundation of real freedom. Further, the human being is creative and imaginative, has desires and wishes, and is able to experience phenomena. Thus, only describing the human being in terms of his needs is insufficient (Eriksson, 1987b; Lindström et al., 2014). The human being becomes patient, and a suffering human being, when he enters the caring context (Eriksson, 1994, 2006).

Health means wholeness and holiness (Eriksson, 1989). Eriksson (1989, 1994, 2006) sees health as striving for being whole in body, soul and spirit. Health is a dynamic event and a movement in doing, being and becoming, where becoming is a sense of direction towards a greater degree of integration and unity. Health is a movement between actuality and potentiality, or a striving towards a realization of one's health potential (Eriksson, 1994, 2006). In doing, the person's thoughts concerning health are focused on healthy living and preventing illness. In being the person strives for balance and harmony, and in becoming the human being becomes whole on a deeper level of integration (Eriksson, 1994, 2006; Lindström et al., 2014).

Suffering is enacted in a drama of three acts in which the human being experiences sorrow related to what is lost, but there is also a possibility for new life through reconciliation. The suffering is both endurable and unendurable. Unendurable suffering paralyzes the human being and prevents him or her from growing. Whereas suffering which is possible to endure is compatible with health and can lead to growth and development (Eriksson, 1994, 2006).

The dimensions of suffering as doing, being and becoming are the same as those of health. Suffering as doing, involves being controlled by external conditions and being alien to oneself and her or his inner desires and abilities. Suffering as being involves a quest for the whole, but also short-term needs satisfaction. Suffering as becoming involves a struggle between hope and hopelessness and between life and death. If life wins, the struggle leads to meaning and a higher degree of integration and reconciliation (Eriksson, 1994, 2006). In suffering the human being has been given space and time to suffer and reach reconciliation. Reconciliation implies living with an imperfection, but seeing a way forward and meaning in suffering (Lindström et al., 2014).

4.2 The body as a unit

In this project the body is considered as a unit. Merleau-Ponty’s (1968, 2002) philosophy of the body and Eriksson’s (1987b, 2018) caring science of the human being describe the body in different ways as a unit. I found it meaningful to understand the two perspectives together and not as concurrent theories. Eriksson (1987b) describes the unit as body, soul and spirit and Merleau-Ponty (1968, 2002) as body and consciousness.

Eriksson (1987b, 2018) has not developed an in depth understanding of the body dimension of the human being. However, Lindwall (2004) has in her PhD-work developed Eriksson’s ideas further and has gained a deeper understanding of the body in a caring science perspective. Lindwall states that the body is interpreted as an abode, a dwelling, where human beings are allowed to feel at home in themselves. The body is something more than a material or an outer physical abode. It is also an abode for the human soul and spirit. Thus, understanding the body as an abode is something wider and deeper than a physical body. The body is a carrier of health and suffering and a place where the human being can feel at home regardless of all his flaws and changes caused by illness (Lindwall, 2004, 2017). The body makes the human being visible to oneself and others.

The body’s defenselessness was also revealed in the study and it appears when the entity is afflicted by illness. The body is something more than the physical body and the something more may affect the caregiver’s understanding of the patient’s defenselessness and vulnerability related to suffering (Lindwall, 2004).

Sivonen and Kasén (2003) have developed a concept analysis where the body is interpreted as a material physical dwelling, but also as a home for the soul and spirit. The body is a unit and a whole that longs for fellowship with other people and God, but the body is also perishable and likely to decay. The human being can, through the body, be related to time, God and other people (Sivonen & Kasén, 2003).

Merleau-Ponty (1968, 2002) has developed a philosophy about the body from an inner sensitive perspective. He states that the body is a mind-body unity in the world, where the embodied presence is the ground for all knowledge and experience. That people exist as both one thing and another, or as both body and consciousness simultaneously, gives the body a deeper and more complex meaning. It is in and through their bodies that people exist and have contact with and knowledge about the world. The body is ambiguous, which means that it is both something we have, and something we are. It is also at the same time both seeing and visible, and affecting and touching. To understand the body in this way is a change in perspective from the body as a thing. The body is experiencing, sensitive and subjective, and in a continuous interaction with the world, which means that people have to return to their bodies to understand the world (Merleau-Ponty, 1968, 2002).

The existential or religious dimension is not present in Merleau-Ponty's (1968, 2002) philosophy of the body in the same way as in Eriksson's caring science (Eriksson, 1987b; Lindström et al., 2014; Eriksson, 2018). However, in his latest and unfinished work, 'The Visible and the Invisible', where Merleau-Ponty (1968) seeks to understand the deepness and inner reality of the human being, there are perspectives that might be associated with Eriksson. Merleau-Ponty describes the body and the world as two mirrors facing one another, forming a reality that is more real than what is visible of the individual. This visibility extends beyond the body or the world's visibility, and is described as a wordless, anonymous depth, as flesh (Merleau-Ponty, 1968). Flesh has a meaning that veers between the scientific, the metaphorical and the mythological (Sellheim, 2010). Flesh is both the limit and the distance of the body to the world, and at the same time flesh is the element that connects the body with the world. Flesh is what brings the human being and the world together and makes the human being human and the world the world. The flesh is the basic condition for both the human being and the things to be seen and felt**.** It is the individual's body, but has also a metaphoric meaning and is an element of being. The description of flesh as the place where mind, body and world cross (Merleau-Ponty, 1968), provides associations to the existential dimensions of life. Sellheim (2010) confirms that flesh has a transcendental quality. However, Merlau-Ponty does not use those words.

To sum up, Lindwall's (2004, 2017) and Merleau-Ponty's (1968, 2002)'s understanding of the body reveals that the body is more than a physical body. It is a unit of body, soul and spirit, or body and mind. The body is a home where the human being can feel protected. The body is also a place where the human being becomes visible to himself, and can feel defenselessness and vulnerability when the unit is afflicted with illness. The body or the flesh connects the human being to the world and are the basic conditions for the human being to see and understand the world (Merleau-Ponty, 1968, 2002; Lindwall, 2004, 2017).

4.3 Dignity

The term dignity is not new. Eriksson's (1987a, 2018) theory of caritative caring is anchored among other in Pico della Mirandola's (1463-1494) Oration on the Dignity of Man (Pico della Mirandola, 1486). Eriksson's (1988) earliest writings about dignity is found in a report from 1988. Thus, in this subchapter I want to describe Eriksson's view on dignity (Eriksson, 1988, 1994, 2006; Lindström et al., 2014; Eriksson, 2018). Edlund (2002) and Edlund et al.'s (2013) theory about dignity is also developed in the same caring science tradition and including it is therefore relevant. In addition, I will highlight some other central theories about dignity (Gallagher, 2004; Jacobsson, 2007; Nordenfelt, 2004) to illuminate the understanding of the two perspectives of dignity upon which the study is built even more.

In Eriksson's theory dignity is one of the basic concepts of caritative caring ethics. Dignity implies being whole as a human being, as an entity of body, soul and spirit. Dignity is based on a source of values and is described as absolute and relative dignity (Eriksson, 1994; Edlund, 2002; Eriksson, 2006; Edlund et al., 2013; Lindström et al., 2014; Eriksson, 2018).

Absolute dignity is inherent in all people, inalienable and granted by the virtue of being a human being. It involves the right to be confirmed as a unique human being. Absolute dignity is rooted in human worth and human equality and cannot be reduced or dissolved (United Nations, 1948; Lindström et al., 2014). The values of absolute dignity are holiness, responsibility, duty, and inner freedom to relate to the situation and serve one's fellow-men. These values are absolute and infinite and impossible to renounce. Absolute dignity is found in the spiritual dimension of the human entity (Eriksson, 1994; Edlund, 2002; Eriksson, 2006; Edlund et al., 2013; Lindström et al., 2014; Eriksson, 2018).

Relative dignity is influenced by and formed through culture with all the rules that the culture involves. Relative dignity is characterized by the bodily and external aesthetic dimensions and the inner ethical physical dimension. Relative dignity can be strengthened through other people or torn down and violated (Edlund, 2002; Edlund et al., 2013; Lindström et al., 2014).

Gallagher (2004) explores dignity from a nursing perspective and describes how dignity can be perceived both objectively and subjectively. Objective dignity has similarities with Eriksson's (Eriksson, 1994, 2006; Lindström et al., 2014) and Edlund's (2002) absolute dignity, as Gallagher (2004) states that human beings have dignity solely through being human. Each human being has human worth and all human beings possess objective dignity regardless of their level of autonomy, dependency, utility, consciousness or ability to reciprocate in human relations.

Subjective dignity is experienced subjectively through the individual's thoughts and feelings, like relative dignity (Edlund, 2002; Edlund et al., 2013; Lindström et al., 2014). People experience their dignity as strengthened when there is a match between circumstances and competencies. Subjective dignity involves both a self-regarding value and other-regarding value, including respect for one's own personal dignity as well as respect for the dignity of others (Gallagher, 2004).

Dignity of universal stature, or dignity as Menschenwürde (Nordenfelt, 2004; Nordenfelt & Edgar, 2005), have qualities in common with absolute dignity and are universal and unchangeable dimensions, inviolable and ever present, due to the absolute worthiness of each human being.

Jacobson (2007), from her position within medical sociology, has also identified two main forms of dignity, human dignity and social dignity, which show similarities with the absolute and relative dignity of Edlund (2002) and Eriksson (Eriksson, 1994, 2006; Lindström et al., 2014). Human dignity is an inherent and universal quality within each human being, which cannot be destroyed. Dignity of identity, or social dignity, has changeable dimensions which can be strengthened but also violated by others and includes dignity-of-self and dignity-in-relation. Dignity-of-self is understood as a quality related to self-respect and experience of self-worth, and is further connected to feelings like confidence and values such as integrity. Dignity-in-relation describes how respect and worthiness of a person is brought out through interaction with others (Jacobson, 2007).

To sum up, dignity is the absolute or objective dimension rooted in human worth and human equality that cannot be violated or destroyed regardless of the human being's level of autonomy, dependency or consciousness. Dignity is also the changeable dimensions, such as relative, subjective or social dignity, where dignity is influenced and formed through external contexts and culture or through the thoughts and feelings of the individual. The latter includes both self-respecting value and other regarding-value that are influenced or formed in interaction with others. In this thesis, I will use Eriksson's and Edlund's view on dignity (Eriksson, 1988, 1994; Edlund, 2002; Eriksson, 2006; Edlund et al., 2013; Lindström et al., 2014; Eriksson, 2018) in the discussion of the results.

5. Methodology

The research methodology applied in the project is Gadamer’s (2004) ontological hermeneutics. Understanding and meaning are central issues in the project, and Gadamer (2004) clarifies conditions for understanding and emphasizes detection and uncovering rather than explaining and proving.

Also, as described in chapter 1.1, the body is part of history and cannot be understood in isolation from history. This harmonizes with Gadamer’s (2004) hermeneutics where he states that humans are all parts of history and that it is impossible to step outside history or context when seeking to understand. I also find Gadamer’s emphasis on the notion of pre-understanding reasonable as a foundation for understanding. Gadamer (2004) states that it is not possible to lose or eliminate one’s preunderstanding; everyone has a preunderstanding of the topic in question (Fleming, Gaidys & Robb, 2003).

The choice of research methodology is also dependent on the phenomena under study (Råholm, Slettebø, Nåden & Lindwall, 2010). Hermeneutics has an ontology and epistemology that open up for thinking and interpreting to attempt to render clear something that appears unclear (Debesay, Nåden & Slettebø, 2008). The body is one such phenomenon, it is mute and unclear and suitable for exploration within a Gadamerian approach.

In this chapter I will first present Gadamer’s ontological hermeneutics with focus on hermeneutic reading and the researcher’s preunderstanding and Bildung (Gadamer, 2004), which are common for all the four studies. I then describe the hermeneutic concept analysis and the empirical studies and how induction, deduction and abduction have been necessary for gaining a deeper understanding (Råholm et al., 2010) of the meaning of the body in order to understand dignity in health and suffering. The hermeneutic concept analysis is presented first even though the nursing study and the collection of data from the relatives study were performed before this study. The non-stringent order in which the research studies are performed and presented illustrates the hermeneutic movement between the parts and the whole, which is characteristic of this type of research.

5.1 Gadamer's ontological hermeneutics

Gadamer's philosophical hermeneutics is a methodology within the interpretivist paradigm (Bowling, 2014). Gadamer (2004) denies that the ability of understanding needs an awareness of rules. Thus, he has not developed a method for understanding, but a philosophical hermeneutics where he reflects on the ability of understanding and the knowledge on which it is based on (Fleming et al., 2003). According to Gadamer (2004), new understanding emerges in a dialectical movement between new knowledge and previous knowledge in the hermeneutic circle or between the text and the reader's preunderstanding.

Gadamer (2004) emphasizes the notion of historical awareness and describes it as a positive condition for knowledge and understanding. He further states that the person's horizon is his vistas, the vision, or his perspectives, which form the basis for understanding. Seeking new understanding means to open up for new horizons and learn to look beyond what is nearby. This is not in order to look away from what is nearby, but to see it better within a larger whole and in truer position (Fleming et al., 2003; Gadamer, 2004).

5.1.1 Hermeneutic reading

In this study texts from the hermeneutic concept analysis and the interviews have been the primary subjects for interpretation. The field notes from the participant observations in the patient study have made up the backdrop that has helped me in the interpretation of the interviews (see chapter 5.5.2). Through the movements between small textual parts in the text, the text as a whole and the reader, the preunderstanding was challenged and new understanding attained. The movement was between the past and the present, the known and the unknown. The preunderstanding, as represented by language, tradition, history and background, is necessary foundation for understanding (Gadamer, 2004) and is further described in 5.1.2, 5.4.2, 5.5.2 and 8.1.

Koskinen and Lindström (2013a) describe hermeneutic reading as a flexible, lingering, repeated reading to carefully uncover meaning. It requires an openness, a sensitivity and an alertness to allow the text to address, touch and arouse wonder. The reader allows the text to speak by posing questions to the text. Hermeneutic reading is about resting in the text and trusting that the text can open up for new visions and understandings (Gadamer, 2004; Koskinen & Lindström, 2013a).

Further, Gadamer (2004) describes the reader as having an ethical positioning towards the text, a willingness to see the otherness and to allow the text to say what it has to say. It is a willingness to set oneself in the hermeneutic situation, to call one's preliminary understanding into question in order to widen one's horizon.

5.1.2 The researcher's preunderstanding and Bildung

Preunderstanding or prejudice is important within a hermeneutic tradition. The preunderstanding can be both positive and negative and might facilitate as well as constrain understanding. It is neither possible nor desirable to free oneself from the preunderstanding (Gadamer, 2004). However, as Gadamer (2004) states: "The important thing is to be aware of one's bias, so that the text can present itself in all its otherness and thus assert its own truth against one's own fore-meanings" (Gadamer, 2004, p. 271-272).

During my career as a nurse and assistant professor in nursing education, I have been concerned about how one, through the body, might understand the human being behind the suffering. Thus, theory and empirical knowledge about the importance of the body in health and suffering have received my attention for many years and is part of my preunderstanding regarding this study. Caring science theory about health and suffering (Eriksson, 1994, 2006; Lindström et al., 2014; Eriksson, 2018) is also a part of my preunderstanding, as are my experiences of working in hospitals and a short stay at hospice as a nurse.

One of the challenges in this project has been not to be "blinded" to my preunderstanding. However, the persistent uneasiness I have felt throughout the project regarding what the bodily concerns are in my empirical material has kept my mind open. I have been searching in research, but also in fiction, to find expressions and theories that can help me to gain a deeper understanding of what the body really is.

Gadamer's (2004) description of Bildung has helped me give words to the continuous process of uneasiness that has driven me in my eagerness to understand more about the ontological meaning of the body. He states that understanding leads beyond what man knows and experiences immediately. It is an ongoing, inner process of formation and cultivation. Gadamer (2004) refers to Hegel who states that to have a theoretical stance is an alienation, which has to do with something that is not immediate, something that is alien and belongs to memory and to thought. Hegel further recommends the world and language of antiquity as especially suitable for this, since this world is remote and alien enough to affect the necessary separation of ourselves from ourselves. However, at the same time he states that the world and language contain “all the exit points and threads of the return to oneself, for becoming acquainted with it and for finding oneself again, but oneself according to the truly universal essence of spirit” (Gadamer, 2004, p 12).

In this project, Merleau-Ponty’s (1968) philosophy of the flesh and the caring science theory about the body as a unit (Eriksson, 1987b; Sivonen & Kasén, 2003; Lindwall, 2004; Lindström et al., 2014; Lindwall, 2017; Eriksson, 2018) have been a door opener in the search to understand more about the bodily aspects in the material. Merleau-Ponty’s philosophy of the flesh, in particular, has in a way dissociated me from my preunderstanding because it has been alien but at the same time, the philosophy had words (metaphors), expressions and meanings that helped me in the process of understanding. Thus, Bildung is a process of becoming (Gadamer, 2004).

5.2 Induction, deduction and abduction

The nursing study is the first study in the project. It started with an inductive approach where I gained an impression of how the nurses experienced the patients’ sick bodies. However, to get an understanding of the meaning of the body, a need for an interpretation of the interviews and the deductive approach arose, as induction cannot originate any new ideas. Deduction is known for setting forth theory filled hypotheses (Alvesson & Sköldberg, 2018). This allowed me as a researcher to begin generating ideas about the body and dignity. However, since the aim is to reach a deeper understanding of the interpreted texts, the studies are also influenced by abduction. Abduction is a combination of induction and deduction. Abduction starts from an empirical basis, like induction, but does not reject theoretical preconceptions and is therefore closer to deduction (Alvesson & Sköldberg, 2018). The abductive approach enabled me to perceive connections on a deeper level and to penetrate beyond the apparent in a deeper sense as theories, in this case theories like Merleau-Ponty’s philosophy of the flesh (Merleau-Ponty, 1968), Eriksson’s (1987b, 1994, 2006, 2018) theory about the human being as an entity, health and suffering, and perspectives about dignity (Eriksson, 1994; Edlund, 2002; Eriksson, 2006; Edlund et al., 2013; Lindström et al., 2014; Eriksson, 2018) directed my attention towards asking certain questions. Abduction dares to take an extra leap in the interpretation process and strives to go ‘beyond the lines’ rather than ‘behind the lines’

(Bertilsson & Christiansen, 1990; Eriksson & Lindström, 1997; M. B. Råholm, 2010; Alvesson & Sköldberg, 2018).

Collecting data from relatives had also an inductive approach. However, before continuing the interpretation process, I felt a need to develop more knowledge about the meaning of the body on an ontological level. Thus, the hermeneutic concept analysis was performed. The hermeneutic concept analysis had a hypothetic deductive approach regarding the data-collection process (Koort, 1975; Eriksson, 2010; Sivonen, Kasen & Eriksson, 2010; Honkavuo, Sivonen, Eriksson & Nåden, 2018), and an impact on the understanding of the meaning of the suffering bodies in the studies of the relatives and the patients.

5.3 The hermeneutic concept analysis

As I have described briefly in the beginning of this chapter, I continuously asked myself about what were the bodily dimensions in the data material collected from the relatives. I experienced there to be something missing in the language and understanding regarding to the body and found it necessary to explore the concept of the body before interpreting the interviews with the relatives and the patients. Eriksson (2010) and Gadamer (2004) state that concepts and the spoken and written words are prerequisites for understanding the substance. The language is our tool with which we can interpret and understand the world. Concepts are important building blocks for science (Eriksson & Herberts, 1993; Gadamer, 2004; Eriksson, 2010; Honkavuo et al., 2018).

Since Merleau-Ponty’s (1968) philosophy of flesh is helpful in the search for understanding the meaning and inner reality of the human body, it was appropriate to perform a concept analysis of flesh and fleshly. It was necessary to perform two analyses as the synonyms of flesh are both nouns (flesh) and adjectives (fleshly) and they had to be separated.

The hermeneutic concept analysis is created by Koort (1975). After his death in 1977, the method has been further used and developed, particularly in caring science (Eriksson & Herberts, 1993; Gabrielsen, Lindström & Nåden, 2009; Eriksson, 2010; Sivonen et al., 2010; Honkavuo et al., 2018). Eriksson’s model of concept determination consists of four elements. The first two are 1) an etymological and semantic analysis and 2) a determination of essence and a basic epistemic category. These two elements together form the ontological determination of the concept. The model further consists of 3) a determination of context of meaning, and 4) a determination of the pragmatic features. The four elements together form the contextual features (Eriksson, 2010). In this project I have used only the first element from her model; the etymologic and semantic analysis. Other research studies have done the same (Gabrielsen et al., 2009; Honkavuo et al., 2018).

The hermeneutic concept analysis entails an analysis of the meaning of linguistic expressions taken from dictionaries. It yields knowledge on how a concept is used and understood in a language during a historical period, as well as what is the meaning content of the concept related to its conceptual family. Concept analysis searches for the nuances, variations and features of a concept. It also involves a search for explanations and investigations of a concept across linguistic occurrences or phenomena hidden behind the symbolic meaning of a concept (Koort, 1975; Eriksson, 2010; Sivonen et al., 2010; Honkavuo et al., 2018). The intention with the method is to gain a deeper understanding of the meaning and content of the concept and thus develop a better understanding of central concepts in the theory building process. The hermeneutic approach makes this methodology unlike that of traditional semantic analysis in philosophy or linguistics as the hermeneutic task is to bring forth better or deeper understanding of conceptual meaning, not only a linguistic meaning of a word. Koort's (1975) ambition was to initiate a hermeneutic dialogue rather than a linguistic monologue. The method is appropriate because its intention is not to divide meaning into pieces, but to make evident the extent meaning variations of the concept in order to better understand the concept.

5.3.1 Steps in the hermeneutic concept analysis

The hermeneutic concept analysis consists of three steps. The first step is to study the history of the concept, an etymological analysis. The second step is to explore the lexical meaning content of the concepts and its related synonyms. Finally, the last step is to do an interpretation of the results from the discrimination paradigm.

Step 1: Etymological analysis and reasons for choice of dictionaries, inclusion and exclusion

Etymological dictionaries were studied in the etymological analysis. According to Koort (1975) and Sivonen et al. (2010), the dictionaries to be included in the analysis should cover as long a period as possible so that the development of the concept and its meaning and synonyms could be revealed. Since the dictionaries were the data material and the foundation of the study, it was important to have valid reasons for both inclusion and exclusions.

Thus, the following etymological dictionaries were selected: *Våre Arveord – etymologisk ordbok* (Bjorvand & Lindeman, 2000), *Etymologisk ordbog over det norske og danske sprog* (Falk & Torp, 1994), *Online Etymology Dictionary, Ordbog over det danske sprog* (1700-1950) and *Svenska Akademiens Ordbok SAOB.*

Etymologisk ordbog over det norske og det danske sprog (Falk & Torp, 1994) was first published in 1903-06. It was the only Norwegian etymological dictionary for nearly a hundred years until the Norwegian etymological dictionary, *Våre arveord - Etymologisk ordbok* (Bjorvand & Lindeman, 2000) was published in 2000, and is classified as one of the best modern etymological dictionaries of any Germanic and Indo European language (Blazek, 2006). *Svenska Akademiens Ordbok (SAOB)* is a comprehensive etymological dictionary that describes the Swedish language from the 1500s and until today. It is the biggest dictionary of its kind in the Nordic countries. *Ordbog over det danske Sprog* is a Danish etymological dictionary that covers the Danish language from 1700-1950. *Online Etymology Dictionary* describes the origins of English language words.

By studying the history of the concepts, I gained a better understanding of the genesis or original meaning of flesh and fleshly and the transformations until today. The etymological study lead to concrete situations and contexts that have formed the humans' mental notions attached to the two concepts (Koort, 1975; Sivonen et al., 2010), but also lead to new meanings that may open up our understanding of the body today.

Step 2: Exploration of the lexical meaning content of the concepts and its related synonyms

After the etymological investigation, the lexical meaning content of related synonyms were explored (Koort, 1975; Sivonen et al., 2010). There are two Norwegian words for flesh, *kjøtt* and *kjød*. These two words were merged in the lexical investigation because they are often synonyms, although *kjød* has a more religious meaning, particularly in the newer dictionaries.

Since the dictionaries were the data material and the foundation of this study, it was important to choose dictionaries from acknowledged editors and from different decades. Nine dictionaries were included, and the dictionaries covered a period from 1937 to 2016 while flesh (kjøt, kjød) does not appear as a noun in the oldest Norwegian dictionaries, *Norsk*

Ordbog over det norske folkesprog (Aasen, 1850) and *Norsk Ordbok med ordtydning paa norsk dansk* (Schjøtt, 1914).

Norsk riksmålsordbok (Knudsen & Sommerfelt, 1937) from 1937 was published during the period 1937-1957. This is a historical, descriptive and literary dictionary with many descriptions of the language in use. *Norsk Synonymordbok* (Gundersen, 1964) from the 1960s is the first dictionary of synonyms in Norway with the recognized research linguist Dag Gundersen. No dictionaries from the 1970s are included. From the 1980s, *Bokmålsordboka* (Landrø & Wangensteen, 1986) and *Cappelens ordbok* (Landfald, 1986) are included. *Bokmålsordboka* (Landrø & Wangensteen, 1986) is published by the Department of Linguistic and Scandinavian Studies at the University of Oslo in cooperation with the Norwegian Language Council.

Two dictionaries from the recognized linguist Tor Guttu are included. These are *Aschehoug og Gyldendals store Norske Ordbok* (Guttu, 1991) from 1991 and *Norsk Ordbok med 1000 illustrasjoner* (Guttu, 2005) from 2005. Another dictionary from the 1990s is *Rettskrivningsordbok med synonymer* (Bøe & Fossestøl, 1992). From the 2000s I have included *Norsk ordbok. Ordbok over det norske folkemålet* (Grønvik, 1978-2012) and *Escolas ordbok* (Taule, 2009). The first dictionary gives an exhaustive account of the vocabulary of Norwegian dialects and Nynorsk and contains more than 300 000 word entries.

Strong and weak synonyms were uncovered in the dictionaries. Dictionaries were excluded if they had no synonyms, or referred only to the concepts in sentences and not as singular concepts. The results were summarized in a table of synonyms (Appendix 8), which also showed the changes in the synonyms in a chronological perspective. Below the table is a brief description of which synonyms were not included.

The table of synonyms (Appendix 8) showed that the concepts had several synonyms, which meant that the analysis could not end here. Thus, I had to move to a more detailed analysis of discrimination of the selected synonyms, an analysis of the related concepts, to obtain characteristics and discriminatory features, described as the matrix phase and the paradigm phase. In this context, synonym tables were formed for every included synonym to explore how all the chosen synonyms were inter-related, finding characteristics that discriminated the meaning contents in the conceptual family. These tables are not shown in the thesis.

In the matrix phase, I made two discrimination matrices (Appendix 9 and 10) on inter-related synonymy between the two main words, flesh and fleshly, and the chosen synonyms. The discrimination matrices showed the number of dictionaries in which the synonyms of the concept's synonyms were identical with the synonyms of the original concept (Koort, 1975; Sivonen et al., 2010). The higher the number in the table, the stronger the connection between the synonyms under investigation.

From the matrices, the interrelatedness of the synonyms of the concept's family members was illustrated in figurative discrimination paradigms shown in chapter 6.2.1 (figure 1 and 2), with main concepts and their calculated synonyms. According to Koort (1975) and Sivonen et al. (2010), the degree of synonymy was estimated as follows:

$$\frac{\text{(Frequency of available references of synonymy between two words) x 100}}{\text{Frequency of possible references for those two words}}$$

Two words have seldom quite identical meaning. According to Koort (1975), only synonyms with more than 40-50 % degree of synonymy should be included in the further analysis. However, synonymy is not a question of percentage or absolute numbers, but of conceptual relationship. Eriksson and Herberts (1993) broadened the perspective and claimed that sometimes even a weak synonym can be included if related to the research interest or to the original meaning content of the word. I have included all the synonyms in the discrimination paradigm, but in the description and interpretation of the results in chapter 6.2.1 and 6.2.2 I concentrated on the words with the strongest bindings.

In the discrimination paradigms described in chapter 6.2.1, I attempted to use synonyms that were singular words, not synonyms in form of sentences, because calculations can only be done between concepts. However, in the examinations of dictionaries, with the exception of etymologic dictionaries, I found many descriptions of the concept of flesh in form of phrases that gave meaning to and showed how the concept was used in different settings. Especially adjectives that characterized flesh, and which were not present in the semantic and etymological analysis, were of concern. To get a more comprehensive understanding I also searched for related synonyms to these adjectives in the dictionaries and prepared a table of the results, see Appendix 11.

Step 3: Interpretation of the results from the discrimination paradigm and the descriptions from dictionaries

In the last step of the analysis, I performed an interpretation of the results from the discrimination paradigm and the descriptions from dictionaries. The interpretation was inspired by Gadamer's (2004) ontological hermeneutics. The results were further interpreted through a dialectical movement between the results with the highest degree of synonymy, the etymological analysis, Merleau-Ponty's (1968) philosophy of flesh, and nursing and caring theory and research. This is further described in chapter 6.2.2.

5.4 The empirical studies

5.4.1 Setting, sample and data collection

Hospice was chosen as research area. Hospice is both the name of a holistic philosophy of caring and the name of an institution (Strømskag, 2012). My experience working at one of the institutions part time some years ago and my cooperation with one of the units in my work as an assistant professor, made me consider the units as good arenas for getting answers to my research questions.

The study has a purposive sampling, which means that the participants who have been selected are participants who will contribute well in relation to the aim of the study (Polit & Beck, 2018). These participants represent good or typical examples of the field (Fangen, 2010). Eight nurses, 12 relatives and 13 patients participated in the study.

I collaborated well with the head nurses at the two hospices who performed the inclusion of the participants and gave the participants the information sheet and collected the informed consent about the study (Appendix 4). The good collaboration was important to make sure that the participants included in the study had rich experiences concerning the issues I was studying.

Inclusion of nurses

Table 1 shows the gender, age, years of work experience as nurse, and further specialization of the nurses included. The nurses included in the study worked at two hospice inpatient units. Other inclusion criteria were that the nurses should have a minimum of two years of work experience and further specialization in oncology nursing or in palliative care. The nurses included in the study had long work experience as nurses. The mean number of years was

18.9 years. Four nurses had further specialization in oncology nursing and four in palliative care. Several nurses had also further specialization in health management and public health nursing. All the nurses were women and their ages ranged from 46-64. The head nurse of the unit selected the nurses according to inclusion criteria.

Table 1: Gender, age, number of years of work experience as a nurse and further specialization

Nurse	Gender	Age	Number of years of work experience as nurse	Further specialization
1	Female	55	18	Oncology nurse
2	Female	56	34	Palliative care
3	Female	46	21	Oncology nurse
4	Female	64	18	Palliative care
5	Female	55	29	Oncology nurse
6	Female	60	15	Palliative care
7	Female	54	9	Oncology nurse
8	Female	59	7	Palliative care

Inclusion of relatives

Table 2 shows the age, gender and relation of the relatives. Relative is per definition the individual the patient feels the closest to (Helse- og omsorgsdepartementet, 1999). In order to assure that this would be the case in this study, I had to make a detour to the patients in the unit. I was invited to a meeting where the patients from the day unit were gathered to receive information on the study. The patients were given an information sheet about the study and were asked if the head nurse of the unit could contact the relative they felt closest to for participation in the study. Other inclusion criteria were that the relatives spoke and understood Norwegian and were mentally aware of time and location. They also had to be relatives to cancer patients at the end of life. Twelve relatives participated, three men and nine women. Ten of the informants were from the hospice day unit and two from a hospice inpatient unit. Their ages ranged from 41-86 years. The men were all husbands; the women were three wives, five grown-up daughters and one friend.

Table 2: Age and relation of the relatives

Relative	Age	Relation
1	63	Friend (female)
2	41	Daughter
3	77	Wife
4	54	Daughter
5	43	Daughter
6	41	Daughter
7	68	Husband

8	73	Husband
9	60	Wife
10	50	Daughter
11	86	Husband
12	68	Wife

Inclusion of patients

Table 3 shows the gender and the age, civil status and bodily symptoms reported by the patients. The patients included in the study were patients at the hospice inpatient unit with advanced cancer diagnosis, experienced bodily changes and were at the end of life. As the patients were to be interviewed and observed, it was important to find patients who had the strength and endurance to complete an interview and who were mentally aware of time and location. The patients included in the study had both visible and invisible bodily changes, such as fatigue, visible tumors, moon face, alopecia and emaciation as the table 3 shows. It was also important to include both patients who lived alone and those who were married or lived in a cohabitant relationship, as one of the research questions was whether the bodily changes had any impact on their relation to others. The patients had to speak and understand Norwegian well. Thirteen patients participated in the study, four men and nine women. Their ages ranged from 53 to 83.

Table 3: Gender, age, civil status, and bodily symptoms reported by the patients

Patient	Gender	Age	Civil status	Bodily symptoms
1	Woman	83	Widow	Weight loss, fatigue
2	Woman	57	Single	Weight loss, anorexia, fatigue
3	Woman	60	Single	Pain
4	Woman	53	Single	Anorexia, weight loss, immobility, dyspnea, coughing, fatigue, pain, sores in mucous membranes
5	Man	60	Common-law husband	Muscle loss, fatigue, pain, lymphedema
6	Woman	75	Single	Lymphedema right arm, leakage of lymph fluid, immobility, dyspnea, itching, pain, diarrhea, insomnia, fatigue
7	Man	77	Married	Balance disorders, dyspnea, numbness in fingertips
8	Man	79	Common-law husband	Fatigue, immobility
9	Woman	56	Single	Double vision, balance disorders, weight loss, sores in mucous membranes, fatigue, numbness in the mouth
10	Woman	75	Married	Coughing, hearing loss, impaired taste, dizziness, alopecia, fatigue, decadron moon face, pain
11	Man	70	Married	Weight loss, anorexia, muscle loss, obstipation, fatigue, immobility, dizziness
12	Woman	57	Single	Alopecia, anorexia, nauseous, ascites in the stomach, fatigue, cognitive disorders, obstipation, nausea, balance disorders
13	Woman	55	Single	Lymphedema in the legs, fatigue, pain

5.4.2 Qualitative interviews

The main data source in hermeneutics is in-depth conversations through which the researcher seeks to gain entrance into the participants’ world (Polit & Beck, 2018).

An interview guide based on open questions provided direction for the individual interviews between the researcher and each participant. The guide contained specific, open-ended questions, as well as key words to encourage the participants’ narration. The interview guide worked as a reminder during the interviews to ensure that the themes I wanted to cover were covered. I did not, however, follow the themes strictly, as it was also important to be open to any new themes that might emerge. Being open was a challenge as my preunderstanding was influenced by my previous work in the field earlier. I was fully aware of this and tried to keep an open mind and a keen awareness of my preunderstanding. However, it was difficult to be sensitive enough and aware of the small but important signals that the patient might send and that might be important to elaborate further. I would probably have approached the subject in a more naive way if the context and the patient group had been completely unknown to me and I would thus have taken nothing for granted. It is, however, not possible to rid oneself of one’s preunderstanding. It influences the whole research process and I cannot ignore it, but must try to make it visible so that I become aware of how it influences my ability to ask the “right” questions, to listen and understand in the interview situations.

The interviews with the nurses (see Appendix 5) started with an open-ended question, asking the nurses to talk about how the bodily changes were expressed in the persons who were ill and how the bodily changes were experienced by the nurses. Other questions focused on how the bodily changes affected the life of the sick person and what was important when meeting patients with bodily changes. Further, the nurses were asked about their experiences regarding patients with severe emaciation, how this condition affected the nurses, which emotions it created and how the patients reacted or related to their emaciation. Lastly, the nurses were asked to describe a situation where the patients had experienced reconciliation, and the value or meaning for the patients of telling their stories about the bodily changes. The interviews lasted between 60 and 90 minutes and were carried out in an office at the two wards.

The interviews with the relatives (see Appendix 6) started with an open-ended question, asking the relatives to say something about how it was to be a relative. Other questions focused on whether the relatives had experienced that their ill relative had gone through any bodily changes and what significance such bodily changes might have for the patient’s experience of dignity. Further, what the bodily changes meant to the relative, if the bodily changes had any impact on their relationship to the patient, and if they had any thoughts on how the nurses could help the patients in relation to bodily changes.

After some interviews, I discovered that I had not used the word ‘dignity’ in my questions to the relatives, and I included a question asking the relatives what they associated with the word dignity. As mentioned in chapter 5.1.2, I noticed an uneasiness throughout the research process regarding the bodily concerns in my material. Likewise, an uneasiness whether the participants who were included had rich enough descriptions of what these bodily changes were like and what they meant to them. Therefore, the last two interviews were performed with relatives whose dear ones were patients at the hospice inpatient unit to see if they reported more bodily changes than those who had their dear ones at the day unit. The interviews lasted between 45 to 75 minutes. By request, seven of the interviews were carried out at the hospice day unit, one interview in the relative’s home and three interviews at the workplace of the researcher.

The interviews with the patients (see Appendix 7) started with an open-ended question, asking the patients to talk about the bodily changes they experienced as a result of their illness. Other questions focused on how their bodies changed during the illness-trajectory and the meaning of the bodily changes to the patient and in relation to other people. However, since the interviews were combined with participant observations, which were mostly performed before the interviews, this gave me greater confidence that the patients would speak because I spent more time with them and thus got to know them better.

The patients showed me great confidence in the extremely vulnerable situation that the interview situation represented. They trusted me and willingly invited me into their lives and generously sharing their experiences, reflections and precious time. Thus, it was my responsibility to manage this trust in a good way. Being gentle in the interview situations and sensitive enough to understand how long the interviews should last required discretion. Openness and an awareness of reserve from me as conversation partner were necessary to enable the patient to bring forth what is important for him or her. I was also sensitive to the ways the patient's vulnerability and bodily changes affected me. Thus, I was mindful of how I met the patients with my body language, what I said and how I, for instance, looked at a patient's edematous body, as my body language might inadvertently show reactions that could hurt the patient.

I did consider whether it would have been more appropriate to have two interviews with each patient. That would probably have made the patients feel safer and give them a feeling of closeness that might reduce the psychological stress that the interviews might induce. However, two interviews were not feasible as the patients were only hospitalized for a short time and I did not consider ethically defensible to take up more of their time. Instead I supplemented the interviews with participant observations, see chapter 5.4.3. The interviews lasted between 35-70 minutes and were carried out in the patient's room.

Gadamer (2004) describes hermeneutics, not as a technique to gain understanding, but as a way to clarify the conditions for understanding. Råholm et al. (2010) asked if we conduct interviews or observations in a way that are consistent with this ideal or whether interviews or observations are too 'sterile' to acquire new understanding. Gadamer (2004) states that the more genuine the conversation is, the less its conduct lies within the will of either partner. Rather, we fall into a conversation. In order to be involved in a genuine conversation, it is crucial to be hermeneutically attuned (Nåden, 2010), see chapter 5.4.3. Bildung (Gadamer,

2004) is a precondition for this to happen. The genuine conversation emerges through Gadamer's descriptions of an inner formative and cultivational process that has nothing to do with a technical construction according to Råholm et al. (2010). One might question whether the conversations I had with the participants were these forms of genuine conversations. However, I attempted to create open and natural conversations and I tried to linger on what the participants said and not rush them, but ask a number of follow-up questions in order to clarify, also in relation to topics that did not immediately seem central to the aim of the study. I experienced that when I dared to linger, important aspects appeared in what was not immediately given. My horizon shifted as I let new ideas challenge my immediate view on what the participants told me.

Transcriptions of the interviews

The interviews were taped and transcribed by me in order to become more familiar with what the participants told me. The material consisted of 137 pages transcribed text from the nursing studies, 141 pages from the relative studies and 223 pages from the patient studies. I decided that transcribing the text myself would help me in the interpretation process. I transcribed the interviews verbatim, and noted pauses with dots in the text. I recorded crying and laughter with a word in brackets. My intention with the transcriptions was to make them reflect the interview situations as accurately as possible. However, it is difficult or even impossible to give a totally "true" picture of the situation. Something will always be lost in the transformation of conversations from speech to words.

5.4.3 Participant observation

In addition to interviews, I chose to perform participant observations of the patients. The participant observation notes were not interpreted independently, but the observations gave me knowledge about the patients and their suffering bodies and a deeper understanding of the patients' situation. As Johnson (2007) states, the body is often mute, silent and difficult to grasp. Thus, participant observations helped me to gain more knowledge about the suffering body by observing how the patients moved their bodies, slow or fast, how they talked about their bodies related to the illness, the tone of their voice and their body language. This way I gained access to information that I probably would not have accessed in an interview situation as bodily issues might be difficult to express with words, as Johnson (2007) states.

The participant observations also helped me get to know the patients better as I spent more time with them than if I were to perform just one single interview with each patient. This probably also gave the patients more confidence in the interview situation.

Polit and Beck (2018) confirm that quality observation can provide a deeper understanding of human behavior and social situations. Such observation enables the researcher to ‘get inside’ a situation and illuminate its complexities. This is valuable in the effort to gain a deeper understanding of the meaning of the body, which is mute and difficult to describe with words.

The patients primarily remained in their hospital rooms and one patient was observed at a time. Since the patients were vulnerable and severely fatigued because of their diagnosis, and the primarily duty as a researcher is to treat the patients with respect and caution, this had consequences for how the observations were performed. Firstly, I did not observe the patients during more than one day-shift each, as most of them had only a 14-day stay and there was a lot going on in the patients’ rooms already. Secondly, I did not stay in the patients’ room during the whole day-shift but walked in and out, joining when the patients interacted with the nurses or doctors, received treatment from the physiotherapists, or during conversations with the occupational therapists. Each patient was observed for approximately 3-4 hours. The observation notes totaled 65 pages.

As an observer, I wore the same working outfit as the other nurses in the unit. I also had a small nameplate with my name on. Presumably, I became a more natural part of the unit wearing the same working outfit. Likewise, the clothes probably reminded the patients that I was a nurse in addition to being a researcher, which might lead to less stress for the patients. Probably, this would further give me more true observation data. Polit and Beck (2018) confirm that the researcher’s role in observation is to gain entrance and establish trust with the patient studied.

I participated only to a small extent in daily life, serving patients drinks and making beds after personal hygiene. Polit and Beck (2018) state that being a fully participating member does not necessarily offer the best perspective for studying a phenomenon.

I did not develop an observation guide as I wanted unstructured observations where the focus was not on specific situations or times, because with such limitations one runs a greater risk of not observing the whole thing (Nåden, 2010). Some issues were the same in all the observations; how the patients talked about the illness, their use of body language, the tone of the voice and whether it was slow or fast, the cooperation with other health personnel and what was said with words or not.

Thoresen and Öhlen (2015) state that emotional experiences are central in doing observations. I used my own senses and bodily responses in the observations to enrich the data collected. Embodied perception is not only a passive reception, but also an active exploration where body movement and body positions and the use of senses affect what is perceived. Paying attention to my own bodily experiences was crucial because I experienced that emotions and responses enabled a mode of attention and increased sensitivity that lead to deeper insight into the aim of the study (Thoresen & Öhlen, 2015). Thus, observation is not primarily a technique of doing, but a mode of being (Savage, 2000).

Nåden (2010) also states that moods and feelings are important in order for the researcher to be hermeneutically attuned. It is through moods that we primarily understand ourselves, the world and other people. He also emphasizes slowness and silence as important in a hermeneutic position. I had to work with myself to remain slow and calm in the observation situations while I felt anxiety and stress in relation to whether I was able to observe everything that happened in the situation. Writing methodological notes helped to reflect upon my own ability to stay in the situation, and to almost forget myself to the advantage of what I was seeing. Bergbom (2007) confirms the importance of hermeneutic attunement when she refers to Gadamer's (2004) philosophy of the play where the observer is the audience in the play, absorbed by what is going on (Gadamer, 2004; Bergbom, 2007).

Writing observation notes

I wrote down the observations during breaks in the day shift and immediately after the day shift was finished. It was important to take notes as soon as possible, as the memory usually moves from details to a more stereotypical description of the event as time goes by (Fangen, 2010). Thus, to make the observation notes as accurate as possible I tried to write as concretely and descriptively as possible what I had observed. I did not write anything during the specific observation situation because I found that this would disturb the situation and give less concentration on what was really going on.

Polit and Beck (2018) state that field notes represent the observer's effort to record information and to synthesize and understand data. Writing field notes is about transforming a transient event to an event that exists on paper and can be re-read repeatedly (Fangen, 2010). The author further states that the success of observations and the quality of material for interpretation depend on the quality of the field notes. Thus, I found it worthwhile to organize the field notes into three different columns: observational notes, theoretical notes and methodological notes (Fangen, 2010), see table 4. The first column contained notes on what happened without much interpretation. In the second column, I wrote down personal and theoretical reflections from the observations, to be used in the interpretation. The third column contained reflections on my experiences about participant observation as method. Although the intention with the field-notes not was independently interpretations, they helped me in the overall understanding of the interviews.

Table 4: Example of field notes with reflections on method and theory

Observational notes	**Theoretical notes**	**Methodological notes**
Foot Massage: The physiotherapist massages the patient's toes. Then she massages the foot with her whole hand slowly and with long strokes. She is cautious in the massage and watches the patient all the time to see her possible reactions. She massages both legs in turn. The patient has her eyes closed, she breathes more calmly now than earlier today. It looks peaceful. When the physiotherapist is finished, the patient jumps. "There was a sound, did you hear it", she asks. The physiotherapist still looks at her and says; "Maybe you dozed off a little?" "Maybe I did", the patient answers.	The physiotherapist gets in touch with deep and wordless dimensions in the human being when offering massage. She communicates directly with the patient's senses when she looks at her and touches her. The massage is performed with slow movements. The physiotherapist is careful and sensitive to the patient's possible physical or emotional reactions and her voice is gentle. It seems as if the physiotherapist, when she did the massage, led the patient away from her struggle and worry and into another mental state. It looks like if the physiotherapist is using all her senses and her voice in contact with the patient's body. She signals with her attentiveness that she takes the patient seriously. The physiotherapist senses the patient's body with her whole self. I observe and reflect on what this might mean for the patient and how it might enhance dignity? When the physiotherapist is finished, the patient shows her gratitude. There was a peace and satisfaction in the patient that I had not seen earlier that day. Breathing became more labored again when the treatment was finished.	To be open to sense the patient's bodily expressions when observing the physiotherapist who gives the patient massage. Working on and paying attention to my own bodily experiences during the observations. I tried to focus on what was going on in the situation and have as little attention as possible to other thoughts.

5.5 Interpretation

5.5.1 Interpretation of the hermeneutic concept analysis

The intention of the analysis of the discrimination paradigm, was to obtain the characteristic features of the concepts of flesh and fleshly and their related concepts. These results were then interpreted together with the descriptions of flesh from the dictionaries, the etymological investigation of flesh, the philosophy of Merleau-Ponty (1968, 2002), and nursing and caring science theory (Eriksson, 1994, 2006; Lindström et al., 2014; Eriksson, 2018) and research. I sought to gain understanding through dialogue with the results and theoretical sources, and sought to avoid dividing meaning into pieces. The aim was to make evident the meaning variations related to a word in order to better understand the whole of the concept according to the hermeneutic principle of parts-whole-parts (Gadamer, 2004; Sivonen et al., 2010). In the next chapter (chapter 5.5.2) the interpretation process, which is also relevant for this study, is more thoroughly described.

5.5.2 Interpretation of the empirical studies

The four steps in Koskinen and Lindström's (2013a) hermeneutic reading inspired the hermeneutic interpretation process. The interpretation started with a first reading of the interviews in their particularity and otherness. The next step was to separate larger textual units that addressed, touched and aroused wonder and extract them from the text. I created mental images of some of these textual units, described more in depth later in this chapter. By lingering and repeated acts of visualizations and reflections of these images, patterns of meaning units were uncovered. The meaning units were then interpreted to gain new understanding.

During the whole research process I strove to uphold a hermeneutic attunement to the textual material. The dialectical movement between the text and the interpreter is not always as fluent as Gadamer (2004) describes in the philosophy of the play, described more thoroughly later in this chapter. Dialectic is, according to Gadamer, not the arguing, but the art of thinking. It is a dialogue of questions and answers, giving and taking. I have tried to have a dialogue with the text, but have experienced difficulties with formulating good questions, which Gadamer describes as crucial for understanding. Gadamer refers to Plato's account of Socrates, who suggests that it is more difficult to ask questions than to answer them. According to Gadamer, to ask a question means to bring something into the open. The difficulty lies in knowing what one does not know and to make the question an open question, to which the answer is not settled (Gadamer, 2004).

However, the preunderstanding was not only a barrier to understanding. Merleau-Ponty’s philosophy of the flesh (Merleau-Ponty, 1968) was a good conversation partner in the interpretation of the texts. Especially his descriptions of the ambiguity between self and world as the essence of human beings set my thoughts in motion and raised questions, which were essential in the dialogical movement process. Likewise, his poetic and metaphoric language stimulated my creativity and ability to question the texts. The metaphors created emotional images that raised new perspectives on phenomena and thus new understanding (Wiklund, 2007). Further reflections and an evaluation of how I dealt with my preunderstanding in this project are described in chapter 8.1.

Creating mental images in the interpretation process

Another way to return to the texts and let the preunderstanding breathe was to let mental images arouse while reading the texts. These images touched and evoked wonder and engaged the senses in a different way than just reading a text would do. Making mental images was inspired by Schuback’s (2011) descriptions of the power of imagination and how that power makes us able to sense a picture. Table 5 shows an example of mental images that were created and which stimulated the interpretation process.

Table 5: Example on mental images, which simulated the interpretation process

Descriptions of the situation:
A relative tells about her husband who has an advanced cancer disease and struggles with severe fatigue. She tells with longing in her voice about the active and meaningful life they had before with long walks and a strong companion in art and culture.

Now he is hardly capable of anything. The wife has still a strong wish that they can live the way they did before, even though she realizes that is not possible. She tells about episodes when she gets angry with him. This may be when he enters the living room with his coffee cup after breakfast and lies down on the sofa instead of going out for a walk. “He should try to exercise more”, she says. “Not just sit down and do nothing. Then he only becomes weaker”. She thinks that he does not try hard enough.

The wife’s longing for what was exceeds the intention of understanding what is. It is painful for her to see that her husband does not have the same strength and will as earlier. She constantly struggles to keep her husband in the life they used to have while it seems like he wants to give up and die. The relative and the patient seem to fight a battle without being aware of it.

A mental image illustrating the relative’s story:
Imagine a fine-meshed net where the patient and the relative stand on opposite sides of the net, each pulling a thread. They pull and pull at threads in the net, which was quite shabby from the start. The net has few knots that bind it together, and thus there is a risk that it soon is torn apart.

This image tells me how fragile their lives were. How they both moved on a knife's-edge, where they were about to fall off. They did not work together towards a common goal, but were lonely, struggling, each on their separate side.

Another mental image:
The relative has an elastic cord around her waist, with which she hauls her husband along the street. She pulls and pulls and he shuffles his feet, following her. Hauling him becomes heavier and heavier, and there is an increasing risk that the elastic cord will tear off soon.
The image tells me about the unbearable suffering of the relative. How long will she be able to pull and he to shuffle?

The mental images described in table 5 helped me to understand more about the unbearable suffering of the wife and her husband, and that they were not able to help each other, but both struggled alone in solitude.

In general, the mental images created movements and engagement. They helped me keep an open attitude and reminded me about Gadamer's (2004) philosophy of the play and his statement that it is the subjective matter that shall be understood and not the researcher's opinion. Gadamer states that the reflection process acts as a game that without strength is in constant movement back and forth, continuously renewing itself. The movement of playing has no goal that brings it to an end, rather it renews itself in constant repetition. The identity of the player does not even continue to exist for anybody, just what they are playing. The play produces and brings into light what otherwise is constantly hidden and withdrawn. It is a transformation into the truth (Gadamer, 2004). Thus, perceiving the intended meaning of understanding as daring to play or engage in a game, might give a person a possibility to, in a natural way, emerge in the encounter with the text (Foss, Nåden & Eriksson, 2016).

Throughout the interpretation process, I discovered that the mental images brought to light what otherwise would be hidden and withdrawn. However, to make these images visible and evident it was important to dress these reflections in words, write them down and pose questions to the images (Gadamer, 2004). The mental images and the inspiration Merleau-Ponty's (1968) philosophy provided in the interpretation process, helped me approach reality by moving away from it, as Gadamer (2004) describes in Bildung. This also gave me the power to be persistent in asking questions and question even further, which is how understanding evolves (Gadamer, 2004) and becomes evident (Eriksson & Martinsen, 2012) than just imagining them. Such persistence is about spending enough time, letting the text move back and forth, with questions, answers, new questions and so on.

The mental images evoked feelings that are crucial for understanding ourselves and others (Schuster, 2013). Gadamer (2004) describes openness to this otherness as not merely being open to others, but also being open to myself, to my own feelings. I noticed that parts of the texts affected me emotionally in ways I was not prepared for. I felt that there was a conflict between me, my preunderstanding and some parts of the texts, which challenged my understanding. Taking my feelings into consideration made me change my understanding of the meaning of these textual parts. It was impossible and would be unethical to reduce understanding to only rational thinking, which would mean to neglect feelings as messengers with something important to tell us (Schuster, 2013) .

The researcher's use of the body in the research process

The mental images also revealed the importance of using the body in the research process. During the interpretation of the texts, I discovered that memories were awakened in my body. (Shakespeare, 2003; Edvardsson & Street, 2007). The body is not ahistorical or just another thing in the world. It is a “mnemonic device, a repository and expression of memories”, as Savage (2000) describes it.

I had to take these memories, which moved me bodily seriously in order to understand what the data material told me. The impressions evoked something creative inside me, as Norlyk, Dreyer, Haahr and Martinsen (2011) describe it. Norlyk et al. (2011) refer to Løgstrup (1983) who states that we must be sensitive and open our minds to an impression and further dwell in the impressions that move us until they have nothing more to tell us and an intuitive flash of insight appears (Norlyk et al., 2011).

Using matrices for organizing and interpreting the texts

As the transcribed interviews were many pages long, I found it necessary to organize the text so I would not lose any perspectives. Thus, the text was organized into matrices, which made it easier to see patterns and common themes. The matrices consisted of three columns with one question in each column: “What does the text say?”, “What does the text mean?” and “What is the deeper meaning to the text?”

The following table shows an example of how a matrix may be used in the interpretation process.

Table 6: Example on interpretation matrix

What does the text say	What does the text mean	What is the deeper meaning of the text
I have a nice picture of him when he was young and in the army. He was such a handsome man, very attractive. My father has always been very good looking. I was very proud of him when I was a little girl. He had dark thick hair. There is not much left of it now... I prefer to think about him the way he looked earlier, before he got sick.	Promoting dignity: A longing to look back on the past, and a decision to keep these good thoughts also today when his body is greatly changed.	Dignity: The longing for what there was and the wish to lift up the goodness from the past in the middle of the suffering.

Although the matrices were suitable for organizing and systematizing the material, the questions also helped me, in the interpretation process, to ask the right questions of the empirical material. Throughout the repeated readings of the texts, there was a dynamic and inner movement between the steps in the matrices, or between the parts of the text and the whole. The repeated readings guided the movement from the empirical to a generic understanding and a deeper meaning of the texts.

However, I also experienced that the matrices could hinder the creative process of interpretation because of the way the texts were organized. The columns seemed to interfere in the questions asked to the text. Thus, it was also important to have creative ways of imagining and interpreting the material, like using mental images as described above.

In addition to setting up matrices, I also wrote summaries of the interviews; these also helped me to gain a deeper understanding of the text.

How each sub-study affects the other studies in the interpretation process

The interpretation of each sub study affected the other sub studies. As described in chapter 3 and 5.2, I started with performing the nursing study, which gave me a growing understanding of the meaning of the body and a beginning understanding about the relative dignity in health and suffering. With this knowledge, I continued developing the relative and patient studies. The knowledge from the nursing study became an important part of the horizon and a basis for understanding the relative study and influenced the data collection in the same study. However, as I have described in chapter 3 and 5.2, I found that I needed to develop a deeper understanding of the body before interpreting the results from the relative study, and as a result I developed the hermeneutic concept analysis of flesh and fleshly.

Furthermore, the results from the nursing study and the hermeneutic concept analysis were in a dialectical movement with the relative study and gradually with the patient study, the overall aim of the study, the theoretical perspective, previous research and my preunderstanding. This way, as Gadamer (2004) states, new understanding emerges between new knowledge and previous knowledge in the hermeneutic circle. In my search for new knowledge, I experienced it as important to open up for new horizons and try to look beyond what was nearby. Likewise, on a few occasions, I experienced that the hermeneutic circle with the movement back and forth between parts and whole also helped me to not move too far away from the overall aim of the project. I sometimes found that in my eagerness to understand I tended to make interpretations that I had to adjust.

5.6 Ethical considerations

Ethical guidelines have been followed in all parts of the study and will be described more thoroughly.

5.6.1 Ethical issues regarding the hermeneutic concept analysis

Hermeneutic concept analysis has explicit criteria regarding inclusion and exclusion, see chapter 5.3, and these were taken into consideration. When gathering data from dictionaries, I chose dictionaries written by recognized and different Norwegian authors. This was important in order to give as broad, representative and true picture of the concepts as possible. However, regarding the etymological dictionaries, I found it appropriate to also include dictionaries from other Nordic countries.

The dictionaries investigated were chosen from as broad a period of time as possible, according to when the concept appeared in the language for the first time, and the dictionaries included were from almost every decade during the past 100 years. This was not as important regarding the etymological dictionaries. I have also attempted to describe which synonyms were excluded and why (Koort, 1975; Sivonen et al., 2010).

5.6.2 Ethical issues regarding the empirical studies – the sampling and data collection process

The study followed the principles of the Declaration of Helsinki of the World Medial Association (WMA, 2018) regarding minimizing the risks and burdens to the individuals, informed consent and confidentiality. The study raised special ethical issues regarding study three and four, as the patients had advanced cancer disease and were at a vulnerable stage in their life and the relatives were in close relationships to the patients. Thoresen (2010) discusses if it is ethically defensible to perform research on vulnerable groups in a hospice context. Previously, within the hospice context and in the society in general, death was a natural phenomenon and should not be hidden or regarded as defeat. However, in modern communities, death has become more private, personal, intimate and confidential. Many believe that the final days before death belongs to the dying person and his family (Thoresen, 2010). Thus, the researcher's presence may be perceived as offensive and objectifying. Regarding my studies, I was fully aware of this and made every effort to be careful and gentle and frequently asked the patients if they were tired and needed a break or wanted to end the interviews. However, I experienced that the patients wanted to tell their stories; it was important to them, and that gave me the courage to carry on with the study, as I found it ethically defensible to do so. Being able to tell their story to someone who is listening can help the patients to gain heath or strengthen dignity. Wiklund-Gustin (2010) and Sæteren (2007) state that telling stories is a human means to create meaning and it is also identity shaping.

Heggestad, Nortvedt and Slettebø (2012) describe moral sensitivity as an important supplement to traditional research ethics, as such sensitivity takes both emotions and reasoning in the situation seriously. I found being morally sensitive to be an important precondition for behaving and judging morally. It was essential to be "touched" both emotionally and cognitively to be able to sense the moral significance of a situation. I was emotionally touched by the stories the participants told me about the shame and the despair they felt regarding a body that was like a wreck or a horror movie. I was also emotionally touched by what I saw when I observed the patients. The stories and observations reminded me of the great suffering the patients experienced and helped me to be morally sensitive to the participants and the subject I was studying.

The ethical principle of minimizing the risks and burdens or doing no harm (Ruyter, Førde & Solbakk, 2014; WMA, 2018) was also particularly important during the individual interviews and in the participant observations when the patients became tired and needed breaks. I had to remain aware of the patients' conditions throughout the observations and interviews, and make sure that the staff would follow up the patients afterwards should the interviews cause feelings or reactions that the participants needed to talk about.

The patients included in the study were not the sickest, and probably not the most vulnerable, patients in the hospice inpatient unit. They had to be awake and have enough strength to participate in a conversation that lasted at least 30 minutes. They also had to be mentally aware of time and place. Thus, the patients had often stayed in the unit for some days before the interviews took place, and they had enough strength to participate in the research project.

The principle of minimizing the risks and burdens or doing no harm (Ruyter et al., 2014; WMA, 2018) was also observed in the recruitment process while informing the participants about the aim of the study. Before the studies started, each participant was given verbal and written information about all aspects of the study (Appendix 4) (Ruyter et al., 2014). A head nurse in the hospice inpatient unit informed the nurses and the patients about the purpose of the study and obtained written consent (Appendix 4). Regarding recruitment of the patients, the nurse collaborated with the interdisciplinary team at the unit about whom it was ethically defensible to ask to participate in the project. Before recruiting the relatives, it was necessary to inform the patients about the aim of the study. This is further described in chapter 5.4.1. When the head nurse received informed consent from the patients, she contacted the relatives and received informed consent from them as well.

The participants were also informed about the principles of confidentiality and anonymity (Ruyter et al., 2014; WMA, 2018). The participants' names were replaced with numbers and the hospice inpatient units were anonymous. The transcriptions of interviews and the observation notes were kept safe, locked in a drawer. The audio files of the interviews were locked in a safe and deleted at the end of the project. Likewise, the computer was locked with password and connected to networks affiliated with the work place.

The participants were also informed about the right to withdraw from the study at any time and without giving any reason, and that such withdrawal would not affect their further care and treatment. They were also informed that there was no risk associated with participation and that talking about their situation can, for some, be perceived as discomfort, but for most people as a relief. Lastly, the participants were informed that the study would not have any direct benefits for them (Ruyter et al., 2014; WMA, 2018), but would in the long run improve the care of severely ill patients, and improve the understanding of the participants' situation related to the theme of the study.

The Norwegian Social Science Data Service (NSD) approved the study (see Appendix 1 and 2). An application was also sent to Regional Committees for Medical and Health Research Ethics (REK), but their response was that the project was outside the scope of the Medical and Health Research Act (Appendix 3).

5.6.3 Ethical issues regarding the interpretation process

I have also striven to read and interpret the material in a precise, earnest and respectful way to ensure the trustworthiness of the data. I have considered openness and transparency important during the whole research process, see chapter 5.1 and chapter 8.2.3.

Listening to what the texts told me was also important in the interpretation process. Koskinen and Lindström (2013b) state that listening is an ethical demand; one has a responsibility to listen with an attention to something outside of oneself.

The very formulation of the texts and the interpretations of the studies also raise ethical considerations that are important to consider. I have tried to be aware of this. Eriksson (2010) states that the choice of language or words reflects the basic values of the whole work, see chapter 8.1.

6 Results

In this chapter the most central results from the four articles are presented, in accordance with the overall aim of the project, which is to gain a deeper understanding of the meaning of the body in order to understand dignity in health and suffering.

As described in chapter 5.3, it was necessary to develop a deeper understanding of the body, what it symbolizes and represents to the suffering human being, before interpreting the data from the relatives, and likewise before interviewing the patients. Thus, a hermeneutic concept analysis was performed, article 2. Since this article was written over a longer period of time and has been important for understanding and interpreting the results in article 3 and 4, it is called article 2 even though it is the last article published.

6.1 Article 1: Being trapped in an "alien" body. Nurses' experiences with patients' physical changes in the palliative phase

The aim of this study was to illuminate the significance of bodily changes in patients in palliative care, based on the nurses' perspectives. A further aim was to find out how nurses might help the patients to become reconciled with their changed body, if possible. Research interviews were conducted with eight nurses working at hospices in Norway.

The bodily experiences and changes were described as disgusting, despairing and furthermore as shameful and loathsome. The suffering body was perceived as alien, and the nurses described that the patients were trapped in their alien bodies. The bodily changes displaced the patient's identity, vulnerability and dignity. The suffering body had no safety net and was given away to the care of others.

Their sick bodies assumed control over the patients and diminished their personal freedom to influence circumstances in their lives. It was handed over to other peoples' protection and was a reminder of the seriousness of death. The suffering body gave the patients no foothold.

The nurses said that the patients were afraid that others would experience them as repulsive. They were concerned about supporting and trying to help the patients to re-establish a relationship with, and a coherence within, their bodies, physically, socially, emotionally and existentially**.** The nurses did so by offering good individual care and used touch or massage to reestablish the relationship and coherence with the broken body. They emphasized the importance of letting nature take its course so that the patients should not use all their power to fight against their bodies, but have enough power to live. Highlighting the beauty in and around the patients was also important. Furthermore, they invited the patients to tell their stories to make the alien bodies visible, to the patients, but also to their surroundings. Likewise, helping the patients to let go and show that one sees and confirms the human being behind the bodily changes was important. The nurses also used narration to help the patients to relate to and become close to their own shame. The narratives helped the patients to uphold dignity, to reconcile and establish new coherence and contact with their alien bodies, both bodily and existentially.

The study showed that when the nurses helped the patients to inhabit their own body, they helped them to be free, to find meaning and rest so they could feel reconciled and find their way back to themselves and the feeling of being at home.

The study also revealed that the nurses were not always aware of the patients' bodily changes, but more concerned of the appearance of the patients. Not noticing the bodily changes might imply insufficient understanding of the meaning and importance of the body in humans' experiences of dignity. It might also imply a lack of courage and curiosity to enter or endure the suffering of the patients or to capture the body's hidden expressions of suffering.

6.2 Article 2: Understanding the meaning of the ambiguous body – a hermeneutic concept analysis of flesh and fleshly

The aim of this study was to explore and understand the meaning and content of the concepts of flesh and fleshly. Likewise, to show how this knowledge might enrich the understanding of the ambiguous body and what the body means to the suffering human being.

The results of the discrimination paradigms of flesh and fleshly revealed how the concepts are used and understood in the language and what the meaning of the concept is, related to its conceptual family. The results from the etymologic analysis are presented in our article that is published (Lorentsen et al., 2019c). In chapter 6.2.2 are the results from the etymologic analysis and the discrimination paradigms interpreted further, which provides knowledge of the body in a deeper sense.

6.2.1 Results from the discrimination paradigms

The synonyms in the discrimination paradigms are marked with arrows. One-way synonyms between two concepts are marked with one-way arrows in the figuration. I have also made visible the synonyms of the synonyms in the diagrams, because they are regarded as characteristics of the concepts.

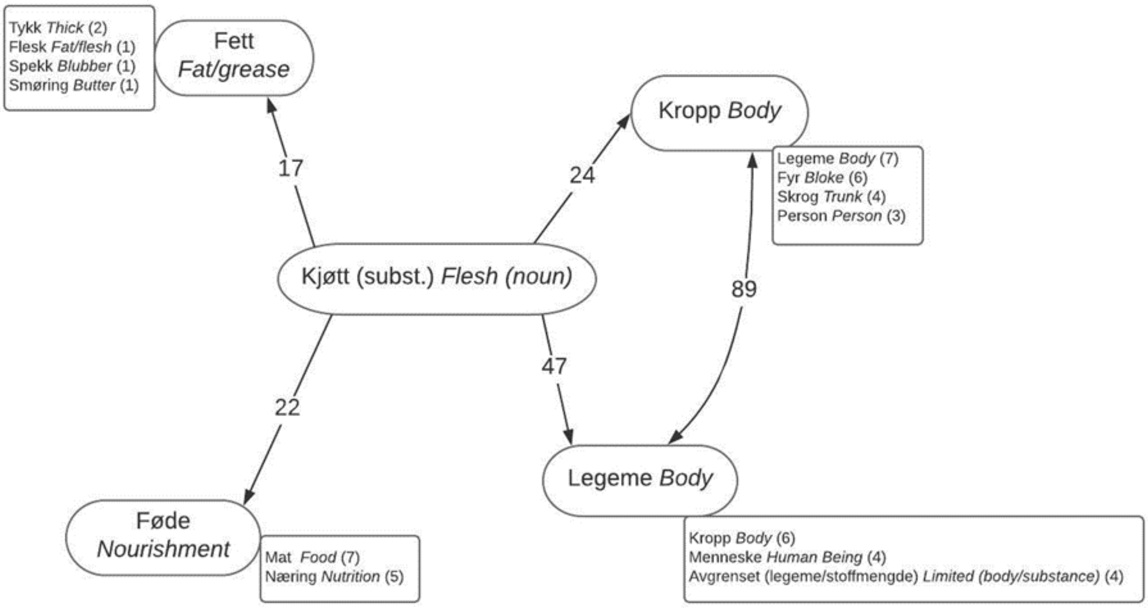


Figure 1: The discrimination paradigm of flesh

The discrimination paradigm of flesh (figure 1) shows that flesh has quite a strong binding to body as *legeme*, and weaker binding to body as *kropp*, fat and nourishment. There is a strong link between the two Norwegian words for body (*legeme* and *kropp*) both ways, which states that *kropp* and *legeme* are nearly synonymous. The other words are isolated because they have no bindings to any of the other concepts except flesh.

The related synonyms to flesh as body are both body as human being and body as body excluding head and limbs. The synonyms have different meanings, but both are included in the further analysis because of the complexity of the concept’s meaning. Body as human being reminds me about the living dimensions of body. Body as body excluding head and limbs reveals a corporeal and protective dimension of the body while it keeps the body upright and together.

The synonyms related to fat are thick, fat, blubber and butter. Butter has both a concrete and an extensional definition, and in this study the extensional definition is appropriate. Blubber is the fat of sea mammals, especially whales and seals. These synonyms have properties of grease and softness, which in a metaphoric way give associations to flesh as the protective body.

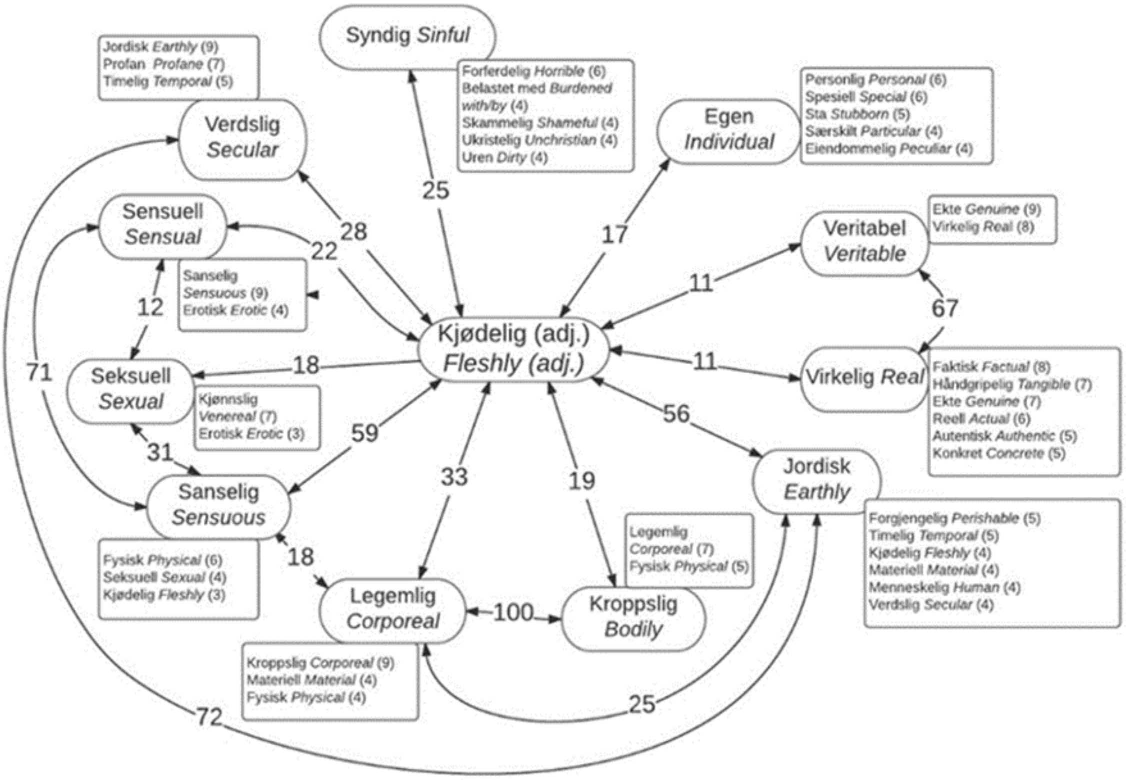


Figure 2: The discrimination paradigm of fleshly

The discrimination paradigm of fleshly (figure 2) shows that fleshly has the strongest bindings to sensuous (sanselig), earthly (jordisk) and corporeal (legemlig). The 100 % link between corporeal and bodily demonstrates that these two concepts are identical. Earthly and secular have also a quite strong binding that indicates a great deal of synonymy. The related synonyms to earthly and corporeal confirm the material dimension. It does not last forever; it decays, perishes and breaks down. The dimensions of flesh as the corporeal and the temporal body emerge.

Sensuous has a weak binding to corporeal, a stronger binding to sexual and quite a strong binding to sensual. This confirms dimensions of desire and flesh as the sensuous body emerges. Fleshly has also a binding to sinful both ways, with its corresponding synonyms horrible, burdened with, shameful and unchristian. Sinful is an isolated word that has no bindings to any other words except fleshly. The synonyms reveal the dimensions of shame and disgracefulness and flesh as the shameful body emerges.

6.2.2 Hermeneutic interpretation of flesh and fleshly

The results from the discrimination paradigms were further interpreted through a dialogue or dialectical movement with the etymological analysis, with Merleau-Ponty's (1968) philosophy of flesh, and with nursing and caring theory and research. The aim was to reach a better understanding of the meaning of the body and what the body means to the suffering human being. The six themes that emerged from the interpretation process will be briefly described.

Flesh as the corporeal body: The physical and material aspects of the body were central in the discrimination paradigms. Being able to stand upright and feel that the body still carries you despite an advanced cancer diagnosis is a way in which the patients confirm their life and existence to themselves and their surroundings. When the body is no longer able to carry the person in an upright position, helplessness and vulnerability remind the human being of the changed conditions due to illness.

Flesh as the protective body: The body as trunk represented elements of protection and goodness while it keeps the person in an upright position and prevents it from falling. The descriptions of flesh as the soft tissue between the body's skin and bones also evoked the body as something good, protective and restful. The results might give associations to the body as bearer of dignity. However, when the body is sick and the relative dignity is threatened, the sick body can rather illuminate dignity as a value inherent to the human being than to what the body is able to perform.

Flesh as the temporal body: The temporal dimension of the body became evident with the synonyms earthly and secular and their related synonyms which shows that flesh is final. Time is irreversible, and life is always a movement towards death. Time as timeless time was also emphasized. Timeless time gives rest, and people may experience renewal and alleviation.

Flesh as the sensuous body: The body has also dimension of sensuousness. The semantic concept analysis and the descriptions of flesh in the dictionaries showed strong elements of sensitiveness or rather sensuousness. The body speaks to the person through sensations that are anchored in meaning derived through experience in the social world.

Flesh as the shameful body: There were elements of shamefulness and dirtiness in the analysis of fleshly. Shame is something that people often hide from others; it is mute and dark and experienced deep inside the human being, exerting a negative influence on the self

Flesh as the vigorous body: Lastly, the analysis showed several synonyms with elements of strength. The synonyms confirm the importance of the life-affirming dimension represented by the body.

These different and apparently contrasting meaning dimensions of flesh and the body revealed in this study, are in accordance with Merleau-Ponty's (1968) philosophy of flesh as both the concrete body and an element of Being. Exploring dimensions of the body may provide knowledge that can help us to articulate and make more visible the invisible dimensions of the body. Insight into metaphorical and literal meaning dimensions of flesh and fleshly provides knowledge of the body in a wider sense that is essential for nursing.

6.3 Article 3: The paradoxical body – a glimpse of a deeper truth through relatives' stories

The aim of this study was to explore the relatives' experiences of the patients' bodily changes from a perspective of dignity. The following research questions guided the work:

- What are the relatives' experiences of the patients' bodily changes?
- How do these experiences give insight into the phenomenon of dignity in a bodily perspective?

Research interviews were conducted with 12 relatives from a hospice unit in Norway. The relatives feared that the patients' bodily changes would paralyze them. They expressed a fear of being devoured and struggled to keep going. The relatives also described difficulties and sadness at living in a relationship with their dear ones who were totally changed physically, but also mentally, socially or existentially. However, despite these bodily changes, all the relatives confirmed that the changing bodies were of no importance to them. The patients remained the same, according to the relatives. The relatives expressed a longing for the way the patients were before they became ill, but they also wished to relate to and confirm the sick bodies as they were today. The patients’ bodies sent blurred signals which the relatives had to use a lot of effort to try to understand. The way the relatives behaved and treated the patients’ sick bodies described the responsibility and loyalty they had to their dear ones’.

The stories about their dear ones’ bodies brought forth stories of anger, sadness, discouragement, provocation, irritation and a body that had become a stranger. The sick bodies were annoying and caused exhausting tensions. However, all the relatives confirmed that the patients remained the same. This shows an ambivalence or an ambiguity that discloses a complexity or an intertwining between contraries in the body; the body as totally changed, but nevertheless the same.

Being in contact with the ambiguous body, the relatives came into contact with matters or truths that otherwise would have remained silent and unspoken to them. The patients’ suffering body brought the relatives to the things themselves, to the truths. The body was like a guide that helped them to become aware of what was at stake and to express it with words. According to Merleau-Ponty (1968), the relatives came into contact with a reality that was more real than the individual’s visibility.

In the study we also asked if the ambivalent expressions of the patient being totally changed and simultaneously the same, might be understood as an ambiguity connected to shame, where the relatives felt a sensitivity to boundaries that should not be crossed and therefore answered in this way.

The unanimous confirmation of the ambivalent body, that the patients were the same, might also be viewed as an act of will or a strong ethical commitment to promote the others’ dignity. Likewise, we also asked if the relatives’ act of will, not allowing their dear ones to let go, might evoke feelings in the patients of not having personal freedom, and that this again might threaten their dignity.

Understanding the meaning of the ambiguous or ambivalent body is crucial in order to understand more about the meaning of the suffering body and dignity in a bodily perspective. Based on Merleau-Ponty’s (1968) philosophy of the flesh, where the body is intertwined with the world and they are mutually dependent on each other, dignity in a bodily perspective is a unity of paradoxical matters or values inherent in the human being and not divided into internal and external dimensions which is common in the theoretical understanding of dignity (Eriksson, 1994; Edlund, 2002; Eriksson, 2006; Edlund et al., 2013). This is confirmed in the way the relatives treated and interacted concerning the opposing and conflicting feelings the patients' sick bodies caused. Dignity is also understood as the fundamental love for being, agape love (Thorkildsen, Eriksson & Råholm, 2013), and the responsibility (Lévinas, 1969) the relatives showed in the interaction with the ambiguous bodies.

6.4 Article 4: The meaning of dignity when the patients' bodies are falling apart

The aim of this study was to explore the patients' experience of bodily changes in relation to dignity. The following research questions guided the work:

- What are the patients' experiences of the bodily changes?
- How do the patients' experiences of bodily changes give insight into the phenomenon of dignity?

Research interviews were conducted with 13 patients from a hospice inpatient unit in Norway. The sick body was described as unpredictable and threatened the patients' identity. The patients were afraid of losing their dignity while the suffering body shook the very foundations of their being. The patients had to relate to bodies they described as wrecks and impossible to repair, and they were no longer able to cover up or ignore the problems.

Their sick and wrecked bodies rocked the patients to the depth of their being. The altered bodies were not able to cover up or ignore problems the way they could when they were healthy. Thus, the sick bodies brought the humans to the things themselves. They were guides or conveyors of existential truths that showed the patients what was at stake in their lives and gave them the possibility to deal with their bodies/lives in an honest and natural way.

The patients showed a strong will for life to keep their unruly bodies together to ensure that their bodies still functioned. The patients also described how they were able to move into new and health-inducing rooms in their bodies to endure their difficult life situation and enhance dignity.

The sick body and the world were in a continuous movement and interaction with each other and the patients strove to be and become a self in this interaction between apparently opposite life experiences. This seems to have helped the patients relate to their bodies in a deeper and more truthful way.

Since the patients, through their sick and wrecked bodies, were shaken to the depth of their being and thus gained the possibility of coming in contact with the existential truth, this gave further insight into dignity from a bodily perspective. Understanding dignity through the lens of ambiguity or interaction between suffering and health, meant to reflect upon what a good ambiguity was to the human being. The meaning of dignity was therefore not found in the well-defined categories, but rather in how human beings lived in a heterogenic synthesis of health and suffering and thus related to their sick bodies in a deeper and more truthful way.

The patients showed, through their suffering bodies, a deep will to be and feel alive. The life-affirming will was discovered as a natural and deep power in their suffering bodies. The patients defied both pain and fatigue to feel and confirm that their bodies were alive and not lifeless. Having active and vital bodies were important for their experiences of health and dignity.

The patients also described the importance of their strong will in discovering new and health-inducing rooms in their sick bodies as a way to take care of themselves and preserve dignity. They tried to fill these rooms with goodness and love, and experienced love as fundamental to being. Confronting their own death, the patients awoke existentially and in the movement towards realization of their health potential the patients strove for a wholeness of body, soul and spirit (Eriksson, 2007).

6.5 Further interpretations of the results

In this chapter, I will describe further the interpretation process of the study and the deeper understanding derived from this process, as illustrated in figure 3. The results from chapter 6.1 to 6.4 constitute the content in column 1. Following repeated reading acts and reflections between the parts and the whole (Gadamer, 2004), I interpreted the summarized central results of the articles into new essential meanings, which I show in column 2. The overall aim of the study, the theoretical perspective and my preunderstanding influenced how I read and interpreted the texts. The summary of central results and the new essential meanings are marked with four different colors. Black represents ‘suffering’, red represents ‘health and dignity’, green represents ‘the dialectical movement between suffering and health’, and blue represents ‘story-telling’.

When I had uncovered the new essential meanings, I interpreted them in a back and forth movement (Gadamer, 2004) between the overall aim of the study, the new essential meanings and the theoretical perspective consisting of body, health, suffering and dignity. This interpretation process resulted in the following themes:

1) Understanding dignity through the meaning of the suffering body
2) Understanding dignity through the meaning of telling stories and dwelling on the suffering body
3) Understanding dignity through the meaning of flesh as metaphor

The themes represent the new knowledge on dignity in health and suffering that I discovered through the interpretation process. This is further explained below.

1) Understanding dignity through the meaning of the suffering body

The figure shows that the suffering body is alien, a stranger, and thus a threat to dignity. The human being expresses shame, sorrow, frustration and anger regarding the bodily changes. Likewise, the body has no protection and this causes feelings of pain and fear. The body is unruly, rocks the depth of the human being, and is a reminder of imminent mortality.

However, the figure also shows that the suffering body is ambiguous. Likewise, the figure shows the substance of love, the act of will and the focus on beauty and on letting what is healthy live in the midst of the body's suffering. This reveals knowledge about the possibility that opposites like suffering and health can meet and exist in a dialectical movement (Eriksson, 1994, 2006) that might lead to reconciliation and dignity.

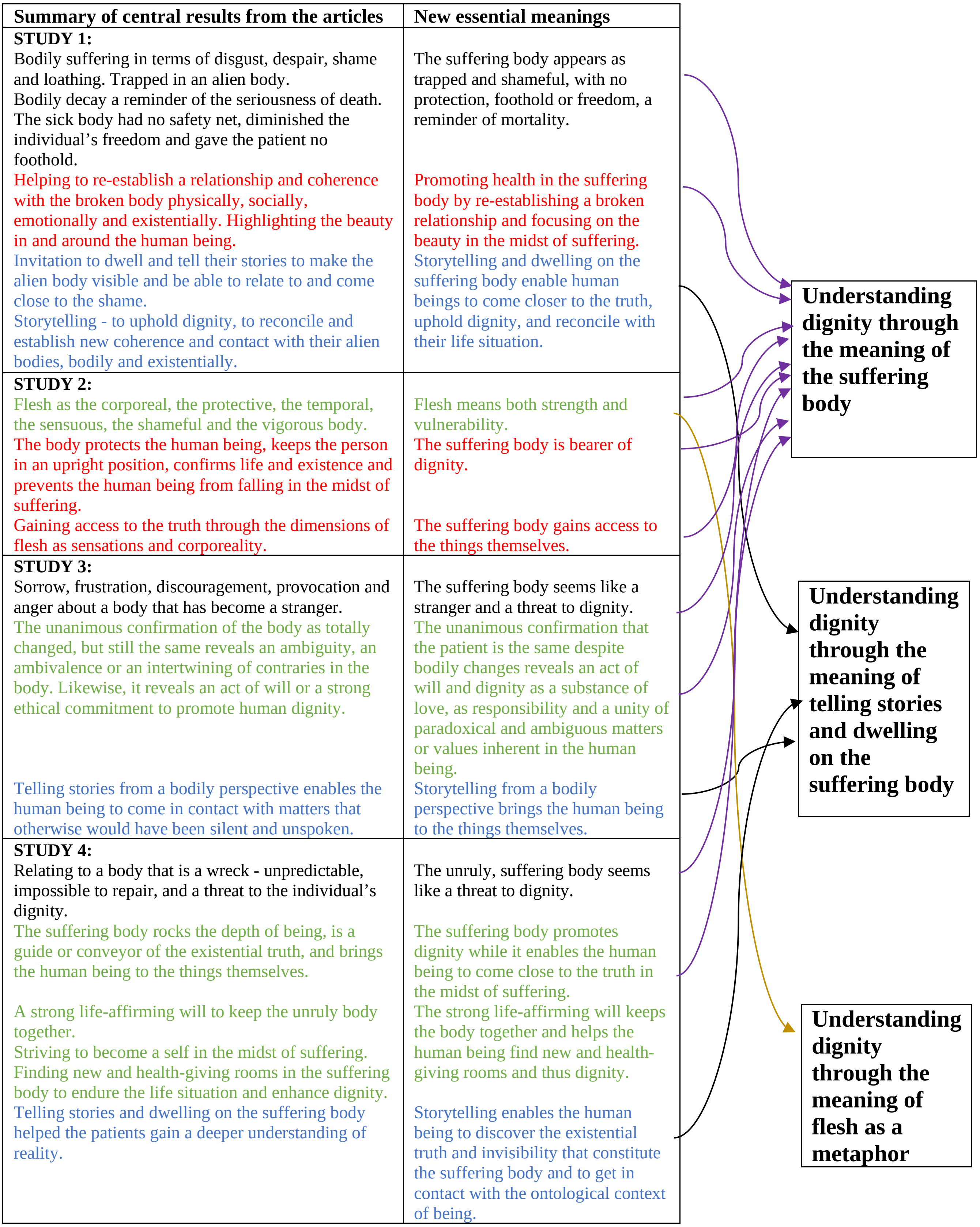
The body is bearer of dignity in that it keeps the human being in an upright position, confirms life and existence, and prevents the human being from falling in the midst of suffering. Dignity appears as the possibility to promote health, to see the beauty and re-establish the relationship to a body that is wrecked, shameful and decaying. Dignity also appears as the substance of love, as a strong ethical commitment and an act of will, discovered in the unanimous confirmation that the patient remains the same, despite great bodily changes. Dignity is the unity of paradoxical matters or values inherent in the human being. Further, the suffering body promotes dignity because it enables human beings to come closer to their truth and to their vulnerable body in an honest way. Lastly, the strong life-affirming will keeps the body together and helps the human being find new and health-giving rooms in the suffering body that promotes dignity.

2) Understanding dignity through the meaning of telling stories and dwelling on the suffering body

The figure shows that telling stories and dwelling on the suffering body helped individuals to new insights and interrelationships in lives marked by ruptures and uncertain futures. Telling their stories was meaningful and a help in upholding dignity, in reconciliating and understanding the truth, but also a source of grief and loss. Storytelling appears both as concrete statements in the interviews and more implicitly as the value of being allowed to talk about and being in contact with the suffering body. Storytelling enabled the individual to discover the existential truth and the invisibility of the suffering body and brought people closer to the things themselves and their ontological context of being, all important elements in experiencing dignity.

3) Understanding dignity through the meaning of flesh as metaphor

The hermeneutic concept analysis in particular revealed that metaphors might be useful to open up new perspectives on body (Sellheim, 2010) and dignity. The interpretations of flesh and fleshly in the hermeneutic concept analysis opened up new meaning dimensions of flesh or the body as strength and vulnerability or as health and suffering. Since dignity might be experienced in this dialectical movement between suffering and health (Eriksson, 1994, 2006), the new meaning dimensions of health and suffering give substance to the concept of dignity.



Summary of central results from the articles	New essential meanings
STUDY 1:	
Bodily suffering in terms of disgust, despair, shame and loathing. Trapped in an alien body. Bodily decay a reminder of the seriousness of death. The sick body had no safety net, diminished the individual's freedom and gave the patient no foothold.	The suffering body appears as trapped and shameful, with no protection, foothold or freedom, a reminder of mortality.
Helping to re-establish a relationship and coherence with the broken body physically, socially, emotionally and existentially. Highlighting the beauty in and around the human being.	Promoting health in the suffering body by re-establishing a broken relationship and focusing on the beauty in the midst of suffering.
Invitation to dwell and tell their stories to make the alien body visible and be able to relate to and come close to the shame. Storytelling - to uphold dignity, to reconcile and establish new coherence and contact with their alien bodies, bodily and existentially.	Storytelling and dwelling on the suffering body enable human beings to come closer to the truth, uphold dignity, and reconcile with their life situation.
STUDY 2:	
Flesh as the corporeal, the protective, the temporal, the sensuous, the shameful and the vigorous body.	Flesh means both strength and vulnerability.
The body protects the human being, keeps the person in an upright position, confirms life and existence and prevents the human being from falling in the midst of suffering.	The suffering body is bearer of dignity.
Gaining access to the truth through the dimensions of flesh as sensations and corporeality.	The suffering body gains access to the things themselves.
STUDY 3:	
Sorrow, frustration, discouragement, provocation and anger about a body that has become a stranger.	The suffering body seems like a stranger and a threat to dignity.
The unanimous confirmation of the body as totally changed, but still the same reveals an ambiguity, an ambivalence or an intertwining of contraries in the body. Likewise, it reveals an act of will or a strong ethical commitment to promote human dignity.	The unanimous confirmation that the patient is the same despite bodily changes reveals an act of will and dignity as a substance of love, as responsibility and a unity of paradoxical and ambiguous matters or values inherent in the human being.
Telling stories from a bodily perspective enables the human being to come in contact with matters that otherwise would have been silent and unspoken.	Storytelling from a bodily perspective brings the human being to the things themselves.
STUDY 4:	
Relating to a body that is a wreck - unpredictable, impossible to repair, and a threat to the individual's dignity.	The unruly, suffering body seems like a threat to dignity.
The suffering body rocks the depth of being, is a guide or conveyor of the existential truth, and brings the human being to the things themselves.	The suffering body promotes dignity while it enables the human being to come close to the truth in the midst of suffering.
A strong life-affirming will to keep the unruly body together. Striving to become a self in the midst of suffering. Finding new and health-giving rooms in the suffering body to endure the life situation and enhance dignity.	The strong life-affirming will keeps the body together and helps the human being find new and health-giving rooms and thus dignity.
Telling stories and dwelling on the suffering body helped the patients gain a deeper understanding of reality.	Storytelling enables the human being to discover the existential truth and invisibility that constitute the suffering body and to get in contact with the ontological context of being.

Figure 3: Further interpretation of the sub-studies

7 Discussion

In this chapter I will discuss the new knowledge represented by the three themes developed through the interpretation process in chapter 6.5.

Additionally, I want to discuss a fourth theme: ‘Understanding dignity through the meaning of cultural impact on the suffering body’. This last theme has not evolved directly from the sub-studies, but through reflections arising from the theoretical perspective (Merleau-Ponty, 1968; Eriksson, 1987b, 1987a, 1994; Merleau-Ponty, 2002; Eriksson, 2006, 2018) of the study and is therefore not included in figure 3. Eriksson and Lindström (2007) state that a human being finds meaning in history and not solely from empirical facts. In chapter 1.1 in this thesis it is also described how our view of the body is based on centuries of history. Likewise, Merleau-Ponty states that culture is intertwined with the body, and the culture and the body are not two separate entities (Merleau-Ponty, 1968, 2002). With this theoretical background knowledge it is appropriate to briefly discuss the meaning of the culture’s impact on understanding the body.

7.1 Understanding dignity through the meaning of the suffering body

Bodily dignity is violated when the body becomes sick and the wholeness is threatened (Lindwall, 2004). The language of suffering is often quite mute, while suffering has been reduced to the language of illness or physical suffering (Eriksson, 1994, 2006). This is also my experience when searching for research studies regarding the inside perspective of suffering (Rehnsfeldt & Eriksson, 2004; Arman, 2007). However, understanding suffering and health through the sick body gives the two phenomena a more articulated voice and language because the body is the ‘touchstone’ of existence (Madjar, 1997). Understanding through the suffering body is a way to see the world more ‘as it is’ or the suffering and health more ‘as it is’, because it is in and through their bodies that people exist and have contact with and knowledge about the world, according to Merleau-Ponty (1968, 2002).

There is a lot of suffering in the participants’ stories. Eriksson (1994, 2006) states that suffering is in its deepest meaning a form of dying away from something. The human beings grieve for what they are losing when they no longer feel whole and complete, and their dignity is threatened. The suffering in itself has no meaning, but pain and suffering make the human beings more sensitive and open to what life is about and they receive the possibility of actualizing their innermost being (Eriksson, 1994, 2006).

Illness breaks down the body (Lindwall, 2004). However, the body might also be understood as a resource for the human being and become a source of understanding and meaning when he or she is affected by illness. The body is a messenger that expresses the expressible, but research shows (Lundgren & Bolund, 2007) that the body also messages the inexpressible and thus helps to avoid that the suffering becomes silent, incomprehensible, obscure and unendurable.

Eriksson (1994, 2006) states that there is a threat to the person's ability to grow in his or her suffering. The threat consists in not being able to recognise the suffering and its possibilities and try to eliminate it or explain it away without making it a part of one's life. The fear of suffering prevents people from getting closer to themselves and becoming aware of their own being. It prevents the humans from experiencing themselves as a unit of body, soul and spirit (Nyström, 2014). If suffering is denied, a part of life is denied and thus the possibility of a person's becoming a whole human being (Eriksson, 1994, 2006) experiencing dignity.

Thus, by returning to the body, the body helps the human being to "reconnect" with the world and become aware of what is at stake. The body and the mind are inextricably intertwined and it is therefore impossible to separate the two entities (Merleau-Ponty, 1968, 2002). Returning to the body might help human beings to orient themselves in the world (Nyström, 2014) and make suffering visible to themselves and make it more endurable. This has been highlighted in this study. Consciousness of one's suffering is a condition of alleviation (Sæteren, Lindström & Nåden, 2011), or as Nyström (2014) emphasizes: awareness of the suffering gives depth to health. The body enables the individual to allow the sick body and the suffering to concern him or her, and lets the person become whole (Eriksson, 1994, 2006) and experience dignity.

Struggle is usually associated with battles where there are either victory or loss. However, struggle understood in a caring perspective (Eriksson, 1994; Wiklund, 2000, 2003; Eriksson, 2006; Sæteren, 2006; Sæteren et al., 2011; Sæteren, Lindström & Nåden, 2015) does not necessarily result in victory, but in reconciliation where opposites can meet and unite and dignity is experienced. In a bodily perspective, where the body and the mind are inextricably intertwined (Merleau-Ponty, 1968, 2002), the struggle is not between opposites, but a struggle to live with and express the ambiguity or ambivalences revealed in the suffering body

(Lorentsen et al., 2019b). This might be understood as being able to accept an existence with great uncertainty where nothing is really settled. Living in the ambivalence or the paradoxes, as this study has highlighted, can be understood as the human coming into contact with the ambiguous body or the flesh, which is the visible body, but also something more which extends beyond the immediately visible (Merleau-Ponty, 1968). The flesh is ontologically what lies beneath and behind the things and holds them together. Thus, being in contact with the flesh might enable the humans to experience coherence, support and dignity, in the midst of suffering (Merleau-Ponty, 1968).

Wiklund (2000, 2003) states that the struggle in suffering and health is about reconciliation between contradictions, such as for example life and death or between hope and hopelessness. Sæteren et al. (2015) identified the struggle as a battle against time and annihilation, which becomes visible to the human being when the body is affected by serious illness. She found that the struggle appears at an ontological level as a struggle of the will between anxiety and love (Sæteren, 2006). Sæteren (2006) further states that the hallmark of anxiety is reticence, constraint and silence and the hallmark of love is interdependence, freedom and communication. Thus, while the body is a messenger that messages the inexpressible (Lundgren & Bolund, 2007), the body might help the human being to open up for the constraint, the silence and the reticence, as this study shows. Thus, the anxiety will not be paralyzing, but will concern the human being and make him or her feel love in the midst of suffering.

Sæteren (2006) further states that the center of rotation for a human being from anxiety to love is through consciousness and will. Thus, in accordance with this study, the body helps the human being to get in contact with their consciousness and will, which makes it possible for anxiety and love to meet and unite in the midst of the suffering. The body hinders that the unbearable suffering (Eriksson, 1994, 2006) that is mute, incomprehensible and without language, takes root in the human being. This is again important with regard to dignity because such unbearable suffering paralyzes the human being and prevents him or her to grow and experience dignity. Thus, being in close contact with the suffering body might be understood as that life is winning and the struggle leads to meaning and a higher degree of integration and reconciliation (Wiklund, 2000, 2003), and thus dignity. The body enables the human to experience dignity in the midst of the struggle between suffering and health.

The dialectical movement or the battle between suffering and health that leads to reconciliation and thus health, strength and dignity, which this study reveals, recalls the good ambiguity described in Merleau-Ponty’s philosophy (Bengtsson, 2001). Merleau-Ponty (1968) states that the movement or ambiguity in the flesh brings the human being and the world together and forms a reality that is more real than the individual’s visibility. The ambiguity or reversibility in flesh gives insight into that there is always something more than the immediately visible in the suffering body. There is a depth in the flesh that might give an impression of an infinity, or a timeless time, as discovered in the concept analysis (Lorentsen et al., 2019c). This depth might be health-giving and especially important when the sick body is almost dissolved and reminds the human being about the end of life. It might help the patients to feel protected and supported in the midst of their suffering and thus become whole on a deeper level of integration (Eriksson, 1994, 2006) and thereby also experience dignity. Sæteren (2006) and Sæteren et al. (2016) also describe the human’s inner room or space and claim that the human being’s life-struggles take place in this innermost room. However, she also emphasises the possibility of life and states that, when time is limited, the possibility of life is hidden in the person’s innermost core, in the space we as human beings give each other, and in the invisible space we as human beings are a part of (Sæteren, 2006).

However, for the suffering bodies to be health-giving and thus promote dignity, there has to be enough space within the body to contain the ambiguity that discloses the complexity or opposites in the bodies. Thus, the space needs to expand when the contrasts become large, like when the body is seriously afflicted by illness. This means that the more wrecked the bodies are, the more important it is to have space for good things that alleviate~~d~~ suffering and strengthen or help the patients to experience coherence and dignity, which this study shows. Sæteren (2006) and Sæteren et al. (2016) state that the culture of the health service pays too little attention to the need that the seriously ill patients have for spatiality.

Eriksson’s (2003, 2007; 2018) theory about ethos might give associations to such health giving rooms in the patient’s body. The resemblance to flesh as the innermost room of the human being (Merleau-Ponty, 1968) is also striking. However, ethos goes a bit further and describes not just the depth in the human being, but also what the person might feel and the strength that arises when humans are in connection with the ethos, the flesh or their self and thus feel at home and at peace. In ethos lies the driving force that gives meaning to life itself (Eriksson, 2003, 2007; Eriksson, 2018).

Being in contact with the ethos gives rest and a feeling of being at home, which gives courage to a human being to listen to the voice of the heart and be in connection with the self. Ethos is the inner ethical dimension within the human being (Hilli & Eriksson, 2019). Aarø (2010) also states that the reversibility or the chiasm in Merleau-Ponty's (1968) philosophy forms a basis for an ethics of being while the flesh inhabits a space in the form of an openness to life being more than what is immediately experienced. The value of openness is also described in Eriksson's (1987a, 1994, 2006, 2018) caring science where she connects openness to being at home. Eriksson (2013) states that a person who is at home in herself has an openness to what she cannot handle, that which transcends the familiar, what works and what we master.

To sum up, the sick body causes huge suffering as it touches some of the deepness in life and diminishes the patients' personal freedom to become whole on a deeper level of integration (Eriksson, 2007). The body is honest and helps the human being to understand what is at stake. Relating to the sick body helps the human being to become closer to their suffering and truth and thus more acquainted with themselves and their flesh (Merleau-Ponty, 1968), while the sick body rocks the depth of their being.

Through their sick body the human beings come into contact with their vulnerability, and dignity is understood as being honest in contact with the vulnerable body. Dignity is also understood as allowing the individual to live and express the ambiguity or ambivalence experienced in the suffering body.

7.2 Understanding dignity through the meaning of telling stories and dwelling on the suffering body

The sub-studies showed that telling stories and dwelling on the suffering body helped the participants to reflect and gain a deeper understanding of reality, which might have a recovering effect in itself. The process was liberating and meaningful and enabled the participants to reconcile with their changed and alien bodies and experience dignity.

The importance of telling their story is confirmed by Eriksson (2003, 2009), who states that words and language are the foundation of humans' being in the world, helping to establish their reality. Words and language are also the basis for humans' ways of thinking, relating and acting and for how they act ethically. When people do not have words, they get lost in their reality. Stories help persons to know themselves and may transform their thinking. The stories provide access to subjective realities that is the individual’s own truth and the meaning of his or her experiences (Råholm, 2008; Wiklund-Gustin, 2010).

Thus, the telling of their stories might be associated with Eriksson’s (1987a) description of the human being’s ability to desire and create. Creation is being able to confirm oneself, striving to express who he or she is and make it possible for the human being to emerge. In the creative act, human beings assimilate the world that exists around them through a synthesis with the inner world (Eriksson, 1987a). Thus, letting the participants tell their stories through the suffering body is a way the humans create themselves, express themselves, being aware of and confirming who they are.

Thus, telling their stories about the vulnerable and sick body enables the human being to understand more about the obvious, but also the more hidden or mute dimensions of life, while it is in and through the bodies that people exist and have contact with and knowledge about the world (Merleau-Ponty, 1968, 2002). Corbin (2003) also confirms that meaning of life is derived from the body, and the body and the self are viewed as a unit until the body no longer can perform according to a person’s will.

However, for the body to be the human being’s access to the world and to life, the body must be visible to itself and others while the body is often mute, silent and difficult to grasp or understand. Johnson (2007) states that it is usual and common to remain in a mind-body dualism when we try to grasp the meaning of an issue or a situation, because the mind-body dualism is so deeply embedded in our philosophical tradition and in our language. Our bodies may easily hide themselves from us in their acts of creating meaning, and we try to separate the emotions from our thinking or interpretation (Johnson, 2007).

The reductionist and reducible knowledge derived from the biomedically and economically driven discourses, which dominate some areas of nursing science today, does not embrace the embodied notions that are subjective and emotionally experienced (Lawler, 1997; J. Draper, 2014; Marchetti et al., 2016). Thus, encouraging the participants to tell about their suffering and blurred bodies by asking questions in a language that is based on the perceived phenomenal body, might help the patients to make the body visible to themselves and their surroundings and build a bridge over the mind-body dualism, so they may experience wholeness and dignity. This is confirmed by Sæteren (2006, 2007) who states that telling stories might be a restoration of the selves while silence can enhance loneliness.

Martinsen (2009) states that by being close to their shame, human beings acquire a touching presence in life. She brings forth the concept dwelling and refers to the later Heidegger who states that the human way of being on earth is by dwelling (Martinsen, 2006). Todres and Galvin (2010) explain dwelling as a willingness to be there. It is about coming home to one’s situation, hearing what there is, abiding, lingering and being at one with what belongs in the situation (Todres & Galvin, 2010). Thus, telling their stories and dwelling on the suffering body might help the participants to dwell, to become grounded, to get in touch with life and further relate to their true existence and thus master the suffering better.

Todres and Galvin (2010) state that dwelling is being grounded in the present moment, but also supported by a past that is arriving and the openness of a future that is calling. Thus, dwelling or being in contact with both the present, past and a future through the suffering body might open up for and help the human beings to come into contact with their ontological level of existence while dwelling is not just a psychological state but describes a relationship of belonging between human beings and their ground (Todres & Galvin, 2010). Allowing the human beings to dwell is thus a way to help them to grow, to be protected and feel at peace (Martinsen, 2006) and experience dignity.

The value of dwelling on, or lingering, to become increasingly at home in oneself is rarely the focus of research studies or praxis. My experience is that nurses are more concerned with how to help the suffering human being in a concrete way by formulating nursing actions/measures than letting the patients stay in their suffering body in order to heal. The health personnel’s eagerness to help, to do something and not let the patients have the opportunity to suffer, might be a result of our modern culture where a target is that everything shall be controlled and fixed (Martinsen, 2009). The tempo in our society or in the health services can also explain why the patients experience that they are not allowed to suffer at their own pace (Martinsen, 2012, 2018). Listening to the patients’ stories about their uncontrollable, wrecked bodies might also create fear and helplessness in those who want to help, which can be difficult to cope with.

The value of slow motion in order to experience health and dignity was emphasized in the research studies of slow ethics (Gallagher, 2013), slow nursing (Lillekroken, 2014) and slow caring (Lohne et al., 2017). Gallagher (2013) has suggested integrating insights from slow movement into clinical ethics practice. She describes slow living as an attempt to live in the present in a meaningful, sustainable, thoughtful and pleasurable way. Her engagement with the Slow Movement began when she attended an exhibition on Slow Art and saw that the objects exhibited were very beautiful, demonstrating a fragility, vulnerability and the most acute attention to detail (Gallagher, 2013). The author referred to Robach (2013) who stated that Slow Art "requires not only courage, but also integrity to dare to take the time and focus entirely on one single project for weeks, months or even years" (Gallagher, 2013, p. 99). Further, Gallagher (2013) describes that slow ethics is not just about speed, but it is a mindset that engages an in-depth manner.

Kaldestad (2018) also highlights the importance of dwelling and states that dignity is strong in those who have the courage to dwell on or linger in the uncertainty in their search for answers and who work hard to explore thoughts and understanding. The urge to understand gives strength to human dignity. To be given the opportunity to dwell on their bodies gave the human being the possibility to become familiar with and relate to their suffering bodies in an honest and true way. It might give the human being access to subjective reality or the truth and make the situation more inhabitable and safe.

By being there in their suffering bodies the human beings cannot be indifferent or irresponsible to what they see or experience. They must relate to and take their bodies seriously. This is confirmed by Eriksson's (2013) works where she describes being as to be in place. Being helps human beings see, think, understand and know, and this requires faithfulness to the truth, the beautiful and the good.

Todres and Galvin (2010) describe that in existential dwelling "human being is inhering in Being; that is, that such dwelling is not just a psychological state, but a description of a relationship of belonging between human being and her/his ground" (Galvin, 2010, p. 4). Dwelling emphasizes a settling into the present moment with an acceptance of things as they are or a willingness to be there whatever this 'being there' is like. The human beings are establishing a new foothold in their body by dwelling. They are making room for belonging between themselves and their ground (Todres & Galvin, 2010).

Eriksson (1987a) states that human beings become conscious about themselves through relationships with other humans. This study revealed that the patients also became conscious about themselves through their relationship with their own bodies. Thus, it is important to give the suffering body the attention it deserves, to really see it, in order to get access and insight into the human beings' lives and experiences of health, suffering and dignity.

7.3 Understanding dignity through the meaning of flesh as metaphor

The physical space has received more attention in the literature than the non-physical space, which has more an existential character (Lassenius, 2005; Sæteren et al., 2016). Lassenius (2005) asks if that is because it might be difficult to articulate such space without using terms of the physical space. Expressing the inner-space through metaphors like flesh has helped me to open up the non-physical or inner space through exploring more of the multiple meaning dimensions of body and flesh both empirically and conceptually. This is important for understanding dignity in a bodily perspective, as dignity implies being whole as a human being (Eriksson, 1994; Edlund, 2002; Eriksson, 2006; Edlund et al., 2013; Lindström et al., 2014; Eriksson, 2018). Thus, in order to experience or promote dignity one has to come in contact with and gain knowledge about the multiple meaning dimensions of the body, which give more insight into what it means to be whole. The meaning dimensions of flesh probably make the ambiguous body, in health and suffering, more understandable.

Vedder (2002) confirms that metaphor is much more than a stylistic figure. It has the potential to open new existence and bring in a new view on life and existence. It is a way of seeing how something is (Vedder, 2002). Metaphors highlight new perspectives on phenomena and open up new horizons of understanding (Wiklund, 2007; Wiklund, 2010). This is important when searching to gain a deeper understanding of dignity, which has been criticized as a vague concept in current research (Macklin, 2003; Barclay, 2016).

Merleau-Ponty (1968) searches, with his philosophy of flesh, for a language for that which is beyond logico-discursive explication and which opens up for a deeper understanding of Being. He seeks to establish a language that shows a connection between the body and the world and searches to make explicit what the words express beyond themselves. Merleau-Ponty wants to grasp the mute contact with things when they are not yet said and is dissatisfied with language that perpetuates dualism and dichotomies (Merleau-Ponty, 1968; Sellheim, 2010).

Sellheim (2010) states that it is Merleau-Ponty’s very failure to develop a precise linguistic framework that might be the source of his success. His language of metaphor is a language that is more appropriate for reaching the primordial origins from which meanings emerge (Sellheim, 2010). However, Crowther (2015) disagrees and states that that is its failure. He claims that there is a danger that the ideas, rather than the problem that the phenomenologist was meant to solve, become the overriding issue and that Merleau-Ponty’s thinking runs a risk of becoming “a *phenom-and-on-and-on-and-on-and-ology*” (Crowther, 2015, p. 274). Despite the criticism, in this work the philosophy of flesh has helped me to open up new perspectives and gain more in depth understanding of the meaning of the body in relation to dignity rather than being a limitation.

7.4 Understanding dignity through the meaning of cultural impact on the suffering body

The culture and the society’s view of disease have an impact on the understanding of the suffering body (Lupton, 2012) and dignity. Eriksson (2003) states that the human’s inner wealth is her culture and history. The culture may help the human being make the world more manageable and understandable because everything is set into and understood in the framework of the culture (Eriksson, 1987a, 2018).

Merleau-Ponty (1968) takes the human being’s or the body’s relationship with the culture a bit further and says that the self and the world are not one, but neither are they completely separated. The reversibility, or the intertwining, between the self and the world or the culture, reveals that the body and the culture are not two separate entities, they are intertwined.

Gadamer’s (2004) concern about preunderstanding also describes how language and history form what we understand. This is further described and explained in chapter 5.1.2.

Lupton (2012) states that there is little tolerance in western society for decaying or dying bodies that are no longer controlled by will, but emit foul substances and even smells. Such bodies might be subject to stigmatization and even disgust by the patients themselves and society. Research into dying patients who had requested euthanasia found that they were ashamed of their bodies and the loss of their bodily integrity as they were no longer able to control their bodies. They were also afraid of dependency, helplessness and of being a burden to others (Street & Kissane, 2011). Independence, strength, vigor, intellectual ability and a healthy body are valued in modern societies (Skott, 2008).

This is also confirmed in Frank’s (2013) research on narratives. He has found three narrative types of illness stories that people who are seriously ill tend to tell to make sense of their difficult or embarrassing situation: the restitution story, the chaos story and the quest story. It seems like the restitution story is culturally preferred in western cultures for it is optimistic and focuses on regaining control, becoming well and doing something about the illness (Lupton, 2012; Frank, 2013). In this study, however, the chaos stories rather emerged, which are different from the restitution stories culturally preferred in the western culture. This may be understood in the light of the hospice culture where this study takes place. Perhaps the hospice culture has more room for dwelling, and thus for enabling the body to become more visible and honest to itself and others than a more hectic hospital ward.

7.5 Towards a more nuanced understanding of dignity

Through the work with the study, the suffering body has revealed a more nuanced understanding of dignity as it has become clearer what is at stake when understanding the world through the suffering body. It is not only the biological body that has been affected, but the entire way of being in the world.

Vulnerability became an essential phenomenon in understanding dignity. Being in honest contact with the vulnerable body helps human beings make the suffering concern them while the body helps them reconnect with the world, with their innermost being or the truth, which are important aspects regarding dignity. Thus, being in honest contact with the vulnerable body enables the individual to experience wholeness and dignity as a human being in the midst of the suffering.

While the body opened up for several ways of seeing and discovering the realities, understanding dignity through the suffering body, made it possible to stem the reductive or limited understandings of the concept. The studies revealed that dignity had both breadth, depth and enough space to contain both health and suffering and the necessary pendulum movement between the two. Thus, to be able to embrace the space which is necessary in order to experience dignity it is necessary to move away from a dualistic or narrow understanding of the concept with static categories of what it is and what it is not, and search for definitions that embrace the goodness and love in ambivalence.

Further, the ambiguity or ambivalence discovered in the suffering body showed some of the greatness, generosity and goodness that characterize the concept dignity. It is not a vague concept, which has been the focus of some of the criticism, but the ambiguity is probably its strength. Likewise, the inner force or value, which keeps the disordered bodies together also shows that dignity is not a weak or diffuse concept, but a concept with much power.

Thus, through the work with this study, there has emerged an understanding of the meaning of dignity in a bodily perspective described as the following:

- Dignity is being in honest contact with the vulnerability of the body
- Dignity is to live in and express the ambiguity or ambivalence experienced in the suffering body
- Dignity is relating to the innermost being through suffering in order to become oneself
- Dignity is experiencing health-giving footholds filled with love and goodness in the midst of suffering
- Dignity is having life-space to contain reversibility, that life is more than immediately experienced

8 Methodological considerations and limitations

There are different ways of evaluating the validity of the study (Lincoln & Guba, 1985; Whittemore, Chase & Mandle, 2001; Lincoln & Guba, 2007; Sandelowski, 2015). The criteria of validity, which these studies use, are not based on hermeneutic ontology, making it problematic to apply the criteria when evaluating the quality of a hermeneutic study, i.e. to evaluate how the understanding has been gained. Philosophical hermeneutics is not finding a “technique” of interpretation, but is an event in which meaning is generated and transformed (Gadamer, 2004; Freeman, 2011). Hermeneutical understanding is a quest for truth that is associated with the perception of an experience instead of certain and verifiable knowledge (Gadamer, 2004; Foss et al., 2016). Thus, critical examination of the validity of the study is not about examining the validity of standards and techniques in the process of interpretation, but rather discussing the conditions under which the hermeneutic understanding takes place.

However, when judging the validity of the study, there is also a need to evaluate how the study has been conducted. Lincoln and Guba’s (1985, 2007) quality criteria are appropriate even though they have their roots in grounded theory. Thus, the evaluation of the validity of the study will consist of two parts:

1. Evaluation of conditions under which understanding took place
2. Evaluation of how the study was conducted

8.1 Evaluation of conditions under which understanding took place

Since hermeneutic understanding is a quest for truth and Eriksson’s (1987a, 1994, 2006, 2018) caring science is the main theoretical foundation of the study, it is reasonable to base this discussion on Eriksson and Lindström (2007) and Eriksson’s (2009) theory of evidence in combination with Gadamer’s (2004) philosophy of understanding, see chapter 5.1. In Eriksson’s theory of evidence she describes the concept of ontological evidence, which involves making visible the core and substance of caring science in thoughts, words, attitudes and actions. Evidence is about seeing and realizing, and is closely related to knowing. The reality is not evident before it is articulated and pronounced in words (Eriksson & Lindström, 2007; Eriksson, 2009).

Identification and reflection on the preunderstanding is important when assessing the validity of the study. What is true in a study is connected to the researcher's preunderstanding and tradition (Näsman & Nyholm, 2015). Making the preunderstanding visible is important to enable readers to judge how the preunderstanding has affected issues such as research questions, choice of research studies and the theoretical perspective (Näsman & Nyholm, 2015). I have struggled to put my preunderstanding into words and make it concrete and visible. Prior to this study my preunderstanding has been implicit and I have needed a few rounds of reflection for it to become more explicit.

The hospice context was familiar to me and a part of my preunderstanding as I had worked part time at the ward earlier. One might think that being familiar with the context of an investigation might make it challenging for a researcher to be open, explorative and curious enough in the conversation situations. It is possible that I would have approached the subject in a more naive way if the context and the patient group had been completely unknown to me. However, even though I was familiar with the context, the subject of the study was new and I experienced that it rather sharpened my ability to ask and follow up questions in the conversations.

I found my preunderstanding to be more of a challenge in the interpretation of the texts than in the interview situations. I experienced that my preunderstanding made it difficult to construct good questions to help me open up for new ways of thinking (Gadamer, 2004), to deepen my understanding of the suffering body and dignity in a bodily perspective. I had to use different methods and sources to set my preunderstanding aside in order to stimulate my ability to reflect and to understand the otherness of the matter (Eriksson & Lindström, 2007). Thus, in this case it was useful to use mental pictures in the interpretation process (see chapter 5.5.2), but also to read other research studies, newspapers and a nonfiction book about living in a sick and vulnerable body (Grue, 2018). The philosophy of Merleau-Ponty (1968) and caring science theory (Eriksson, 1987a, 1994, 2006; Lindström et al., 2014; Eriksson, 2018) also helped me to create good questions that could be asked in the studies and further my understanding.

During my time as a PhD candidate, I have also participated in different research forums and scientific conferences where I have discussed my study. This has helped me to correct and develop my preunderstanding.

The constant and demanding uneasiness that I felt during the whole research process about what the bodily concerns were, helped me keep my mind open and reflecting. The uneasiness is described in chapter 5.1.2 as an inner formation and cultivation (Gadamer, 2004), or as a driving force to discover what is beyond the immediate understanding of the subject of the study. In the search for understanding more about the meaning of the body and thus dignity in health and suffering, the formation was experienced as a process or a dialogue that was continually evolving between the known, my preunderstanding and the foreign where the pieces of understanding melted gradually together into a new and collective understanding.

The interpretation process was long, demanding and dependent on a willingness to linger, to ask good and enough questions and not conclude on any results before an understanding had been reached between the parts and the whole and the whole and the parts (Gadamer, 2004). However, this was sometimes difficult. Thus, to be conscious of how I worked in the research process, I found it useful to write a research diary where I focused on my role as a researcher and what influenced me in the research process. Reading my notes helped me avoid making hasty conclusions, and to stay in the interpretation process as long as necessary. The research diary made me aware of my preunderstanding and my own transformation throughout the research process. Eriksson and Lindström (2007) confirm the importance of listening, lingering and letting the text speak in its otherness, and describe how the preunderstanding can invite to a hermeneutic dialogue with the otherness of the matter and allow the universal to emerge.

Words form our thoughts and our understanding of reality. They also reflect our values and traditions (Eriksson & Lindström, 2007; Eriksson, 2009). According to Eriksson and Lindström (2007), Eriksson (2009) and Gadamer (2004), words are the basic condition for something to be evident. Nothing is evident until it is pronounced and dressed in words. Words are needed in order to make visible what one has seen and understood (Gadamer, 2004; Eriksson & Lindström, 2007; Eriksson, 2009). Thus, it is important to reflect on how I have used language when evaluating conditions for how understanding has taken place. Eriksson (2009) states that being a carrier of ethos involves a willingness to choose words that make us feel at home. She compares ethos to a musical key that makes us attentive to the voice of the heart and opens up to what is holy and eternal (Eriksson, 2009). Thus, the words must be chosen with care and sensitivity. I have struggled when writing the articles and also this thesis with finding the right formulations and the right words and phrases to carry the ethos of Eriksson’s (1987a, 1994, 2006, 2018) caring science. Choosing the right words requires a great deal of sensitivity, reflection and practice.

In addition to choosing the right words, it is also important that the quality of the interviews is good. The interviews and the participant observation notes from the patient study and the results from the hermeneutic concept analysis form the basis of the study and later become the material to be interpreted. Näsman and Nyholm (2015) state that the material should be sufficiently rich in substance and not represent a universal truth, but have the ability to invite the researcher to reflect beyond his own horizon of understanding. Thus, it has been important to me make a careful selection of participants in cooperation with the head nurses at the two hospices in order to choose those who had rich experiences concerning the issues I was studying, see chapter 5.4.1. I find that I have acquired many stories that were rich in substance and others that were not. However, all in all, I find that the material has given me good insight in order to achieve the overall aim of the study. The material and the uneasiness I have felt throughout the research process have invited me to reflect beyond my immediate horizon of understanding.

When considering the conditions of hermeneutic understanding where the validity is related to the process or the relationship between the parts in the study (Gadamer, 2004) and the whole, it was also essential to reflect upon whether there was a balance or interrelationship between the four part-studies, the thesis and the overall aim of the project. Likewise, whether there was harmony (Gadamer, 2004) between the research questions, the data collection and the analysis technique in the whole project. The overall aim of the study made it appropriate to collect data in a context of persons with advanced cancer, because the cancer disease and its treatment have great negative impact on the body, physically, psychological, socially and existentially (Teunissen et al., 2007; Stark et al., 2012; Oechsle et al., 2013; Chang, 2019). It was also appropriate to include patients, relatives and nurses into the study because these groups had different access and relationships to the suffering body, which might give a deeper and broader understanding of the subject of the study. Further, it was meaningful to develop a hermeneutic concept analysis in addition to the three empirical studies to gain a deeper understanding of the meaning of the body.

The choice of hermeneutic concept analysis as a method for exploring and understanding the meaning of flesh and fleshly could at first glance seem antagonistic to Merleau-Ponty’s belief in language. He claims that things expressed metaphorically mirror the activity of life more closely than a language that is more semantically resolvable (Sellheim, 2010). However, since the hermeneutic concept analysis is substance oriented on an ontological level, the method was found appropriate and trustworthy for developing a deeper understanding of the concept. The method differs from the Wilson tradition of concept analysis frequently used in nursing science, which is context-oriented, forming model cases from nursing practice (Sivonen et al., 2010). Even though the choice of concept analysis seems in harmony with Merleau-Ponty's view on language (Sellheim, 2010), one might still ask if it might have been more suitable to choose a context-oriented model for this study, as the empirical studies are performed in a specific context of persons with advanced cancer disease. However, since the overall aim of the study is on a universal level, it seems relevant to choose a concept analysis that is not context-oriented.

The study seeks to understand the meaning of the body from different perspectives. The final interpretation of the four part-studies described in chapter 7 shows an even deeper meaning of the suffering body and dignity from a bodily perspective. This confirms that there is an internal logic (Larsson, 1994) in the study while the four part studies and the thesis are all parts of the same whole and dependent on each other in order to understand or explore more deeply the subject of the study.

8.2 Evaluation of how the study was conducted

When examining the validity of the study, it is also important to evaluate how the study was conducted. As described in the beginning of chapter 8, many criteria for evaluating qualitative research are not developed within an interpretive or hermeneutic tradition. That makes it problematic to apply these criteria when evaluating the quality of a hermeneutic study (Gabrielsen, Lindström & Nåden, 2013). However, when judging the validity of how the study was conducted, I have borrowed the credibility, fairness, dependability and transferability-criteria from Lincoln and Guba (1985, 2007), even though they have their roots in grounded theory. I find that unproblematic as the evaluation is not of how understanding was gained but rather of how the study was conducted.

8.2.1 Credibility

Credibility refers to the truth in how data is collected or the value and believability of the results. In this study evaluation of prolonged engagements and persistent observations

(Lincoln & Guba, 1985, 2007) are especially important. Additionally, comprehensive field notes and rigor transcriptions (Polit & Beck, 2018) were also relevant when judging credibility.

While most of the patients in this study had only a 14-days stay at the hospice inpatient unit, it did not seem ethically responsible to occupy too much of their time. Thus, I visited and interviewed each patient for one day-shift only and observed approximately 3-4 hours. This means that there was no prolonged engagement or persistent observations in the patient study (Lincoln & Guba, 1985, 2007). However, my former personal knowledge of the research field during my work as a nurse helped me to also understand the culture and the participants I was studying. As described in chapter 5.1.1, 5.4.2 and 8, my former knowledge of the research field might have become an obstacle to understanding if the preunderstanding was strong and may have blocked some of my ability to see and understand the situation or the subject properly.

In the patient study both participant observations and individual interviews were used to gain a deeper understanding of the patients' experiences of bodily changes in relation to dignity. Even though the observations were limited and were not independently interpreted, combining both methods made it possible to understand the subject of the study better from different perspectives, and thus enhance credibility (Lincoln & Guba, 1985, 2007).

A challenge when combining interviews and participant observations is to prepare observation notes of good enough quality. It was not possible to write objective field notes because the preunderstanding and previous knowledge influenced what was seen, heard and noted down as field notes. It was easier to write down what the participants said rather than to describe what happened in the observation situations (Fangen, 2010). Likewise, it was challenging to put into words the wordless behavior I experienced. Fangen (2010) presumes that the good observer can describe the wordlessness and move behind the trivial. Thus, I tried to be as descriptive, concrete and detailed as possible in the descriptions to make observation notes of good quality, but it was difficult because the writing had to be done after the observations had taken place. This is further described in chapter 5.4.3.

Rigor transcriptions are also described as important regarding credibility (Polit & Beck, 2018). The interviews were audiotaped to secure verbatim transcriptions for interpretation and pauses, crying and laughter were noted in the text. Schuster (2013) describes the challenges of reading a text transcribed in the way I did in this study. The author claims that the form of the text itself forces the reader into readings that are much too fast and she thus transcribed some interviews one more time, breaking the lines at any pauses in the respondent’s speech. The quotations then took more form of a poem and the text evolved more slowly. In a retrospective perspective, it would have been interesting to do the transcription in this way, because the text might become alive in different way than traditional transcription, and both silences and speech might emerge more clearly.

8.2.2 Fairness

Considerations as to whether the interpretations are reasonable must also be taken into account. Lincoln and Guba (2007) describe fairness as a balanced view that presents all constructions and the values that underlie them. This was an important issue in the hermeneutic concept analysis in particular, but also in the empirical material.

I experienced on a few occasions that I tended to make interpretations of the empirical studies that were not close enough to the results and the research questions or the aim of the study. This may have been because I had worked with the material over a long period of time and certain issues had remained implicit in me and difficult to articulate. Especially the transition from the result section to the discussion section was challenging. I had to make sure that the interpretations were in terms with the results. In the patient study, for example, I needed to revise the text and use the words ‘dignity’ and ‘health’ more actively in the subheadings and in the text to make sure that these terms guided my work. It then became more clear that what I was discussing was in accordance with the aim of the study. An example is the subheading: ‘The life affirming will – a natural inner force to feel present and alive’. This subheading was changed to: ‘The life affirming will – a natural force to achieve health and experience dignity’. I experienced that using the hermeneutic circle and continually ask questions about whether my interpretations were reasonable in light of the study’s aim, helped me to make the interpretations reasonable.

8.2.3 Dependability

There are several ways to evaluate the dependability of the study (Lincoln & Guba, 1985, 2007). In this study transparency is a relevant criteria when judging dependability. Throughout the whole research process I strove to describe as concrete and transparent as possible the choices made regarding the planning of the project, inclusion of participants, formulation of results and how the level of interpretation was reached.

Concept analysis has been criticized for lacking transparency regarding inclusion and exclusion criteria of data (P. Draper, 2014). However, the hermeneutic concept analysis performed in this project has some explicit criteria regarding inclusion and exclusion of data which respond to this criticism: 1) The dictionaries included should be from every decade in which the concept exists, and 2) The family of concepts should be as wide as possible (Koort, 1975; Sivonen et al., 2010). Both criteria are almost achieved and described in the research article, which then confirm that there is transparency in the data extraction process.

The transcribed interviews and observation notes were shared with the supervisors, and formulations of results and categories of interpretation were discussed, to ensure an increase in transparency. However, being transparent was challenging due to the many implicit assumptions or preunderstandings that arise when one has worked with a subject for a long time, and it was difficult to recognize and make explicit all this, see chapter 5.1.2, 5.4.2 and 8.1.

8.2.4 Transferability

Lincoln and Guba (1985, 2007) describe thick descriptive data or thick descriptions as the way to judge the transferability of the study. ‘Thick’ here refers to detailed descriptions of context and other aspects of the research setting so other researchers can make comparisons. In this project I tried to describe as thoroughly as possible the research process, especially in the thesis, so that other researchers get as much insight into the process as possible in order to apply and judge the choices that were made.

8.3 Limitations

The interviews were performed in hospice contexts. The calm and gentle atmosphere or culture that characterize these settings (Steenfeldt, 2017) might have influenced the results. Collecting data in other contexts, where the atmosphere is more hectic, might have given other answers.

It is reasonable to believe that the patients and the relatives who participated in this research study were those who were able and had the strength to talk about their own suffering bodies or the others’. Likewise, that they had a more or less clarified or reconciled relationship to the bodily changes. Eriksson (1994, 2006) describes suffering as endurable and unendurable. Unendurable suffering paralyses and prevents human growth and the capacity for health breaks down. Thus, it is reasonable to believe that those who participated in the study were those who were not caught in unendurable suffering, as they would probably not have the strength or the words to complete the in-depth interviews.

An inherent strength in qualitative research is the relatively small number of participants and thus the possibility for in depth research. Thus, generalizing the results to include the entire population within the inclusion criteria is not possible (Polit & Beck, 2018). Still I believe, after the new and deeper understanding of the body and of dignity from the study as a whole, (see chapter 7), that the results from the study could be transferred to some extent to other vulnerable groups and probably give glimpses of something universal about the meaning of the suffering body and dignity in a vulnerable and bodily perspective.

The number of men and women in the study is not equal. There are only women in the nurse study. Likewise, the women are overrepresented in both the patient- and the relative study because they were the easiest to recruit. The results might have had other dimensions if each gender were equally represented or if there were only males or only females in the study. This is in line with the research study of Hilário (2016), who shows that the altered body is of greater concern to women than to men at the end of life.

The relatives who participated in the study were spouses, grown-up children and a friend. The results might perhaps have been different if the inclusion criteria were more specific, such as only spouses or only grown-up children. However, the relative included was the one the patient felt closest to (Helse- og omsorgsdepartementet, 1999) and thus it might not be a limitation after all.

Some of the patients and the relatives showed emotional reactions like crying and despair during the interviews. According to the ethical principle of doing no harm (Ruyter et al., 2014; WMA, 2018) and sheltering the participants' dignity (Nordenfelt, 2004) I decided to perform only one interview with each participant.

The participant observations in the patient study were primarily performed to give me more background knowledge about the suffering body and to gain a deeper understanding of the patient's situation. And as I spent more time with the patients, they probably became more confident regarding me as a researcher and more open in the interview situations. Looking back, however, I can see that if I had interpreted the data from the participant observations more closely, that would probably have increased my understanding about the bodily issues in the study.

The theoretical framework influences the whole research process, both in the part studies and in the study as a whole. Thus, using other theoretical frameworks would probably develop an alternative understanding of the subject under study.

A theoretical perspective might constitute a challenge as such a perspective may obstruct understanding if it is too strong. At the same time I believe that everyone has a theoretical perspective. Thus, articulating the theoretical perspective allows me to deal with it consciously and carefully and make it visible so that the reader knows and might judge how it affects the results when reading the text. Likewise, how it is used in the interpretation process and the discussion of the results.

The four articles in the study are written over a long period of time. As I have developed academically during the study, it is reasonable to assume that there are aspects in the articles that could have been elaborated further. I will suggest a few aspects here. In article 1 there are several statements that I might have interpreted better and elaborated on if I had integrated the theoretical perspective better in the argumentation and interpretation. In article 3 I could have included a more detailed description of the interpretation process with concrete examples of what I did. This would have made the research process more transparent. In study 4, the method section could also have been expanded, especially the section where I describe the qualitative interviews and participant observations. Likewise, I might have expanded the description of my use of Merleau-Ponty’s phenomenology as theoretical perspective and integrated it in the interpretation of the results.

9 Conclusion and future perspectives

The overall aim of the project was to gain a deeper understanding of the meaning of the body in order to understand dignity in health and suffering.

All the studies revealed that the body is both the concrete body, and an element of Being. The meaning dimensions of the flesh as the corporeal, protective, temporal, sensuous, shameful and vigorous body in the hermeneutic concept analysis confirms this.

The participants were forced, or given the opportunity, to deal with their own or the others' bodies in an honest way when it was no longer possible to cover up the bodily changes. The sick body was described with terms like wreck, a stranger and as being trapped in an 'alien' body. On the other hand, the body was described as a resource for understanding and gaining meaning. The body was like a guiding star that made the participants aware of what was at stake and gave them the authority to express it with words. The body expressed the expressible, but also the inexpressible, and thus kept the suffering from becoming silent and incomprehensible.

Understanding through the suffering body is a way to see suffering, health and dignity more 'as it is'. People exist in and through their bodies, and it is through the body they have contact with and knowledge about the world. Awareness of the suffering through the body enables human beings to let the sick body and the suffering concern them and give them the possibility of becoming a whole human being and thus experience dignity.

The studies revealed the participants' great struggles. However, the struggle in a bodily perspective is not between opposites, but a struggle to live in and express the ambiguity or ambivalence revealed in the suffering body. Dignity is explored in terms of how it is possible to embrace the contrasting, conflicting and ambiguous meaning dimensions springing from living in or relating to a body that is almost dissolved. However, for that to be possible, there has to be enough space within the body to contain the ambiguity and establish the health giving rooms, or ethos, filled with love, goodness, beauty and dignity.

The importance of storytelling for experiencing dignity was also revealed in the study. Being in close contact with the suffering body by telling their story or dwelling on the suffering body, enabled the participants to let life win and not the unbearable suffering, which is mute and lacks the language that the body is bearer of. The stories enable human beings to understand and know themselves and can transform their thinking. Dwelling on the suffering body helps human beings to dwell, to be in contact with the present, the past and the future through the suffering body, which might open up for and help them come in contact with their ontological level of existence and thus become increasingly at home in themselves and experience dignity.

The mute and the paradoxical aspects of the body have been visible during this study. Martinsen (2009) states that it is important to keep in mind or reflect upon this mystery, the strangeness or foreignness that people experience, because these mute or incomprehensible aspects of life contain values that are necessary for the human being. Kaldestad (2018) describes the holiness of the human being, or man’s innermost room as a mystery and states that the innermost being of dignity or the essence of dignity is experienced in this room.

9.1 Implications for nursing practice

Studies reveal that there has been lack of theoretical investigation of the body and embodiment in nursing research. The medical perspective has dominated, which emphasizes the ‘object’ body rather than the ‘subject’ body (J. Draper, 2014; Marchetti et al., 2016). Martinsen (2009) states that western rationality tries to suppress the body’s sensuality, impalpability and mystery. The rationality of consciousness has little space for metaphysical phenomena, which are important dimensions in the body and in nursing (Martinsen, 2009).

In my studies, I revealed that the body could bring us to the things themselves. Thus, listening to or being concerned with letting the suffering body speak might give the nurses valuable knowledge of what is at stake for the human being. However, to be able to do so the nurses must be concerned with what sort of questions they ask the patients in their daily speech. This study has shown that the body-mind dualism is strong in our language and that we still separate emotions from thinking. Likewise, that the economical and biomedical discourses dominate nursing practice and nursing science today (J. Draper, 2014; Wolf, 2014). Thus, formulating questions that make the subject body visible means that nurses must also use another language, a language that encompasses more embodied notions that are subjective and emotionally experienced.

Madjar (1997) finds that we often ask questions about symptoms. This might be alienating because we focus on the observable and measurable aspects of illness and ignore perhaps the subjective and embodied nature (Madjar, 1997). Thus, formulating questions regarding how the body is experienced, how the body has changed and what the bodily changes mean to the patient or the relative as we did in our studies, might turn the perspectives away from the ‘object’ body to the ‘subject’ body. Using the word ‘body’ in the questions might also be a reminder for both the patients and the health care personnel to make the body more visible and concrete.

The value of treating the body as a resource rather than a problem when the patient is seriously ill is also an aspect that was revealed in our studies. Especially the will for life and love and the human beings’ ability to enter into their health-giving rooms or flesh/ethos was discovered. This gave the participants power and hope that helped them in their suffering. Thus, nurses should search for and be aware of health-providing resources in the patients’ lives, also when the diagnosis is serious and even life-threatening.

It is also important that nurses have knowledge and awareness of the body as both something we have and something we are (Merleau-Ponty, 2002), which means that human beings’ experiences are channeled through their bodies. This confirms why it might be fruitful to ask the patients how their lives feel related to bodily experiences in order to gain insight into their life situations. In the body, we have the most certain knowledge (Tyreman, 2015) and the body might enable the patients to understand what is going on in their lives. Thus, making the body visible might give the patients valuable information that can help them feel coherence and safety in a life situation that otherwise might be chaotic and confusing. When the body becomes visible, it also makes us responsible for treating it with dignity, as Eriksson describes in the caritative caring mantra: “I was there, I saw, I witnessed and I became responsible” (Eriksson, 2013, p. 70).

This study reveals that in order to provide good nursing care, the nurses must understand the meaning of the body, physically, socially, emotionally and existentially. However, since the body is taken-for-granted as part of ourselves, this is probably a reason for why it is vague and confusing. We simply forget to focus on it because we take it for granted, especially when we are healthy (Lupton, 2012).

Thus, it is important to have attention on the body in nursing education. Studies show that the theoretical perspective in nursing research has changed, away from humanism towards a more medical and organizational perspective. Likewise, that the relational aspects of nursing science are little emphasized. Nursing science today seems to emphasize empirical knowledge rather than the development of new theories and concepts specific to nursing science (Jensen

& Knutstad, 2019). However, studies reveal that there is a need to clarify the disciplinary perspective of nursing which is just as important today as for 50 years ago (Lidell, 2019; Smith, 2019).

Further, if the nursing profession develops away from the humanistic perspective, a substantial part of the knowledge base may become unclear. Such a development might provide scarce conditions for further scientific inquiry of the discipline. Nursing science becomes rather a part of a larger health profession where medical knowledge, medical research ideals and knowledge from other disciplines take precedence rather than nursing knowledge (Jensen & Knutstad, 2019; Lidell, 2019; Smith, 2019).

Thus, understanding the suffering body was not only important for the participants in order to gain or promote health and dignity. The body also reveals new ways of seeing and understanding the world, which are important for nursing science and nursing practice (Nortvedt, 2008; Sharma, Reimer-Kirkham & Cochrane, 2009).

9.2 Recommendations for further research

As stated in chapter 2.2, there is a trend in dignity research to analyze dignity in terms of the broader notion of a good health care or of a good death rather than addressing dignity more specifically. It is challenging to give the suffering body a language that captures the internal dimensions of the body and dignity, even though the silent but embodied world of trauma has been noted by many researchers (Lauffenburger, 2016). Thus, there is a need to develop a ‘dignity conserving model’ like Chochinov and his team did (Chochinov et al., 2002), with focus on dignity in a bodily perspective. The model might give the nurses a tool and a language to express some of the mute dimensions of the body in a dignity perspective. Thus, it might help the nurses to capture, be aware of and develop a vocabulary to talk about the bodily phenomena in the interaction with patients and their relatives.

The hermeneutic concept analysis revealed meaning dimensions about the body. Perhaps it is possible to explore the meaning dimensions more in depth through qualitative studies and use the results as a basis for further development of the ‘dignity conserving model’. The model might be a basis for developing conversation guides for nursing practice and for instruments measuring dignity in a bodily perspective. Likewise, it might be a help when formulating dignity in the nursing documentation system.

In this work I have tried to understand more about and grasp with words the wordless, mysterious, unpredictable and repulsive body that we carry with us every day and which becomes even more evident when the body is affected by serious illness. With this work, I hope to challenge the mechanistic or medical reality picture that characterizes parts of the epistemology of nursing today.

I would like, as Grue (2018) writes, to open the concept of body again. If the body is only something to be repaired, lived life can harden or freeze in this language and the body becomes more of an expense item, an object and not a living life. Since the body is the touchstone of existence, it is natural that the body is an important part of the foundation for understanding dignity.

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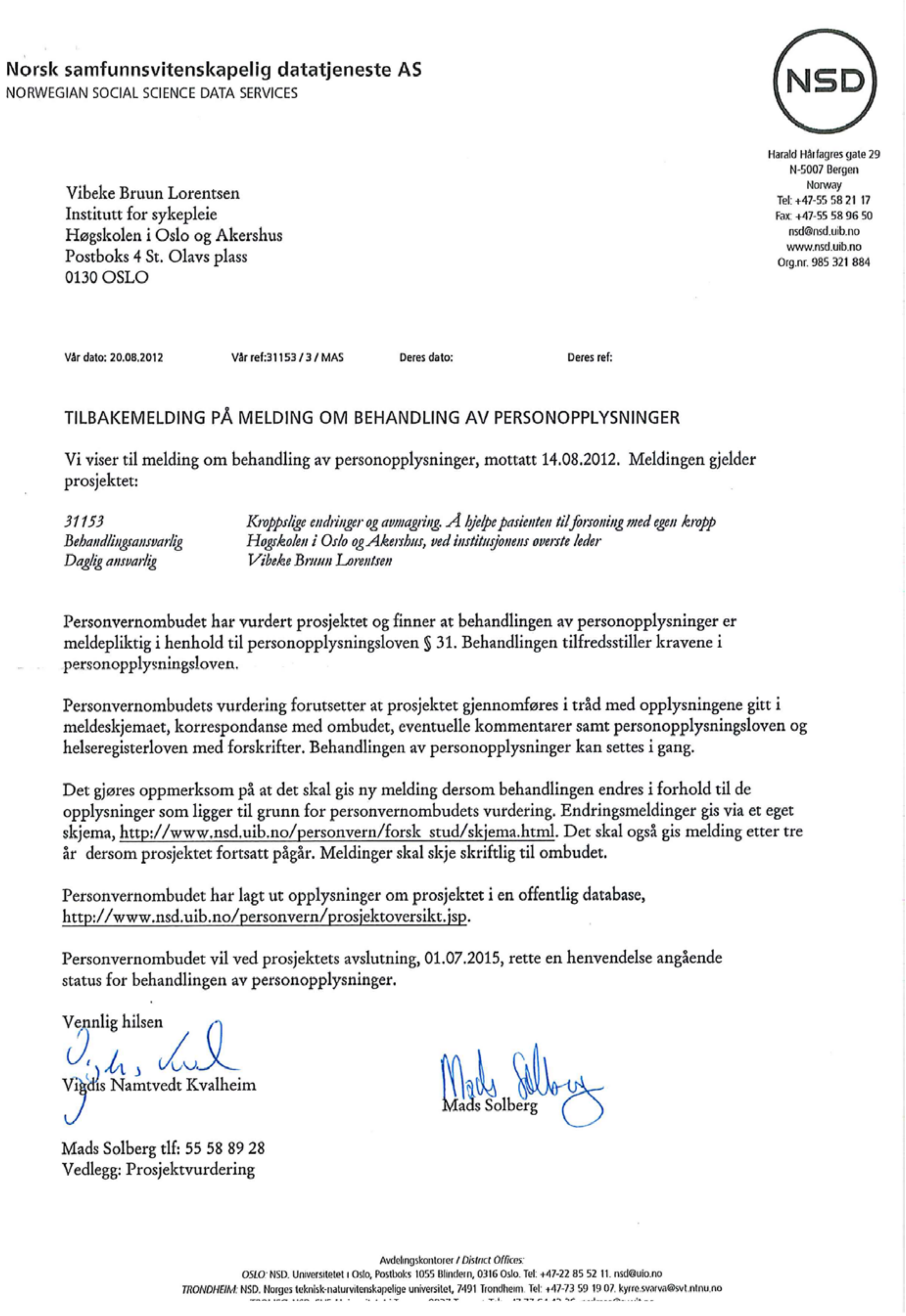
Appendixes

Appendix 1: Ethical approval from the Norwegian Social Science Data Service (NSD), project no 31153



Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

NSD

Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Vibeke Bruun Lorentsen
Institutt for sykepleie
Høgskolen i Oslo og Akershus
Postboks 4 St. Olavs plass
0130 OSLO

Vår dato: 20.08.2012 **Vår ref:31153 / 3 / MAS** **Deres dato:** **Deres ref:**

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 14.08.2012. Meldingen gjelder prosjektet:

31153	*Kroppslige endringer og avmagring. Å hjelpe pasienten til forsoning med egen kropp*
Behandlingsansvarlig	*Høgskolen i Oslo og Akershus, ved institusjonens øverste leder*
Daglig ansvarlig	*Vibeke Bruun Lorentsen*

Personvernombudet har vurdert prosjektet og finner at behandlingen av personopplysninger er meldepliktig i henhold til personopplysningsloven § 31. Behandlingen tilfredsstiller kravene i personopplysningsloven.

Personvernombudets vurdering forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/forsk_stud/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://www.nsd.uib.no/personvern/prosjektoversikt.jsp.

Personvernombudet vil ved prosjektets avslutning, 01.07.2015, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Vigdis Namtvedt Kvalheim

Mads Solberg

Mads Solberg tlf: 55 58 89 28
Vedlegg: Prosjektvurdering

Appendix 2: Ethical approval from the Norwegian Social Science Data Service (NSD), project no 42503

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

NSD

Harald Hårfagres gate 2
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Vibeke Bruun Lorentsen
Institutt for sykepleie Høgskolen i Oslo og Akershus
Postboks 4 St. Olavs plass
0130 OSLO

Vår dato: 07.04.2015	Vår ref: 42503 / 3 / AMS	Deres dato:	Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 27.02.2015. Meldingen gjelder prosjektet:

42503	*Kroppen som bærer av verdighet*
Behandlingsansvarlig	*Høgskolen i Oslo og Akershus, ved institusjonens øverste leder*
Daglig ansvarlig	*Vibeke Bruun Lorentsen*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/meldeplikt/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://pvo.nsd.no/prosjekt.

Personvernombudet vil ved prosjektets avslutning, 31.12.2018, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Katrine Utaaker Segadal

Anne-Mette Somby

Kontaktperson: Anne-Mette Somby tlf: 55 58 24 10
Vedlegg: Prosjektvurdering

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

Avdelingskontorer / *District Offices:*
OSLO: NSD. Universitetet i Oslo, Postboks 1055 Blindern, 0316 Oslo. Tel: +47-22 85 52 11. nsd@uio.no
TRONDHEIM: NSD. Norges teknisk-naturvitenskapelige universitet, 7491 Trondheim. Tel: +47-73 59 19 07. kyrre.svarva@svt.ntnu.no
TROMSØ: NSD. SVF, Universitetet i Tromsø, 9037 Tromsø. Tel: +47-77 64 43 36. nsdmaa@sv.uit.no

Personvernombudet for forskning

Prosjektvurdering - Kommentar

Prosjektnr: 42503

FORMÅL

Formålet er en dypere forståelse for kroppen og kroppens betydning for å lindre lidelse og fremme pasientens verdighet og helse, belyst fra pasient og pårørendes perspektiv. Følgende forskningsspørsmål vil bli undersøkt: 1) Hvilken betydning har kroppslige endringer for pasienters opplevelse av verdighet? 2) Hvilken betydning mener pårørende at kroppslige endringer har for pasientens opplevelse av verdighet?

INFORMASJON OG SAMTYKKE

Rekrutteringen skjer ved at ansatte ved hospice formidler informasjon om prosjektet. Utvalgene informeres skriftlig og muntlig om prosjektet og samtykker til deltakelse. Informasjonsskrivene er godt utformet. Forsker opplyser at pasientene er samtykkekompetente.

SENSITIVE OPPLYSNINGER

Det behandles sensitive personopplysninger om helseforhold, jf. personopplysningsloven § 2 nr. 8 c).

INFORMASJONSSIKKERHET

Personvernombudet legger til grunn at forsker etterfølger Høgskolen i Oslo og Akershus sine interne rutiner for datasikkerhet.

Høgskolen i Oslo og Akershus må inngå skriftlig avtale med en transkriberingsassistent om hvordan personopplysninger skal behandles, jf. personopplysningsloven § 15. For råd om hva databehandleravtalen bør inneholde, se Datatilsynets veileder: http://www.datatilsynet.no/Sikkerhet-internkontroll/Databehandleravtale

PROSJEKTSLUTT OG ANONYMISERING

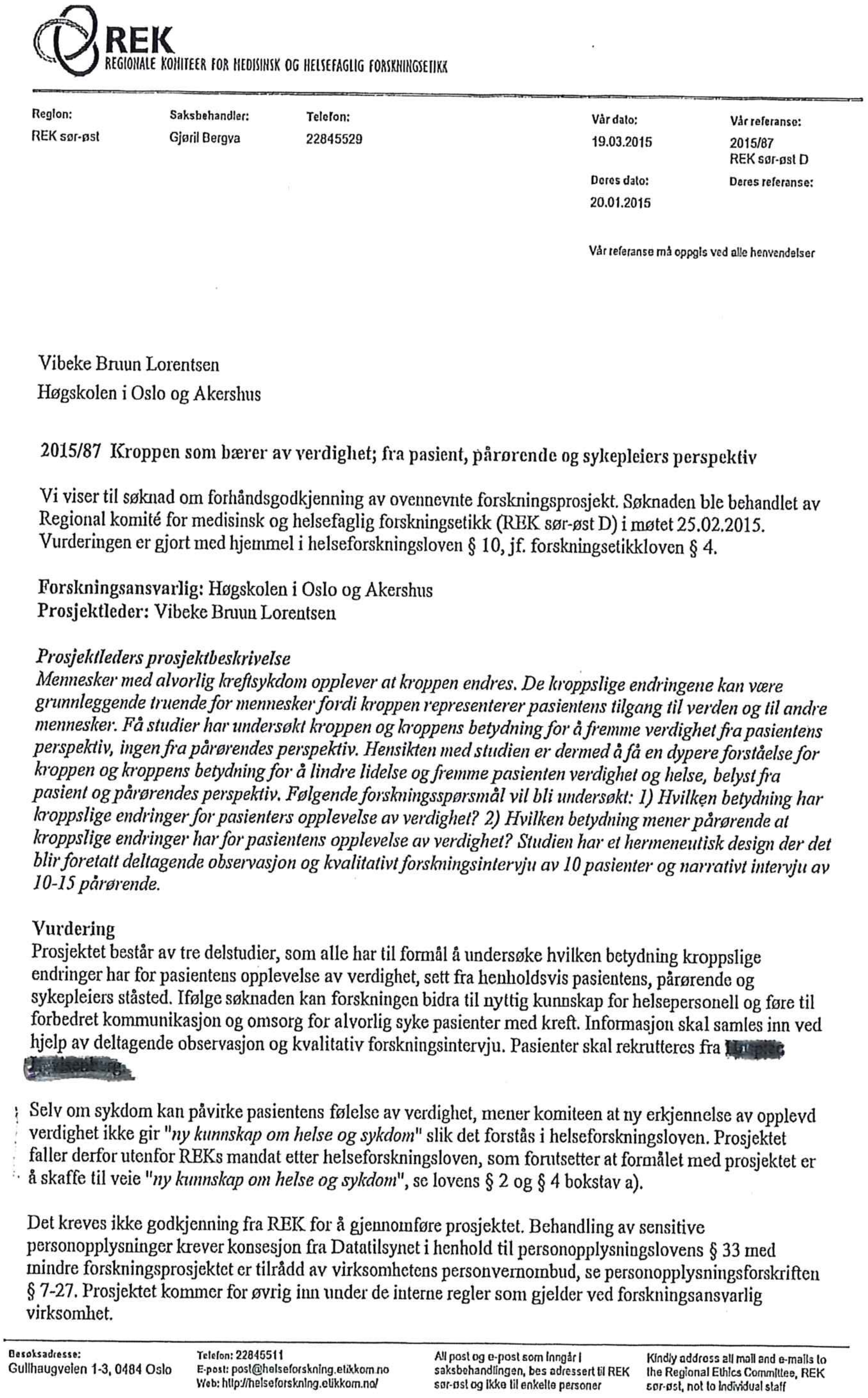
Forventet prosjektslutt er 31.12.2018. Ifølge prosjektmeldingen skal innsamlede opplysninger da anonymiseres. Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan gjenkjennes. Det gjøres ved å:

- slette direkte personopplysninger (som navn/koblingsnøkkel)
- slette/omskrive indirekte personopplysninger (identifiserende sammenstilling av bakgrunnsopplysninger som f.eks. bosted/arbeidssted, alder og kjønn)
- slette lydopptak

ANDRE VURDERINGER

REK har vurdert at prosjektet ikke er omfattet av Helseforskningsloven (2015/87 REK Sør-øst D).

Appendix 3: Response letter from Regional Committees for Medical and Health Research Ethics (REK), 2015/87c



REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst	Gjøril Bergva	22845529	19.03.2015	2015/87 REK sør-øst D
			Deres dato:	Deres referanse:
			20.01.2015	

Vår referanse må oppgis ved alle henvendelser

Vibeke Bruun Lorentsen
Høgskolen i Oslo og Akershus

2015/87 Kroppen som bærer av verdighet; fra pasient, pårørende og sykepleiers perspektiv

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst D) i møtet 25.02.2015. Vurderingen er gjort med hjemmel i helseforskningsloven § 10, jf. forskningsetikkloven § 4.

Forskningsansvarlig: Høgskolen i Oslo og Akershus
Prosjektleder: Vibeke Bruun Lorentsen

Prosjektleders prosjektbeskrivelse
Mennesker med alvorlig kreftsykdom opplever at kroppen endres. De kroppslige endringene kan være grunnleggende truende for mennesker fordi kroppen representerer pasientens tilgang til verden og til andre mennesker. Få studier har undersøkt kroppen og kroppens betydning for å fremme verdighet fra pasientens perspektiv, ingen fra pårørendes perspektiv. Hensikten med studien er dermed å få en dypere forståelse for kroppen og kroppens betydning for å lindre lidelse og fremme pasienten verdighet og helse, belyst fra pasient og pårørendes perspektiv. Følgende forskningsspørsmål vil bli undersøkt: 1) Hvilken betydning har kroppslige endringer for pasienters opplevelse av verdighet? 2) Hvilken betydning mener pårørende at kroppslige endringer har for pasientens opplevelse av verdighet? Studien har et hermeneutisk design der det blir foretatt deltagende observasjon og kvalitativt forskningsintervju av 10 pasienter og narrativt intervju av 10-15 pårørende.

Vurdering
Prosjektet består av tre delstudier, som alle har til formål å undersøke hvilken betydning kroppslige endringer har for pasientens opplevelse av verdighet, sett fra henholdsvis pasientens, pårørende og sykepleiers ståsted. Ifølge søknaden kan forskningen bidra til nyttig kunnskap for helsepersonell og føre til forbedret kommunikasjon og omsorg for alvorlig syke pasienter med kreft. Informasjon skal samles inn ved hjelp av deltagende observasjon og kvalitativ forskningsintervju. Pasienter skal rekrutteres fra [redacted].

Selv om sykdom kan påvirke pasientens følelse av verdighet, mener komiteen at ny erkjennelse av opplevd verdighet ikke gir "*ny kunnskap om helse og sykdom*" slik det forstås i helseforskningsloven. Prosjektet faller derfor utenfor REKs mandat etter helseforskningsloven, som forutsetter at formålet med prosjektet er å skaffe til veie "*ny kunnskap om helse og sykdom*", se lovens § 2 og § 4 bokstav a).

Det kreves ikke godkjenning fra REK for å gjennomføre prosjektet. Behandling av sensitive personopplysninger krever konsesjon fra Datatilsynet i henhold til personopplysningslovens § 33 med mindre forskningsprosjektet er tilrådd av virksomhetens personvernombud, se personopplysningsforskriften § 7-27. Prosjektet kommer for øvrig inn under de interne regler som gjelder ved forskningsansvarlig virksomhet.

Vedtak
Prosjektet faller utenfor helseforskningslovens virkeområde, jf. § 2 og § 4 bokstav a). Det kreves ikke godkjenning fra REK for å gjennomføre prosjektet.

Klageadgang
REKs vedtak kan påklages, jf. forvaltningslovens § 28 flg. Klagen sendes til REK sør-øst D. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst D, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Vi ber om at alle henvendelser sendes inn på korrekt skjema via vår saksportal: http://helseforskning.etikkom.no. Dersom det ikke finnes passende skjema kan henvendelsen rettes på e-post til: post@helseforskning.etikkom.no.

Vennligst oppgi vårt referansenummer i korrespondansen.

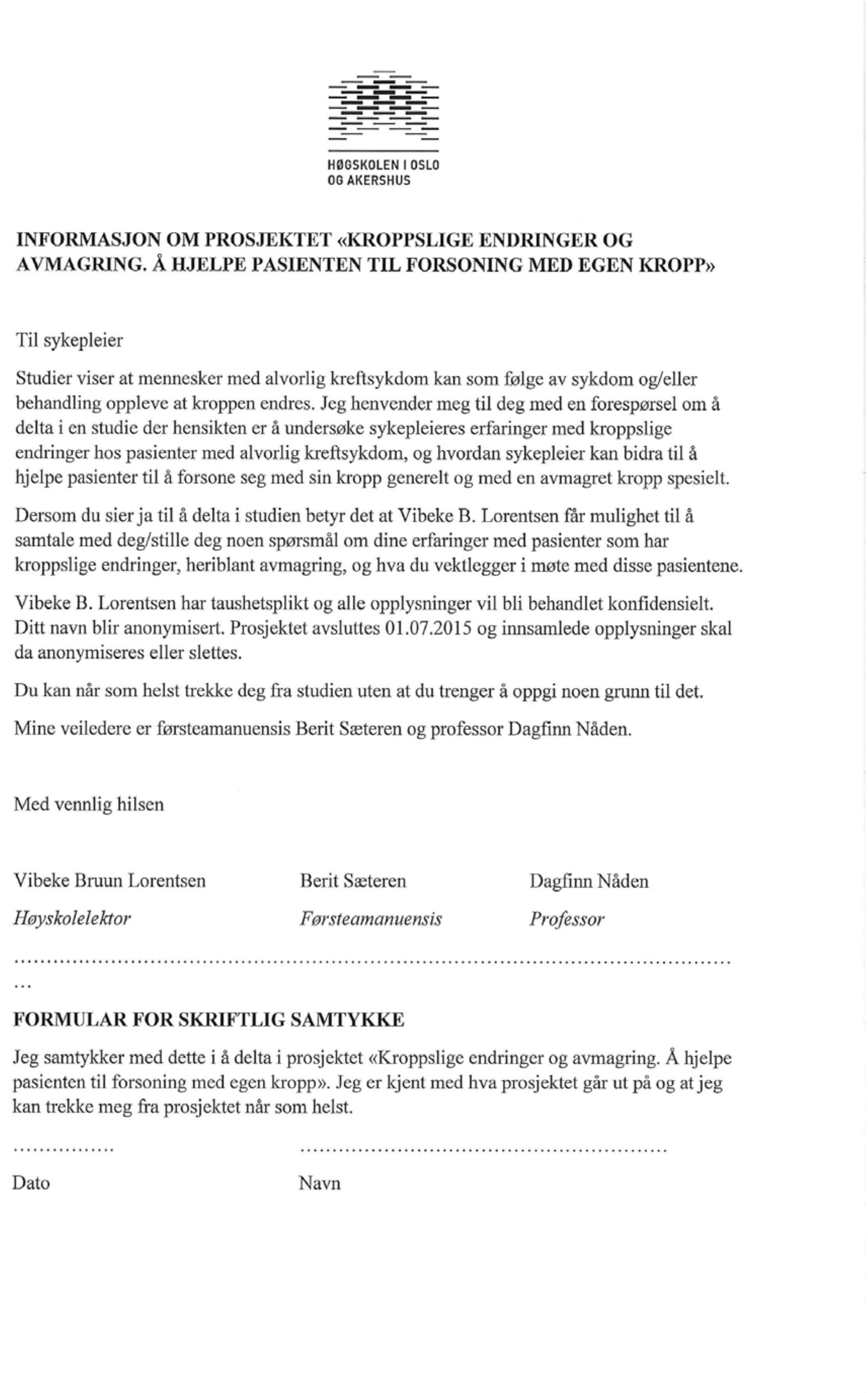
Med vennlig hilsen

Finn Wisløff
Professor em. dr. med.
Leder

Gjøril Bergva
Rådgiver

Kopi til: fou-hf@hioa.no
Høgskolen i Oslo og Akershus ved øverste administrative ledelse: postmottak@hioa.no

Appendix 4: Information and informed consent sheets



HØGSKOLEN I OSLO
OG AKERSHUS

INFORMASJON OM PROSJEKTET «KROPPSLIGE ENDRINGER OG AVMAGRING. Å HJELPE PASIENTEN TIL FORSONING MED EGEN KROPP»

Til sykepleier

Studier viser at mennesker med alvorlig kreftsykdom kan som følge av sykdom og/eller behandling oppleve at kroppen endres. Jeg henvender meg til deg med en forespørsel om å delta i en studie der hensikten er å undersøke sykepleieres erfaringer med kroppslige endringer hos pasienter med alvorlig kreftsykdom, og hvordan sykepleier kan bidra til å hjelpe pasienter til å forsone seg med sin kropp generelt og med en avmagret kropp spesielt.

Dersom du sier ja til å delta i studien betyr det at Vibeke B. Lorentsen får mulighet til å samtale med deg/stille deg noen spørsmål om dine erfaringer med pasienter som har kroppslige endringer, heriblant avmagring, og hva du vektlegger i møte med disse pasientene.

Vibeke B. Lorentsen har taushetsplikt og alle opplysninger vil bli behandlet konfidensielt. Ditt navn blir anonymisert. Prosjektet avsluttes 01.07.2015 og innsamlede opplysninger skal da anonymiseres eller slettes.

Du kan når som helst trekke deg fra studien uten at du trenger å oppgi noen grunn til det.

Mine veiledere er førsteamanuensis Berit Sæteren og professor Dagfinn Nåden.

Med vennlig hilsen

Vibeke Bruun Lorentsen	Berit Sæteren	Dagfinn Nåden
Høyskolelektor	*Førsteamanuensis*	*Professor*

……………………………………………………………………………………………………
…

FORMULAR FOR SKRIFTLIG SAMTYKKE

Jeg samtykker med dette i å delta i prosjektet «Kroppslige endringer og avmagring. Å hjelpe pasienten til forsoning med egen kropp». Jeg er kjent med hva prosjektet går ut på og at jeg kan trekke meg fra prosjektet når som helst.

…………….	…………………………………………………
Dato	Navn

HØGSKOLEN I OSLO
OG AKERSHUS

Forespørsel om deltakelse i forskningsprosjekt

«Kroppen som bærer av verdighet; fra pårørendes perspektiv»

Bakgrunn og hensikt

Dette er et spørsmål til deg som pårørende om å delta i et forskningsprosjekt med tittel: «Kroppen som bærer av verdighet». Tidligere forskning viser at kroppen forandres ved sykdom og behandling, noe som ofte medfører lidelse for pasienten. Forskning om pårørendes opplevelser når en av deres nærmeste er kroppslig forandret er også mangelfull. Hensikten med denne studien er å få en dypere forståelse for kroppen og kroppens betydning for å lindre lidelse og fremme pasientens helse og verdighet fra pårørendes perspektiv.

Studien er en del av Vibeke Bruun Lorentsens doktorgradsarbeid ved Høyskolen i Oslo og Akershus, fakultet for helsefag, institutt for Sykepleie. Veiledere er førsteamanuensis Berit Sæteren og professor Dagfinn Nåden.

Hva innebærer studien

Dersom du sier ja til å delta i denne studien betyr det at sykepleier og stipendiat Vibeke Bruun Lorentsen får mulighet til å samtale med deg om dine erfaringer som pårørende til pasienter med kroppslige endringer. Intervjuet vil vare ½ til 1 time.

Hva skjer med informasjonen om deg?

Informasjonen som registreres fra samtalen vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennelige opplysninger. Det er kun autorisert personell knyttet til studien som har adgang til opplysningene fra deg. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Dersom du ikke har noe imot det vil det benyttes båndopptager under intervjuet. Lydbåndet vil bli slettet ved prosjektets slutt 31.12.2018.

Mulige ulemper

Det er ingen risiko knyttet til deltagelse. Å snakke om sine erfaringer rundt det å være pårørende kan for noen oppleves ubehagelig, for de fleste som en lettelse. Studien vil ikke ha noen direkte fordeler for deg, men vil på sikt kunne bedre forståelsen av pårørendes situasjon relatert til studiens tema.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dette vil ikke få konsekvenser for deg. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på neste side. Dersom du senere skulle ønske å trekke deg eller har spørsmål til studien, kan du kontakte Vibeke Bruun Lorentsen, tlf: 93 24 93 13.

HØGSKOLEN I OSLO
OG AKERSHUS

Samtykke til deltagelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

HØGSKOLEN I OSLO
OG AKERSHUS

Forespørsel om deltakelse i forskningsprosjekt

«Kroppen som bærer av verdighet; fra pasients perspektiv»

Bakgrunn og hensikt

Dette er et spørsmål til deg som pasient om å delta i et forskningsprosjekt med tittel: «Kroppen som bærer av verdighet». Tidligere forskning viser at kroppen forandres ved sykdom og behandling, noe som ofte medfører lidelse for pasienten. Hensikten med denne studien er å få en dypere forståelse for kroppen og kroppens betydning for å lindre lidelse og fremme pasientens helse og verdighet.

Studien er en del av Vibeke Bruun Lorentsens doktorgradsarbeid ved Høyskolen i Oslo og Akershus, fakultet for helsefag, institutt for sykepleie og helsefremmende arbeid. Veiledere er førsteamanuensis Berit Sæteren og professor Dagfinn Nåden.

Hva innebærer studien

Dersom du sier ja til å delta i denne studien betyr det at sykepleier og stipendiat Vibeke Bruun Lorentsen får mulighet til å samtale med deg om dine erfaringer med kroppslige endringer. I tillegg vil forskeren være tilstede i avdelingen og delta ved ulike gjøremål relatert til de behov du har for hjelp. Både tilstedeværelse og intervju vil bli avpasset i forhold til dine krefter og ønsker.

Hva skjer med informasjonen om deg?

Informasjonen som registreres fra samtalene og kontakten med deg vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennelige opplysninger. Det er kun autorisert personell knyttet til studien som har adgang til opplysningene fra deg. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Dersom du ikke har noe imot det vil det benyttes båndopptager under intervjuet. Lydbåndet vil bli slettet ved prosjektets slutt 31.12.2018.

Mulige ulemper

Det er ingen risiko forbundet med deltagelse. Å snakke om sin situasjon kan for noen oppleves som ubehag, for de fleste som en lettelse. Studien vil ikke ha noen direkte fordeler for deg, men vil på sikt kunne bedre omsorgen for alvorlig syke pasienter.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dette vil ikke få konsekvenser for din videre omsorg og behandling. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på neste side. Dersom du senere skulle ønske å trekke deg eller har spørsmål til studien, kan du kontakte Vibeke Bruun Lorentsen, tlf: 93 24 93 13.

HØGSKOLEN I OSLO
OG AKERSHUS

Samtykke til deltagelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

Appendix 5: Interview guide for interview of nurses

SEMISTRUKTURERT INTERVJUGUIDE TIL PROSJEKTET «Kroppslige endringer og avmagring. Å hjelpe pasienter til forsoning med egen kropp»

SEMISTRUCTURED INTERVIEW GUIDE FOR THE PROJECT «Bodily changes and emaciation. Helping the patients to become reconciliated with their own body »

Som følge av sykdom og/eller behandling, opplever mange pasienter med alvorlig kreftsykdom at kroppen endres. Kan du si noe om hvordan kroppslige endringer

As a consequence of illness and/or treatment, many patients with a serious cancer disease experience that their body changes. Can you say something about how bodily changes

- *gir seg uttrykk hos den som er syk / are expressed in the person who is ill*
- erfares/oppleves av deg som sykepleier */ are experienced by you as a nurse*

Hvordan innvirker kroppslige endringer på livet til den som er syk? *How do bodily changes affect the life of the person who is ill?*

Kan du beskrive en situasjon der du møter en pasient som erfarer kroppslige endringer. *Can you describe a situation where you meet a patient who experiences bodily changes.*

Hva synes du er viktig i forhold til å møte pasienter som opplever kroppslige endringer? *What do you feel is important in relation to meeting patients who experience bodily changes?*

Avmagring forekommer hos mange pasienter med langtkommen kreftsykdom. Hvordan opplever du å møte en pasient som er sterkt avmagret? *Emaciation occurs in many patients with advanced cancer disease. How do you experience meeting a patient who is severely emaciated?*

- Hva gjør det med deg? *How does it affect you?*
- Hvilke følelser vekker det i deg? *What emotions do this evoke in you?*

Ut fra din erfaring; hvordan forholder pasienter seg til dette med avmagring? *Based on your experience; how do patients deal with emaciation?*

Hvilke tanker/assosiasjoner gjør du deg i forhold til fenomenet forsoning? *What thoughts/associations do you have in relation to the phenomenon of reconciliation?*

Kan du si litt om spesielle ting du vil vektlegge for at pasienter kan forsone seg med seg selv og sin kropp/situasjon? *Is there anything in particular that you would emphasize for patients so they may become reconciliated with themselves and their body/situation?*

- Verdien av at pasienter får sette ord på sine kroppslige endringer. *The value of patients being able to put into words the bodily changes they experience.*

Og/eller: Kan du beskrive en situasjon der du opplever at en pasient blir forsonet med seg selv og sin situasjon? *And/or: Can you describe a situation in which you experience that a patient becomes reconciliated with herself and her situation?*

Appendix 6: Interview guide for interview of relatives

SEMISTRUKTURERT INTERVJUGUIDE TIL PROSJEKTET «Kroppen som bærer av verdighet; fra pårørendes perspektiv» (Revidert*)

SEMISTRUCTURED INTERVIEW GUIDE FOR THE PROJECT «The body as bearer of dignity; from the perspective of the family » (Revised *)

Kan du si litt om hvordan det er å være pårørende? *Can you say something about how it is to be a relative?*

- Hvordan har du det? *How are you doing?*
- Hva er viktig for deg i den situasjonen du er nå? *What is important to you in the situation you are in right now?*
- Hva er vondt/vanskelig for deg i den situasjonen du er nå? *What is painful/difficult for you in the situation you are in right now?*

Jeg er opptatt av kroppen. Som følge av sykdom og/eller behandling, opplever mange pasienter med alvorlig kreftsykdom at kroppen endres. *I am concerned with the body. As a consequence of illness and/or treatment, many patients with serious cancer disease experience that their body changes.*

- Har du opplevd at kroppen har endret seg hos den som er syk? *Have you experienced that the body has changed for the one who is ill?*

Kan du si noe om hvordan kroppen har endret seg gjennom sykdomsforløpet? *Can you say something about how the body has changed throughout the illness trajectory?*

*Jeg er opptatt av hvilken betydning kroppslige endringer kan ha for pasientens opplevelse av verdighet. *I am concerned with what meaning any bodily changes may have for the patient's experience of dignity.*

- Hvilken betydning mener du at kroppslige endringer kan ha for pasientens opplevelse av verdighet? *According to you, what meaning do you feel that any bodily changes may have for the patient's experience of dignity?*
- (*Hva tenker du om kropp og verdighet? *Kroppen som bærer av verdighet) (*What are your thoughts on body and dignity? The body as the bearer of dignity)*

Hva betyr de kroppslige endringene for deg? *What do the bodily changes mean to you?*

Har de kroppslige endringene noen betydning for ditt forhold til pasienten? *Do the bodily changes have any significance for your relationship with the patient?*

Har du noen tanker om hvordan vi som sykepleiere kan bidra til at pasienter får gode kroppsopplevelser? *What are your thoughts on what we, as nurses, may do so that the patient will have good bodily experiences?*

- *Fra et verdighetsperspektiv? *From a perspective of dignity?*
- *Du har snakket om hvilken betydning kroppslige endringer kan ha for pasientens opplevelse av verdighet. Hva kan vi som sykepleiere bidra med for å fremme pasientens verdighet fra et kroppsperspektiv? *You have talked about what significance bodily changes may have for the patient's experience of dignity. What can we, as nurses, do to promote the patient's dignity from a bodily perspective?*

Har du noen tanker om hva vi som sykepleiere kan bidra med for deg som pårørende i forhold til pasientens kroppslige endringer? *What are your thoughts on what we, as nurses, can do for you as a relative in relation to the patient's bodily changes?*

*Revidert betyr: Etter noen intervjuer så jeg at verdighetsbegrepet trengte å tydeliggjøres mer. Derfor ble spørsmålene merket med * lagt til intervjuguiden.

*Revised means: After some interviews, I realized that the concept of dignity needed more explanation. Thus, the questions marked with * was added to the interview guide.*

Appendix 7: Interview guide for interview of patients

SEMISTRUKTURERT INTERVJUGUIDE TIL PROSJEKTET «Kroppen som bærer av verdighet; fra pasients perspektiv»

SEMISTRUCTURED INTERVIEW GUIDE FOR THE PROJECT «The body as bearer of dignity; from the perspective of the patients »

Jeg er opptatt av kroppen. Som følge av sykdom og/eller behandling, opplever mange pasienter med alvorlig kreftsykdom at kroppen endres. *I am concerned about the body. As a result of illness and/or treatment, many patients with advanced cancer disease experience bodily changes.*

Kan du si noe om hvilke kroppslige erfaringer du har i forhold til det å være syk? *Can you tell me about the bodily experiences you have had in relation to being sick?*

- Har du opplevd at kroppen har endret seg som følge av sykdom og/eller behandling? *Have you experienced that your body has changed as a result of illness and/or treatment?*

Kan du si noe om hvordan kroppen har endret seg for deg gjennom sykdomsforløpet? *Can you say something about how your body has changed throughout the course of the disease?*

Hva betyr de kroppslige endringene for deg? *What do the bodily changes mean to you?*

Har de kroppslige endringene noen betydning for hvordan du ser på deg selv? *Do the bodily changes affect how you see yourself?*

Har de kroppslige endringene noen betydning for ditt forhold til andre? *Do the bodily changes have any importance for your relationship with others?*

Har du noen tanker om hvordan vi som sykepleiere kan bidra til at du/pasienter får gode kroppsopplevelser? *Do you have any thoughts on how we as nurses can help you/the patients to have good bodily experiences?*

Appendix 8: Synonym table of flesh and fleshly

KJØTT/ **KJØD** (noun) ***FLESH***	Norsk Riksmålsordbok	Norsk Synonymordbok	Bokmålsordboka. Definisjon og rettskriving	Cappelens ordbok bokmål 1986	Aschehoug og Gyldendals store Norske Ordbok 1991	Rettskrivningsordbok med synonymer 1992	Norsk ordbok. Ordbok over det norske folkemålet	Norsk Ordbok med 1000 illustrasjoner (2. utg.) 2005	Escolas ordbok, 7. utg. 2009	Total
Legeme *Body*	x	x	x	x	x	x	x	x	x	9
Kropp *Body*	x	x				x	x		x	5
Føde (fra dyr) *Nourishment*	x			x	x			x		4
Fett *Fat/grease*				x			x			2
KJØDELIG **(adjective)** ***FLESHLY***										
Sanselig *Sensuous*	x	x			x	x	x	x	x	7
Jordisk *Earthly*	x	x				x		x	x	5
Legemlig *Corporeal*		x		x	x			x	x	5
Kroppslig *Bodily*		x			x			x		3
Seksuell *Sexual*		x			x			x		3
Sensuell *Sensual*		x			x			x		3

Verdslig *Secular*		x			x			x		3
Syndig *Sinful*	x	x				x				3
Egen *Own/Individual*		x								1
Veritabel *Veritable*		x								1
Virkelig *Real*		x								1

Muscle tissue and consanguine (blodbeslektet) have bindings to fleshly, but since there is no singular synonym of the concepts, they cannot be used in the semantic analysis. Stout (hold) has bindings to flesh, but is not included in the table because it has meanings that differ from the meaning content relevant in this study. This might occur when meaning content of a word is illuminated by semantic analysis and is something the researcher has to appraise (Sivonen et al., 2010).

Appendix 9: Discriminatory matrix for flesh (noun) based on 9 dictionaries

Discriminatory matrix for flesh (noun) based on 9 dictionaries	Kjøtt *Flesh*	Legeme *Body*	Føde *Nourishment*	Fett *Fat/grease*	Kropp *Body*
Kjøtt *Flesh*	-	9	4	2	5
Legeme *Body*	0	-	0	0	7
Føde *Nourishment*	0	0	-	0	0
Fett *Fat/grease*	0	0	0	-	0
Kropp *Body*	0	9	0	0	-

Appendix 10: Discriminatory matrix for fleshly (adjective) based on 9 dictionaries

Discriminatory matrix for fleshly (adjective) based on 9 dictionaries	Kjødelig *Fleshly*	Syndig *Sinful*	Egen *Own/ individual*	Veritabel *Veritable*	Virkelig *Real*	Jordisk *Earthly*	Kroppslig *Bodily*	Legemlig *Corporeal*	Sanselig *Sensuous*	Seksuell *Sexual*	Sensuell *Sensual*	Verdslig *Secular*
Kjødelig *Fleshly*	-	3	1	1	1	5	3	5	7	3	3	3
Syndig *Sinful*	1	-	0	0	0	0	0	0	0	0	0	0
Egen *Own/individual*	2	0	-	0	0	0	0	0	0	0	0	0
Veritabel *Veritable*	1	0	0	-	7	0	0	0	0	0	0	0
Virkelig *Real*	1	0	0	0	-	0	0	0	0	0	0	0
Jordisk *Earthly*	4	0	0	0	0	-	0	3	0	0	0	4
Kroppslig *Bodily*	1	0	0	0	0	0	-	7	0	0	0	0
Legemlig *Corporeal*	1	0	0	0	0	1	9	-	1	0	0	0
Sanselig *Sensuous*	3	0	0	0	0	0	0	2	-	4	3	0
Seksuell *Sexual*	0	0	0	0	0	0	0	0	1	-	1	0
Sensuell *Sensual*	1	0	0	0	0	0	0	0	9	1	-	0
Verdslig *Secular*	2	0	0	0	0	9	0	0	0	0	0	-

Appendix 11: Descriptions of flesh in the dictionaries with related synonyms for the adjectives

Descriptions of flesh in the dictionaries	**Adjectives**	**Related synonyms to adjectives**
Bløtere kroppsvev. *Softer body tissue* Myke deler av (muskelvev, fettvev) av kroppen hos mennesker og dyr *The soft parts (muscle tissue, fatty tissue) of the body of humans or animals*	Bløt(ere) *Soft(er)*	Myk *Supple*
		Våt *Wet*
		Svak *Weak*
		Veik *Feeble*
Levende menneske (menneske av kjøtt og blod) *Living human (human of flesh and blood)* Samnavn på levende organismer, vesener av alt levende, av alt kjød (1 Mos 6:19). *Name of living organisms, creatures of every living thing, of all flesh (Genesis 6:19).*	Levende *Living*	I live *Alive*
		Livlig *Lively*
		Eksistere(nde) *Existing*
		Aktuell *Current*
Saftig fruktvev *Juicy flesh of the fruit*	Saftig *Juicy*	Saftfull *Succulent*
		Kraftig *Strong*
		Djerv *Bold*
Mykt saftrikt fruktvev *Soft luscious flesh/tissue of the fruit* Saftrikt vev i planter, særlig i visse frukter	(Mykt) saftrikt *(Soft) Luscious*	Saftig *Juicy*

Luscious tissue in plants, particularly in certain fruits		
Ånden er villig, men kjødet er skrøpelig (Mt 26:41) *The spirit is willing, but the flesh is weak (Mt 26:41)*	Skrøpelig *Fragile*	Svak *Weak*
		Skral *Frail*
		Ufullkommen *Imperfect*
		Mangelfull *Insufficient*

Articles in full text

Article 1

Lorentsen, V.B., Nåden, D. & Sæteren, B. (2016). Fanget i en «fremmed kropp». Sykepleieres erfaringer med kroppslige endringer hos pasienter i palliativ fase. *Nordisk Sygeplejeforskning*, 6(2), 163-177. (Published). DOI: **https://doi.org/10.18261/issn.1892-2686-2016-02-06**

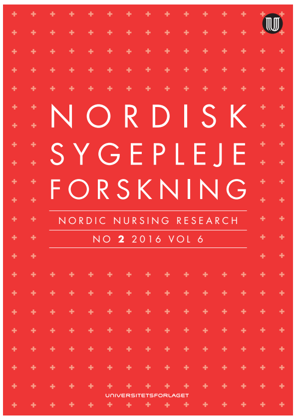
Fanget i en «fremmed kropp»

Sykepleiers erfaringer med kroppslige endringer hos pasienter i palliativ fase

Vibeke Bruun Lorentsen
Høgskolelektor, Høgskolen i Oslo og Akershus, Institutt for Sykepleie og helsefremmende arbeid. Vibeke.Bruun-Lorentsen@hioa.no

Dagfinn Nåden
Professor, Høgskolen i Oslo og Akershus. Institutt for Sykepleie og helsefremmende arbeid. Dagfinn.Naden@hioa.no

Berit Sæteren
Førsteamanuensis, Høgskolen i Oslo og Akershus. Institutt for Sykepleie og helsefremmende arbeid. Berit.Sateren@hioa.no



Nordisk Sygeplejeforskning/
Nordic Nursing Research,
volume 6, no 2-2016 p. 163–177
ISSN Online: 1892-2686
DOI: 10.18261/issn.1892-2686-2016-02-06

PEER REVIEWED ARTICLE

SAMMENDRAG

Hensikten med denne studien er å belyse hvilken betydning kroppslige endringer har for pasienter i den palliative fase ut fra sykepleiers perspektiv, og på hvilken måte sykepleier kan bidra til at pasienter om mulig forsoner seg med sin endrede kropp. Studien har et hermeneutisk design, og det er gjennomført intervjuer med åtte sykepleiere ved hospice i Norge. Resultatene presenteres i to hovedtemaer: Betydningen av kroppslige endringer og sykepleiers bidrag i forsoningsprosessen. Pasienters opplevelser beskrives som at de er fanget i en «fremmed kropp», kroppslig lidelse i form av avsky, skam og vemmelse, og at kroppslig forfall påminner om dødens alvor. Sykepleierne er opptatt av å hjelpe pasienter til å oppleve sammenheng og mening i sitt liv ved å invitere til samtaler, utføre godt stell, bruk av berøring/massasje i pleien og fremheving av det skjønne i og rundt pasienten. Studien avdekker at sykepleiere har for liten kunnskap og forståelse for kroppens betydning i palliativ fase.

Nøkkelord

Forsoning, kropp, lindrende behandling, psykososiale aspekter ved sykdom, sykepleie

BEING TRAPPED IN AN «ALIEN BODY». NURSES' EXPERIENCES WITH PATIENTS' PHYSICAL CHANGES IN THE PALLIATIVE PHASE

The purpose of this study is to illuminate the significance of bodily changes of patients in the palliative care based on the nurses' perspective. Further how nurses may help patients' reconciliation with their changing body, if possible. Data were collected through qualitative interviews with eight nurses working at hospices in Norway. A hermeneutic approach was used for data interpretation. The results are summarized in two main topics: The importance of bodily changes and nurses' contribution in the process of reconciliation. Patient`s experiences are described as being trapped in an «alien body», as bodily suffering in terms of disgust, as

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shame and loathing, and as the decay of their body reminding the patients of the seriousness of death. The nurses are concerned about supporting patients to experience coherence and meaning in life by inviting them to conversations, individual care, use of touch/massage in care and highlighting the beauty in and around the patient. The study reveals that nurses have insufficient knowledge of the body's importance in the palliative phase.

Keywords
Body, nursing, palliative care, psychosocial aspects of illness, reconciliation

Behandling av pasienter i palliativ fase har blitt intensivert og kraftig forbedret de siste årene, noe som har gitt pasienter en bedre helsetilstand og lengre levetid. På tross av dette opplever mennesker med progredierende kreftsykdom at kroppen endres som følge av sykdom og/eller behandling. Kroppslige endringer forårsaket av kreftsykdom og behandling omfatter avmagring, hårtap, fatigue, arrdannelse, sår, tap av kroppsdel, men også usynlige forandringer som endringer i tarmfunksjon, urinveier og seksualfunksjon (1,2). At kroppen endres er truende, fordi kroppen representerer pasientens tilgang til verden og andre mennesker. Det som har endret seg i den syke kroppen er ikke bare noen biologiske funksjonsendringer, men et meningsmønster som pasienten må finne ut av (3).

Sykepleiere har en viktig funksjon i å lindre plager av både kroppslig, psykososial og åndelig karakter i den palliative fasen. Det er gjort litteratursøk i databasene Cinahl, Medline og Psych Info med følgende søkeord: nursing, neoplasms, palliative care or hospice and palliative nursing, body image, body, psychosocial aspects of nursing og reconciliation. Det er ikke funnet studier som i dybden har undersøkt hvordan sykepleiere erfarer kreftpasienters kroppslige endringer fra et psykososialt perspektiv, og hvordan de kan hjelpe pasienter til eventuelt å forsones med sin endrede kropp. Flere studier viser at helsepersonell ikke tar opp kroppslige problemer med pasienter fordi de opplever det som tabu, og at det skaper mer stress enn gavn. Dessuten mener sykepleierne at de har få hjelpetiltak å sette i gang, og derfor tar de ikke initiativ til å sette i gang slike samtaler (4–6). Forskning viser også at kroppslige endringer har innvirkning på sykepleieres liv og møte med pasientene de skal hjelpe. Illeluktende kreftsår er noe av det som er vanskeligst å forholde seg til for både pasienter og sykepleiere (7–9). Sykepleiere trenger støtte for å møte disse pasientene på en best mulig måte (10).

Pasienter har stort behov for psykososial omsorg. De ønsker å snakke med helsepersonell om sine kroppslige endringer, og hvordan kreftsykdommen har innvirkning på deres liv og forhold til andre (10). De opplever en kultur i helsetjenesten der kroppslige endringer er noe de ikke kan snakke om (11). Pasienters lidelse er ofte taus, og pasienter opplever ensomhet i sin lidelse (12–13). De mørke sidene ved lidelsen er lite utforsket. Den intense sårbarheten i menneskets lidelse kan være vanskelig å forstå (14).

Ifølge Eriksson (15) og Gustafsson, Wiklund-Gustin og Lindström (16) muliggjøres mening i lidelsen når mennesker forsoner seg med sin situasjon. Søk på «Reconciliation» viser at det finnes begrenset med forskning om forsoning ved sykdom og lidelse. Forsoning ved sykdom og lidelse er et tema som framkommer mer sekundært i studier enten som sitering av pasienters opplevelse eller som tolket tema (16). Forsoning handler om å akseptere livet slik det arter seg her og nå. Det betyr å forsone seg med sin endrede livssituasjon, og at lidelse og helse forsones i en heterogen syntese. Lidelse er en del av det menneskelige livet og således en del av helsen. Ved å kunne se bakover og framover på livet, det vil si å kunne forene både fortid, nåtid og framtid, kan mennesket oppleve at livet er en helhet. Forsoning er en prosess som åpner opp for ny innsikt. Det er en overgang der pasienter erfarer livet på en ny måte. Mennesker opplever sammenheng og mening med livet (15,16).

Forskningsoversikten viser at det ikke er funnet studier som i dybden har undersøkt sykepleieres erfaringer med alvorlig syke kreftpasienters kroppslige lidelser fra et psykososialt perspektiv. Videre finnes det lite forskning om forsoning ved sykdom og lidelse. Det er et stort behov for mer forskning på dette området da kroppslige endringer kan virke grunnleggende truende på menneskers liv, og pasientens lidelse er ofte taus og ensom. Denne innsikten kan bidra til en mer helhetlig omsorg for alvorlig syke pasienter med kreft.

STUDIENS TOLKNINGSRAMME

Studiens tolkningsramme er Erikssons (15) teori om helse, lidelse og forsoning. Helse forstås som et flerdimensjonalt begrep. I Erikssons ontologiske helsemodell innebærer helse en bevegelse mellom ulike nivåer som å gjøre, å være og vorde. Ved helse som vorden er mennesket i en tilblivelsesprosess og ikke fremmed for lidelse, men strever etter å forsone seg med livets omstendigheter (15,17).

Lidelse er knyttet til det enkelte menneske og dets unike livssituasjon, og lar seg dermed vanskelig definere. Den er knyttet til sykdom og behandling, til det å leve, og når sykdommen skrider fram; å bli mer og mer avhengig av andre (13,15). Lidelse og helse utgjør to sider av menneskets livsprosess. Forsoning handler om at lidelse og helse forsones i en heterogen syntese, da forsoning er å akseptere livet slik det erfares her og nå. Det er en prosess som leder til ny innsikt og åpner opp for livet (16).

HENSIKT

Hensikten med denne studien er å belyse hvilken betydning sykepleiere mener at kroppslige endringer har for pasienter i den palliative fase, samt på hvilken måte sykepleier kan bidra til at pasienter om mulig forsoner seg med de kroppslige endringer og sin situasjon.

Metodologi

Studien har en hermeneutisk design, inspirert av Gadamers ontologiske hermeneutikk (18). Intensjonen med den hermeneutiske virksomhet er å avdekke sannhet, å søke bakenfor den synlige virkelighet for å kunne forstå de bakenforliggende indre prosesser. Gadamer tilbyr ingen tolkningslære for å oppnå sannhet, men angir nøkkelbegreper som fungerer som ledetråder i den hermeneutiske kunnskapssøken som den hermeneutiske sirkel, åpenhet, spørsmål, svar, helhet, del, horisontsammensmelting. Forståelse muliggjøres når det i dialogen, i møtet mellom forforståelse og datamaterialet, skjer en sammensmelting av en eller flere horisonter på meningsplanet. Dette kan skje gjennom langsom dvelende lesing av tekst der teksten er en av disse horisontene, og den andre er forskeren som leser tekstene. Med lesingen tilegner man seg det fremmede, og gjennom en justering av forståelseshorisonten skjer en gradvis horisontsammensmelting. Når man som tolker når forståelse av en tekst, innebærer det at ens egen horisont smelter sammen med tekstens, og ny forståelse av teksten trer fram (18).

Kvalitativt forskningsintervju ble valgt, fordi hensikten med slike intervjuer er å innhente beskrivelser fra den intervjuedes subjektive erfaringer (19). Intervju som datainnsamlingsmetode kan være et godt redskap for å få fram bakenforliggende tanker og følelser i forhold til et tema, noe som er relevant i denne studien.

Utvalg

Studien ble utført i 2012 ved to av de fire hospice som finnes i Norge. Valget av informanter ble foretatt av leder for sykepleietjenesten som kjente personalet og sørget for at åtte sykepleiere ble valgt. Sykepleierne var alle kvinner i alderen 46–64 år. Fire informanter hadde videreutdanning i kreftsykepleie, tre i palliativ omsorg og en i geriatrisk sykepleie. I tillegg hadde flere videreutdanning i ledelse- og helsesøsterfaget.

Datainnsamling

Det ble utarbeidet en semistrukturert intervjuguide på bakgrunn av hensikt med studien og teori. Intervjuene ble foretatt på informantenes arbeidsplass. De ble tatt opp på bånd og deretter transkribert av førsteforfatter. Det ble lyttet til lydbåndene to ganger for å sikre at nedtegnelsene ble ordrette. Varighet av intervjuene var 1 til 1 ½ time. Den skrevne teksten og lydopptakene utgjør til sammen materialet for analyse og fortolkning.

Analyse og fortolkning

Gadamer (18) har ikke utviklet noen systematiske regler for tolkning. Tolkningsprosessen har foregått over flere faser for å kunne trenge inn i teksten og få til en bevegelse fra det konkret empiriske og fram til forståelse. Det har vært viktig å gjøre forforståelsen bevisst fordi den har betydning for hvordan teksten blir forstått. Forforståelse handler i denne sammenheng om de erfaringer forskerne har med pasienter i livets siste fase. Forskerne er sykepleiere og har lang erfaring fra møter med, undervisning om og forskning på denne pasientgruppen. Studiens tolkningsramme er også forskernes forforståelse.

Tolkningsprosessen har foregått gjennom gjentatte lesninger av teksten og spørsmål og svar ut fra den hermeneutiske regel om at man forstår helheten ut fra delene og delene ut fra helheten (18). Søken har vært å lete etter hva som ligger bakenfor informantenes uttalelser og sammenhengen og bevegelsen i det som sies og det som formidles. Det er forsøkt å være så åpen som mulig for å kunne høre hva teksten har å si. Ved gjentatte lesninger opplevde forskerne at sin horisont og tekstens horisont nærmet seg hverandre. Ved å være åpen for tekstens annerledeshet ble også egen forforståelse utfordret.

Analysen har blitt delt inn i trinn der det er foretatt en åpen inndeling av tekstens struktur ut fra meningsenheter (direkte sitater fra empirien: hva som sies) og betydningsenheter (hva det tales om) med fremvekst av subtema og tema (20). Det har vært en dynamikk og indre bevegelse mellom trinnene. Nedenfor gis følgende eksempel på analyse- og fortolkningsprosessen:

TABELL 1. ANALYSE- OG FORTOLKNINGSMATRISE

Meningsenheter Hva som sies	**Betydningsenheter Hva det tales om**	**Subtema**	**Tema**
Det var en dame; hvis hun skulle ut på badet måtte vi klistre en kladd rundt speilet. Hun ville ikke se seg selv. Om det var fordi hun var syk, eller at hun var så endret, det er jeg litt usikker på	Å ikke ville se seg selv i speilet. Ved å se blir du minnet på hvor dårlig du er.	Å ikke våge å se seg selv skaper kroppslig lidelse som gir seg uttrykk i skam og avsky.	Kroppslig lidelse i form av avsky og skam

Etiske overveielser

Studien er godkjent av Norsk samfunnsvitenskapelig datatjeneste, referanse nr. 31153. Siden pasienter ikke er involvert i studien var det ikke nødvendig å søke regional etisk komite for medisinsk forskning (REK). Lederne på hospice innhentet skriftlig samtykke for sykepleiere som kunne delta i studien. Informantene ble informert om studiens hensikt, anonymitet, konfidensialitet og retten til å trekke seg når som helst uten å oppgi årsak. De ble videre informert om at lydbåndopptakene ble slettet umiddelbart etter at studien var gjennomført. Det at lederne på hospice spurte sykepleierne, kan føre til en viss risiko for at deltagerne følte seg forpliktet. Samtidig er dette sykepleiere med videreutdanning som man kan forvente at har trygghet til å svare ærlig om de vil delta eller ikke.

Studien tar dessuten opp sårbare temaer. Prinsippet om å ikke skade dem som er involvert (21) har vært en viktig ledetråd i alle faser av studien. Å ikke skade handler blant annet om å ivareta deltagerne slik at de i ettertid kan ta kontakt med forsker hvis spørsmål eller tanker knyttet til det som har kommet fram i studien dukker opp.

RESULTATER

Gjennom analyse og fortolkning av data steg følgende to hovedtemaer med undertemaer fram:

TABELL 2. OVERSIKT OVER HOVED- OG UNDERTEMAER

Betydningen av kroppslige endringer
1. Fanget i en «fremmed kropp»
2. Kroppslig lidelse i form av avsky, skam og vemmelse
3. Kroppslig forfall – en påminnelse om dødens alvor
Sykepleiers bidrag i forsoningsprosessen
1. Å bidra til kroppslig velvære
2. Å sette ord på sitt liv og sin lidelse
3. Å bekrefte pasienten
4. Å gi slipp på livet og føle seg hjemme

Betydningen av kroppslige endringer

Fanget i en «fremmed kropp»

Flere pasienter opplever ifølge sykepleierne å være fanget i en «fremmed kropp» som konsekvens av sykdommen. Informantene gir eksempler på sår som sprekker, sår som lukter og kropper som får nye proporsjoner med avmagring eller stor buk på grunn av væskeansamling. Pasienter streber etter kontroll, etter å opprettholde verdighet midt i en sykdom som lever sitt eget liv.

Utfra datamaterialet kommer pasientene lettere over de synlige tapene. Det er vanskeligere å akseptere den usigelige trøttheten og det å ikke lenger være selvhjulpen. *«Å ikke orke noe som helst, bare ligge der. Hva gjør det med psyken din»* spør en av sykepleierne. Hun sier videre at en ting er å være syk, men samtidig å kjenne på at kroppen ikke orker noe som helst, gjør det ekstra vanskelig. *«Særlig det med krefter er kanskje mere vanskelig å akseptere. Du blir avhengig av andre som skal hjelpe deg. Du klarer ikke å stelle deg sånn som du har gjort det før.»*

Kroppslig lidelse i form av avsky, skam og vemmelse

Sykepleierne hevder at de kroppslige forandringene synes å rokke ved pasienters identitet, sårbarhet og verdighet. *«Jeg tror det er ganske grunnleggende vondt det at du begynner å bli så endret. Det er veldig sårt, og jeg tror det går på noe av det innerste.»*

Det understrekes videre at pasientene ikke har noe sikkerhetsnett, men er utlevert i andres ivaretagelse. De opplever avsky, fortvilelse og vemmelse over en kropp som er forandret. Dette blir spesielt framtredende i stellsituasjoner. Pasienter skammer seg over de kroppslige endringene, spesielt vond lukt, og de føler seg ekle og ubehagelige fordi de lukter, og lukt er vanskelig å skjule.

Informantene beskriver også pasienter som ikke ønsker å se seg selv i speilet fordi de ikke vil bli minnet på de kroppslige forandringene.

> *Det var en dame; hvis hun skulle ut på badet måtte vi klistre en kladd rundt speilet. Hun ville ikke se seg selv. Om det var fordi hun var syk, eller at hun var så endret, det er jeg litt usikker på.*

Dette vitner om en enorm kroppslig lidelse i form av avsky og skam. Pasientene orker ikke å ta innover seg hvordan kroppen har blitt.

Kroppslig forfall – en påminnelse om dødens alvor

Sykepleiere beskriver at pasienter blir minnet om alvoret i situasjonen når de ser seg selv i speilet og ser sin svært avmagrede kropp, eller opplever en kropp som er så ødematøs at klærne ikke lenger passer. De kroppslige endringene blir en bekreftelse for pasienten om sykdommens alvorlighetsgrad og at døden er nært forestående.

> *En dame så seg selv i speilet. Det eneste hun så var øynene som stakk ut. Hun sa; jeg ser jo mer død enn levende ut. Tennene er nesten for store i forhold til ansiktet, ingenting igjen av hendene.*

En annen forteller om en dame som ikke lenger fikk på seg linbuksene som hun pleide å gå med på grunn av økt væskeansamling i kroppen. *Hun sa; «Se hvor dårlig jeg er blitt, nå får jeg ikke en gang på meg buksene som jeg brukte».* Kroppsendringen bekreftet alvoret i situasjonen.

Det ser ikke ut som om kroppen har like stor betydning for alle pasienter i palliativ fase. Flere sykepleiere startet intervjuet med å si at de opplevde at pasienten er forbi det stadiet at kropp er viktig. Det er andre ting som blir mer framtredende som forholdet til døden og tiden de har igjen. Kroppen synes underordnet. Sykepleiere undrer seg over at pasientene distanserer seg så mye fra kroppen i denne fasen. Et eksempel er pasienter som ikke bryr seg om at de er blottlagt under stellet. Det synes sykepleierne er merkelig, det blir de ikke fortrolig med.

Sykepleiers bidrag i forsoningsprosessen

Å bidra til kroppslig velvære

Sykepleierne fremhevet tre områder for å fremme kroppslig velvære: 1) La det friske leve, 2) Godt stell og 3) Berøring/massasje.

Å la det friske leve handler om at sykepleiere styrker det friske og naturlige hos pasienter. De lar pasienter kjenne sildrende vann over kroppen eller avlaster pasienter for aktiviteter som de strever med. Pasienter opplever helse når de klarer å leve i det naturlige, det friske som gir kraft.

Sykepleier forteller om en pasient som var opptatt av å få besøk av venner på sykehuset, gå korte turer rundt kvartalet og fortsatt drikke kaffe på kaffebaren i nærheten så lenge han klarte det. Han ville gi det friske plass i sitt liv slik at det overskygget at han var svært alvorlig syk og hadde et sterkt forandret utseende. *«Andre utenifra ville nok si at hans kroppslige endringer var noe av det verste de hadde sett, men selv hadde han nok ikke forstått hva de tenkte med det.»*

Å gi pasienter et godt stell fremmer helse, ifølge informantene. Å føle seg ren, få hjelp til å bli sminket, være ren i tøyet og ha det ryddig rundt seg er viktig. Det kan gi opplevelse av velbefinnende og fremme verdighet. *«Utseende har mye å si. Det å få stelt håret, ha det rent og pent. Ikke bli oppfattet som råtten nedfallsfrukt.»*

Skjønnhetens betydning for helse kommer også fram i resultatene. Sykepleierne er opptatt av å kommenterer det som er pent ved pasienten eller i pasientens omgivelser, og ser at det oppleves godt. Det kan være pene klær, et vakkert nyvasket frisert hår, eller menneskets indre skjønnhet. *«Hun så ikke ut når du så på henne, men hun var et nydelig menneske. Så jeg tenkte at det er en trøst at mennesker som ikke ser ut faktisk kan være vakre.»*

Sykepleierne beskriver også hvordan berøring eller massasje kan stimulere helse og bidra til at pasienten aksepterer kroppen i større grad.

> *Ved å ta på kroppen aksepteres den som den er. Ved å massere prøver en å få kroppen til å henge sammen, og ved terapeutisk berøring kan man hjelpe den man behandler til å samle kroppen, til å lage grenser. Kroppen er ikke bare en utflytende sak som ligger i sengen.*

Å sette ord på sitt liv og sin lidelse

Informantene oppfordrer pasienter til å fortelle sine historier og ha tilbakeblikk på sitt liv. De forteller at både livsfortellinger og personlige bilder kan gi tilbakeblikk, og være gode påminnelser på det livet pasienter har levd. Det kan hjelpe pasienter til ny innsikt og sammenheng i et liv som er preget av brudd og uviss framtid. Fortellingene kan hjelpe pasienter i en forsoningsprosess, men det kan også være en kilde til sorg og savn. En samtale om det kroppslige kan bli en samtale om sårbarhet, identitet og eksistensielle spørsmål.

Sykepleierne ser det som sitt ansvar å sette i gang samtaler med pasientene, selv om det kan være krevende. De kan ikke alltid gi svar eller trøste, men de kan sette i gang en bearbeidelsesprosess som kan lede til at forsoning skjer. De uttrykker at de trenger mot for å sette i gang disse samtalene. De må våge å være til stede i smerten og gråten og tåle avvisning.

> *Pasienten mister mye av det som gir identitet fordi kroppen endrer seg. Det er tøft og forsones med det, men for å kunne begynne prosessen til forsoning, så må en våge å prate om det. Det er ofte der jeg føler at jeg kommer mest til kort. Jeg kan ikke alltid gi svar eller trøste og si at dette går over, eller at dette blir bedre. Men vi har ihvertfall snakket om det, og det setter i gang en bearbeidelsesprosess hos den andre som kanskje forhåpentligvis kan føre til forsoning.*

Å bekrefte pasienten

Informantene er opptatt av å bekrefte pasienten ved ikke å overse eller avvise pasienten i sin lidelse. De ønsker at pasienten skal merke at de er tilstede med hele seg, og at de tar imot pasienter på en slik måte at de ikke føler seg avvist på noe av det som er mest sårbart for dem. De ønsker å ta pasientens lidelse på alvor og snakker om betydningen av å fange opp signaler og vise at de har tid når de merker at pasienter har behov for samtale.

Betydningen av å bli sett fremheves. Det kan være korte blikk der sykepleier og pasients øyne møtes, som kan utgjøre en forskjell for pasienten. Det er ikke alltid nødvendig med ord. «*Jeg tror det var greit for henne å se at blikkene møttes i speilet. Jeg kan jo ikke bare si noen trøstens ord heller.*»

Sykepleierne har oppmerksomhet mot det å se og bekrefte mennesket bak de kroppslige forandringene. De ønsker å bekrefte overfor pasienten at han er den samme selv om *«innpakningen har blitt litt annerledes»*. En informant er overrasket fordi hun ikke har tenkt over at pasienten er forandret. «*Jeg ble litt overrasket fordi jeg har ikke tenkt på at du er forandret. Jeg har lært deg å kjenne som du er, og tenker at du er flott sånn.*»

En sykepleier problematiserer sykepleierens evne til å se. Hun spør om lang erfaring av og til kan svekke denne evnen. «*Noen ganger kan erfaring være til hjelp, mens andre ganger kan det faktisk også bremse. De med kort erfaring kan kanskje klare å være mere åpne.*»

Å gi slipp på livet og føle seg hjemme

Forsoningsprosessen er for mange en stilltiende prosess. Det skjer ofte en gradvis akseptering av sin situasjon gjennom sykdomsprosessen. Den syke kroppen hjelper pasienter til å gi slipp, overgi seg og ikke kjempe mot lenger. Pasienter orker mindre og klarer i mindre grad å forholde seg til omgivelsene. En sykepleier sammenligner det med naturen. «*Hvor viktig det er å slippe taket. Det er bedre å seile med enn å kjempe mot, la naturen gå sin gang. For meg så er naturen så viselig innrettet.*»

Å hjelpe pasienter til å gi slipp handler om å hjelpe pasienter til å leve gjennom ulike stadier i sykdomsprosessen og likeledes å bearbeide tapene underveis mot døden, og ikke kun ha oppmerksomhet mot det å skulle dø. Det kan være tap av kroppsbilde, tap av roller og kroppslige funksjoner. Å oppmuntre pasienter til å ta imot hjelp til stell slik at de har krefter igjen når pårørende kommer på besøk handler også om å gi slipp. For noen kan det å gi slipp på sin egen selvhjulpenhet være det vanskeligste, hevder sykepleierne.

Betydningen av at pasienten føler seg hjemme i eget sykdomsforløp, kommer også fram i resultatene. Å ikke erkjenne at en er alvorlig syk og at døden er et ikke-tema på tross av alvorlige kroppslige forandringer gir en opplevelse av hjemløshet.

> *Det berører sterkt når pasienten ikke er på plass i sitt eget sykdomsforløp, døden er et ikke-tema og kroppen er tydelig preget av sykdom. Pasienten er ikke der, han skal leve videre. Det berører, for da vet vi at vi har en vei å gå sammen alle vi som jobber rundt pasienten og pårørende.*

Å hjelpe pasienten til å føle seg hjemme handler om at pasienter føler seg respektert som den de er med sine behov og ønsker. Sykepleier forteller om urolige pasienter som kommer til avdelingen. De vil ikke være der, men etter hvert faller de til ro fordi de blir møtt på en god og respektfull måte. At pasientene faller til ro åpner opp for pasientens forsoningsprosess.

DISKUSJON

Betydningen av kroppslige endringer

Et av hovedresultatene er at pasienter synes å være fanget i en «fremmede kropp». Sykepleierne hevder at den syke kroppen tar makten over pasienten og svekker den personlige frihet til å påvirke omstendigheter i sitt liv (22,23). Dette kan oppleves som en krenking av pasientens verdighet. Kroppen setter begrensninger for at pasienten kan ta ansvar for seg selv og sine handlinger som er grunnleggende for å oppleve frihet og verdighet (24).

I tillegg til at pasienter opplever at de er fanget så er kroppen en fremmed og noe de skammer seg over og har avsky for. Dette kan forstås som at pasienter opplever en «dobbel lidelse» der de lever i en kropp som de ikke lenger kjenner, verken på det indre eller ytre plan. Pasientene opplever sårbarhet og frykt for å bli forlatt da de er redd kroppen vekker avsky. Sykepleierne gir kanskje her et glimt av den mørke siden ved lidelse, som har vært lite utforsket ifølge Arman og Rehnsfeldt (14).

Det synes som om pasientene er redde for at andre skal oppleve dem som ekle. Informantene trekker spesielt fram den vonde lukta som noe de ikke kan beskytte seg mot. Den er gjennomtrengende og et stort tabu. Dette bekreftes også i andre studier. Vond lukt er et av de mest stressende symptomer for kreftpasienter. Det er en enorm psykisk påkjenning å leve med sår som lukter (7,9,25).

Å være fremmed vil ifølge synonymordbok bety å tilhøre andre og være hjemløs (26). I resultatene er det ikke bare de fysiske forandringene, men også den eksistensielle uro og manglende erkjennelse ved det å være alvorlig syk og skulle dø som gir opplevelse av hjemløshet. Dette kan tolkes som om å ikke være på plass i eget sykdomsløp. Synonymordbok forklarer hjemløshet som blant annet utrygghet og manglende styrke (26). Gabrielsen (27) og Gabrielsen, Nåden og Lindström (28) har studert det å tilsykne og lide og finner at det er en bevegelse med økende grad av fremmedgjøring overfor seg selv som menneske. Symptomene fører til uro over ikke å være seg selv. Pasienten har ikke lenger føringer over livet sitt. Enheten kropp, sjel og ånd er truet (ibid.). Andre studier beskriver også at den kroppslige tillit og tillit til livet blir utfordret ved alvorlig sykdom (29,30). Pasienter er vare for og lytter til kroppslige signaler på en helt annen måte enn tidligere på grunn av frykten for tilbakefall. Kroppen blir bærer av eksistensiell angst som konsekvens av at den ikke lenger kan stoles på (ibid.).

Forsoning: Å skape rom for å bebo en fremmed kropp

Resultater viser at sykepleierne er opptatt av å prøve å reetablere relasjon til en kropp som er fremmed og som er brutt sammen ved sykdom ved å gi pasienter et godt stell, bruk av berøring/massasje i pleien og fremheving av det skjønne i pasienten og hans omgivelser. Ved å være sanselig og levende tilstede i stellet av den sykes kropp, viser informantene at de tar den syke kroppen på alvor og pasienten kan oppleve helse og føle seg hjemme på et dypere integrasjonsnivå som kan forstås som helsens «vorden» i Erikssons helsemodell (15). Å bevege seg mot helse og forsoning handler dypest sett om å bebo seg selv og finne tilbake til seg selv fra sin opplevelse av hjemløshet (16,27). Det er en prosess der pasienter reetablerer relasjon til sin kropp både kroppslig, sjelelig og åndelig for å oppleve helse og bli hel (16). Å føle seg hjemme kan gi mot til å være det man innerst inne er (31), og gi følelsen av fred, hvile, tillit og pusterom i menneskets lidelse, som også er noe av forsoningens vesen. Mennesker opplever seg hel både kroppslig, sjelelig og åndelig (32).

Betydningen fortellingen har for å skape sammenheng i et liv som er preget av manglende sammenheng og en uviss framtid understrekes. Å fortelle sin historie kan være meningsskapende og frigjørende ifølge sykepleierne. Det kan være en vei for pasienten til å finne tilbake til seg selv og la det fremmede bli kjent og synlig for seg og sine omgivelser. Fortellingen kan bygge bro mellom fortid og nåtid og gi opplevelse av sammenheng og mening, noe som har betydning for forsoningsprosessen (16,32). Å forholde seg til det fremmede handler om å hjelpe pasienten til å være nær egen skam og urørlighetssone og å la det angå en (33). Skammen i den moderne kulturen har blitt tausere og mer utydelig (33,34). Ved at en skam blir satt i tale kan det bli mindre skam (34,35). Det fremmede blir ikke lenger så truende. Noe av det samme skjer i forsoningsprosessen der mennesker får tilgang til deler av sitt liv som tidligere var utilgjengelig og usynlig av ulike grunner (32).

Sykepleierne ser det som sitt ansvar å sette i gang samtaler med pasienter om deres kroppslige endringer, selv om det er krevende å være tilstede i pasientens smerte og gråt. De formidler samtidig at de ikke alltid er oppmerksomme på pasienters kroppslige endringer. De ser kun det vakre i menneskene. Å se det vakre, det innvendige mennesket, kan gi pasienter opplevelse av verdighet (36). Men det at informantene ikke ser de kroppslige endringene kan også oppleves uverdig. Det kan tyde på at sykepleierne har for liten forståelse for hvordan kroppen kan gripe inn i menneskers opplevelse av verdighet (24). Å ikke se kan også handle om mangelen på mot til å gå inn i og utholde andres lidelse, eller mot til å fange opp kroppens skjulte lidelsesuttrykk (17). Dette bekreftes også i denne studien. Sykepleieren er kanskje ikke søkende nysgjerrig og fantasifull nok til å våge og stå i det åpne, å være fornemmende og bevegende for å lete etter hvordan pasienten er sperret inne i sin lidelse (33). De mørke sidene ved lidelse er vanskelig å forstå og forholde seg til (14).

Studier viser at pasienters ensomhet ofte er knyttet til eksistensielle forhold (13), men ensomheten kan også handle om at de er alene med sine kroppslige erfaringer. Sykepleierne formidlet at de ikke var kjent med om pasientene var forbi det stadiet i livet der kropp var viktig. Dette kan tyde på at samtaler om pasienters opplevelse av sin kropp ikke er noe som naturlig blir tatt opp med pasientene. Andre studier viser at helsepersonell ikke tar opp kroppslige problemer med pasienter fordi de opplever det som tabu, og tror at det kan skape mer stress enn gavn. De opplever at de har få tiltak de kan sette i gang, eller at de selv er usikre og hjelpeløse til hvordan pasienter vil reagere hvis de tar initiativ til slike samtaler (4–6,37).

Resultater viser at å bebo sin egen kropp handler også om å hjelpe pasienter til å gi slipp og la naturen gå sin gang, slik at de ikke bruker alle krefter på å kjempe imot, men har krefter nok til å leve. Det handler om å hjelpe pasienter til å finne mening og ro slik at de føler seg hjemme og er hovedperson i eget liv, slik at forsoning om mulig kan skje. Den syke kroppen kan hjelpe pasienter til å gi slipp, men Edlund (24) påpeker at kroppen også kan være et hinder for frihet (ibid.). Å gi slipp er en prosess som skjer over tid der pasienter går gjennom flere stadier og til slutt opplever at de kan være seg selv. Pasienter opplever at de blir sett som mennesker og kjenner seg betydningsfulle og forstått i sin eksistensielle situasjon.

METODOLOGISKE OVERVEIELSER

Det har vært viktig å velge informanter som har god kunnskap om temaet for å styrke studiens troverdighet. Flere studier bekrefter betydningen videreutdanning har for sykepleiernes kompetanseutvikling (17,38). For å få et mest mulig rikt materiale, har informantene derfor videreutdanning i tillegg til flere års praksiserfaring ved hospiceenhetene. Det at det kun er kvinnelige informanter kan muligens ha betydning for resultatet.

Kvalitativ metode gir grunnlag for fordypning i de fenomener som skal undersøkes, og ikke generalisering som i kvantitativ forskning (19). Studien viser likevel noen tendenser som kan overføres eller gjenkjennes i andre settinger.

For å vurdere studiens validitet ble utdrag fra studiens tolkningsprosess presentert for sykepleiere som jobbet med tilsvarende pasientgrupper. De hadde mange av de samme erfaringer som informantene i studien, noe som styrker studiens troverdighet. Ved at alle forskerne deltok i tolkningsprosessen, ble også hver enkelt sine fordommer utfordret. Dette har også hatt betydning for studiens validitet.

KLINISKE IMPLIKASJONER

Resultatene vitner om en enorm livs- og sykdomslidelse (15) som det er viktig at sykepleiere er klar over i møte med alvorlig syke pasienter med kreft. For å kunne lindre pasientens lidelse og bidra til at forsoning kan skje, må sykepleierne hjelpe pasienten til og settes fri ved å avdekke det fremmede i pasientens kropp, og reetablere relasjon til det som er brutt sammen ved sykdom. Betydningen av et godt stell og samtaler i forsoningsprosessen er diskutert i artikkelen. I tillegg er det viktig at temaet «Kroppens betydning i helse og lidelse» blir satt mer på dagsorden i sykepleie for å kunne gi en mer helhetlig sykepleie som er i tråd med verdier i den palliative kulturen (39).

KONKLUSJON

Kroppslige endringer som konsekvens av sykdom og behandling påminner pasienter om deres alvorlige livssituasjon. De kroppslige endringene synes å rokke ved noe av det dypeste i menneskers liv, deres verdighet. Sykepleierne forteller at pasienter opplever å være fanget i en kropp som er ukjent, ukontrollerbar og fremmed, og som de skammer seg over. For å kunne hjelpe pasienter til om mulig forsones med sine kroppslige endringer, er sykepleierne opptatt av å avkle det fremmede og ukjente i pasienters liv gjennom god kroppslig pleie og samtaler. På tross av dette avdekker studien at sykepleiere har for liten kunnskap og forståelse for kroppens betydning i palliativ fase. Nasjonalt handlingsprogram med retningslinjer for palliasjon i kreftomsorgen (39) påpeker at mangelen på oppmerksomhet om kroppens betydning i helse og lidelse kan tyde på at dette er et tema som i likhet med skammen i det moderne (34) er utydelig og taust, som mennesker mangler språk om.

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Article 2

Lorentsen, V.B., Nåden, D. & Sæteren, B. (2019). Understanding the Meaning of the Ambiguous Body – A Hermeneutic Concept Analysis of Flesh and Fleshly. *International Journal of Caring Sciences*, 12 (2), 593-602. (Published).
URL: **http://www.internationaljournalofcaringsciences.org/Issue.aspx?issueID=52**

Original Article

Understanding the Meaning of the Ambiguous Body – A Hermeneutic Concept Analysis of Flesh and Fleshly

Lorentsen, Vibeke Bruun, RN
Assistant Professor, OsloMet – Oslo Metropolitan University, (former Oslo and Akershus University College of Applied Sciences), Department of Nursing and Health Promotion, Oslo, Norway

Nåden, Dagfinn, RN, PhD
Professor, OsloMet – Oslo Metropolitan University, Oslo, Norway

Sæteren, Berit, RN, PhD
Professor, OsloMet – Oslo Metropolitan University, Oslo, Norway

Correspondence: Lorentsen, Vibeke Bruun, RN, Assistant Professor, OsloMet – Oslo Metropolitan University (former Oslo and Akershus University College of Applied Sciences), Department of Nursing and Health Promotion, PB 4, St Olavs plass, 0130 Oslo, Norway e-mail: vibekebl@oslomet.no

Abstract

Background: When the body becomes sick it sends out signals that might be difficult to interpret for the suffering human being. If the patient has no concepts or language that helps him to understand what is going on in his body, the bodily changes might be perceived as confusing and perhaps frightening and thus promote suffering. Merleau-Ponty seeks to describe the visible, but also the invisible body in order to understand the deepness and inner reality of the human being with his philosophy of flesh, a concept which may deepen our understanding of the human body.
Aim: The aim of the study is to explore and understand the meaning and content of the concepts of flesh and fleshly. Likewise, to show how this knowledge can enrich the understanding of the ambiguous body and what the body means to the suffering human being.
Method: To bring forth a deeper clarity and meaning of flesh and fleshly and hence the body, it was necessary to perform a hermeneutic concept analysis of flesh and fleshly, created by Koort and further developed by Sivonen, Kasén and Eriksson, and a review of descriptions of flesh in the dictionaries.
Results and conclusion: The study reveals dimensions of flesh as corporeal, protective, temporal, sensuous, shameful and vigorous body. It is important that nurses are aware of these bodily dimensions in order to help the patients articulate and make visible some of the wordlessness and invisibility, which concern the body, and thus help the patients regain feelings of dignity and health.

Key words: Body, flesh, fleshly, life experiences, concept analysis

Introduction

The rational or objective dimension of the body has got most attention in nursing practice and in nursing research (Draper, 2014; Sandelowski, 2002; Wolf, 2014). However, when the body becomes sick, it might become like an alerting device that sends out signals and inhabits meanings that are beyond the rational or objective meaning dimensions of the body. The body speaks to the person through sensations and not through objective diagnostic labeling (Picco, Santoro, & Garrino, 2010; Sakalys, 2006). The patients are sensible to bodily signals and try to understand what they mean according to the illness. It is crucial to make the invisible meaning dimensions of the body more visible by expressing them with words. Otherwise, if the patient has no concepts or language that helps him to understand what is going on in his body, the bodily changes might be perceived as vague, confusing and probably frightening and thus promote suffering. It is through concepts or language people understand the world and make things meaningful (Eriksson, 2010; Gadamer, 2004). The language forms the basis for understanding (Eriksson, 2010).

In order to understand more about what the body represents and means to the suffering human being we looked for a concept that captured the ambiguous body. We found that Merleau-Ponty (1968, 2002)'s philosophy of flesh inhabited this dimension. Merleau-Ponty (2002) states that the body is not only a physical object, but also the human existence is based in the body. Thus, the body is something we have, but the body is also something we are (Merleau-Ponty, 2002). In his latest and unfinished work, Merleau-Ponty (1968) goes a bit further and seeks to capture and express both the visible but also the invisible dimensions of the body in order to understand the deepness and inner reality of the human being. He describes flesh as the individual's body, but it has also a metaphoric meaning and is an element of being (Merleau-Ponty, 1968; Sandelowski, 2002; Wolf, 2014).

Scientific articles (Gabrielsen, Lindström, & Nåden, 2009; Honkavuo, Sivonen, Eriksson, & Nåden, 2018; Werkander Harstäde, Roxberg, Andershed, & Brunt, 2012) refer to hermeneutic concept analysis to explore the meaning of a concept. Thus, we found it suitable to perform a hermeneutic concept analysis (Eriksson, 2010; Koort, 1975; Sivonen, Kasén, & Eriksson, 2010) of flesh and fleshly and a review of descriptions of flesh in the dictionaries to bring forth a deeper meaning of flesh and fleshly and hence the ambiguous body. It was necessary to perform two analysis because flesh has synonyms that are nouns (flesh) and adjectives (fleshly), and they have to be separated according to the method.

Few studies have explored in a deeper sense the meaning of body. Sivonen and Kasén (2003) have done a concept analysis of body, and Lindwall (2004) has done a modified semantic analysis of body in her doctoral thesis. There seems to be no semantic analysis of flesh and fleshly.

The aim of this study is therefore to explore and understand the meaning and content of the concepts flesh and fleshly. Likewise, to show how this knowledge can enrich the understanding of the ambiguous body and what the body means to the suffering human being.

Method

The hermeneutic concept analysis was created by Koort (1975) and further developed by Eriksson (2010) and Sivonen, Kasén, and Eriksson (2010). The intention of this analysis is to gain a deeper understanding of the meaning content of a concept by doing an analysis of the lexical meaning of the concept related to its conceptual family. The analysis searches to capture the depth and core of the concept by detecting nuances, variations, and features, which might enable a deeper understanding of its meanings (Eriksson, 2010; Honkavuo et al., 2018).

The dictionaries to be included should cover as long a period as possible so that a development of the concept and its meaning and synonyms can be seen. In this study five etymological dictionaries and nine Norwegian language dictionaries, published between 1937 and 2016 have been investigated. The dictionaries, except the etymological ones, are shown in table 1. No older dictionaries were included because flesh does not appear in the oldest Norwegian dictionaries. The authority of the dictionaries was taken into consideration when selecting them for inclusion.

The first step in the analysis is to study the history of the concept (an etymological analysis). The analysis yields knowledge on how a concept is used and understood in a language during a historical period. The original and ancient meaning of a word, even if concrete and old fashioned, can reveal the intrinsic meaning content of the concept and lead to concrete situations and contexts that have formed our mental notions attached to the word, but also lead to new meanings that may open up our understanding of the body today.

The second step was to explore the lexical meaning content of the concepts and its related synonyms and strong and weak synonyms were uncovered (table 1). If the examination of the dictionaries shows that the synonyms are the same in all the dictionaries the semantic analysis is completed. However, when this was not the case in our study, discrimination matrixes were made which show the number of dictionaries in which the synonyms of the concept's synonyms are identical with the synonyms of the original concept. Then the interrelatedness or the degree of synonyms from the matrixes were estimated and the results are illustrated in two maps or discrimination paradigms with main concepts and the synonyms of the synonyms which are regarded as characteristics of the concept (the paradigm phase) (figure 1 & 2).

According to Koort (1975) only synonyms with 40-50 % degree of synonymy should be included in the further analysis. Eriksson and Herberts (1993) broadened the perspective and claimed that sometimes even a weak synonym can be included if related to the research interest or to the original meaning content of the word. In line with the above statement, we have included all the synonyms in the discrimination paradigm, but in the description of results, we will concentrate on the words with the strongest bindings.

In the last phase, we did an interpretation of the results from the discrimination paradigms and the descriptions from dictionaries. The interpretation was inspired by Gadamer (2004)'s ontological hermeneutics. The results were interpreted through a dialogue or dialectical movement between the results with the highest degree of synonymy from the discrimination paradigms (figure 1 & 2), the etymological analysis, Merleau-Ponty's philosophy of flesh and nursing and caring theory and research.

Descriptions of flesh in the dictionaries

In the examinations of dictionaries, with the exception of etymological dictionaries, we find many descriptions of the concept of flesh in the form of phrases that give meaning to the concepts and show how it is used in different settings. These phrases cannot be included in the hermeneutic concept analysis, which is only possible on singular terms. Especially adjectives in the phrases that characterize flesh, and which are not present in the semantic and etymological analysis, are of concern. To gain a more comprehensive understanding, we also search for related synonyms to the adjectives in the dictionaries.

Results

In this section, we present the results from the hermeneutic concept analysis and the descriptions from the dictionaries and show how meaning dimensions of the body emerge through the analysis of flesh and fleshly.

Etymological analysis

Flesh is a common word in the Western and Northern Germanic languages. Etymologically, the word is related to the old English word *flæsc* and means the muscular parts of animals' and humans' bodies. It is the soft, bloody and greasy part of the human or animal body, in contrast to bones and sinews (Bjorvand & Lindeman, 2000; Online Etymology Dictionary; Ordbog over det danske sprog. Historisk ordbog 1700-1950; Svenska Akademiens Ordbok SAOB).

Flesh has, in the Bible, a figurative use as carnal nature, animal or physical nature of man, especially in Paul's use of the Greek *sarx*. This leads to a sense of 'sensual appetites' from the 1200s. In a religious tract from 1548 we find *fleshling*, meaning 'a sensual person' (Online Etymology Dictionary). In Norwegian, flesh is an inherited word that, when used in religious settings has the Norwegian and Danish word-form *kjød* (Bjorvand & Lindeman, 2000; Falk & Torp, 1994). It is the bodily condition as opposed to the spiritual.

Flesh has also the meaning of fruit from 1570 (Online Etymology Dictionary). Other meanings are 'living creature' and 'near kindred,' as in the phrase 'flesh and blood'. Here flesh describes a living human being with human needs and desires. Flesh is also used in a phrase from the 1660s, meaning with figurative extensions, 'to clothe or embody with flesh', here related to fleshed and fleshing (Online Etymology Dictionary). An old English poetry word for body was *flæsc-hama*, literally 'flesh-home' (Online Etymology Dictionary). Another Norse word related to flesh (*kjotr*) is *kvett* (Falk & Torp, 1994). *Kvett* exists in skaldic poetry and has the meaning 'piece of meat of whale' (Bjorvand & Lindeman, 2000).

Hermeneutic concept analysis

The synonym table (table 1) shows that the concepts that appear frequently according to flesh are the two Norwegian words of body (legeme and kropp) and nourishment. The meaning content of fleshly in the oldest dictionary was sensuous, earthly and sinful. In recent dictionaries corporeal, bodily, sexual, secular and sensual appear. Since the authors of the dictionaries seem to disagree about the synonyms of flesh and fleshly, it is necessary to conduct a discrimination analysis with all the synonyms which shows the connections and directions of the synonyms to the concepts flesh and fleshly. This begins with discriminatory matrixes and continues with discrimination paradigms of flesh (Fig. 1) and fleshly (Fig. 2).

Table 1. Synonym table for flesh and fleshly

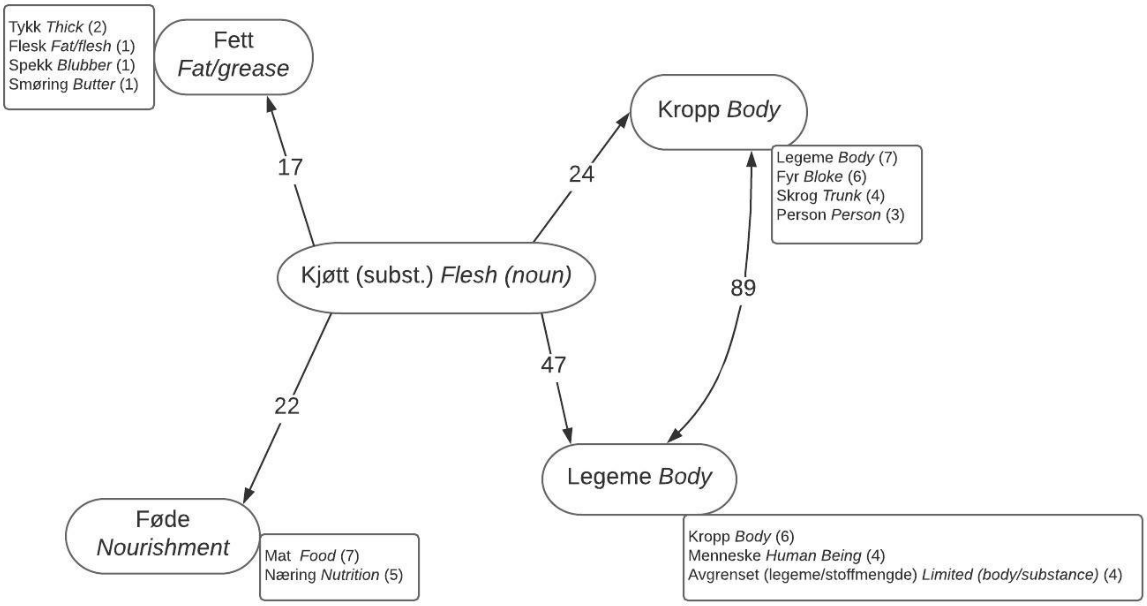
KJØTT/KJØD (noun) ***FLESH***	Norsk Riksmålsordbok 1937	Norsk Synonymordbok 1964	Bokmålsordboka. Definisjon og rettskriving 1986	Cappelens ordbok bokmål 1986	Aschehoug og Gyldendals store Norske Ordbok 1991	Rettskrivningsordbok med synonymer 1992	Norsk ordbok. Ordbok over det norske folkemålet 2001	Norsk Ordbok med 1000 illustrasjoner (2. utg.) 2005	Escolas ordbok, 7. utg. 2009	Total
Legeme *Body*	x	x	x	x	x	x	x	x	x	9
Kropp *Body*	x	x				x	x		x	5
Føde (fra dyr) *Nourishment*	x			x	x			x		4
Fett *Fat/grease*				x			x			2
KJØDELIG (adjective) ***FLESHLY***										
Sanselig *Sensuous*	x	x			x	x	x	x	x	7
Jordisk *Earthly*	x	x				x		x	x	5
Legemlig *Corporeal*		x		x	x			x	x	5
Kroppslig *Bodily*		x			x			x		3
Seksuell *Sexual*		x			x			x		3
Sensuell *Sensual*		x			x			x		3
Verdslig *Secular*		x			x			x		3
Syndig *Sinful*	x	x				x				3
Egen *Own/Individual*		x								1
Veritabel *Veritable*		x								1
Virkelig *Real*		x								1

The discrimination paradigm of flesh (Fig. 1) shows that flesh has quite a strong binding to body as *legeme*, and weaker binding to body as *kropp*, fat and nourishment. The related synonyms to flesh as body are both body as human being and body as body excluding head and limbs. Both are included in the further analysis because of the complex meaning dimensions of the concept. Body as human being reminds us of the living dimension of body. Body as body excluding head and limbs has a corporeal and a protective meaning while it keeps the body upright and together.

Another synonym of flesh is fat. The synonyms related to fat are thick, blubber and butter. Butter has both a concrete and an extensional definition, and in this study, the extensional definition is appropriate. Blubber has a specific meaning as the fat of sea mammals, especially whales and seals. These synonyms have properties of grease and softness, which in a metaphoric way give associations to flesh as the protective body.

The relationship between the above synonyms is visualized in figure 1.

Figure 1. The discrimination paradigm of flesh.



The discrimination paradigm of fleshly (Fig. 2) shows that fleshly has the strongest bindings to sensuous, earthly and corporeal. The 100 % link between corporeal and bodily demonstrates that these two concepts are identical.

Earthly and secular have also quite a strong binding that indicates a great deal of synonymy. The related synonyms to earthly and corporeal confirm the material dimension. Flesh does not last forever; it decays, perishes and breaks down and the dimension of flesh as the corporeal and the temporal body emerges.

Sensuous, with its strong binding to sexual and sensual, confirms the dimension of desire and flesh as the sensuous body appears. Fleshly has also a binding to sinful, with its corresponding synonyms horrible, burdened with, shameful and unchristian. These synonyms confirm dimensions of shame and disgracefulness and flesh as the shameful body emerge. The relationship between the above synonyms is visualized in figure 2.

Descriptions of flesh in the dictionaries

The meaning content of the descriptions of flesh in phrases reveals meanings of strength (juicy and luscious), living and fragility. These give associations to flesh as the vigorous body and not just a dead material. Likewise, fragility gives associations to flesh as the temporal and shameful body.

Interpretative discussion

Due to Eriksson's theory about the human being as an entity of body, soul and spirit (Eriksson, 2006), it is impossible to separate the body from the entity. Thus, while flesh is both the individual's body but has also a metaphoric meaning and is an element of being (Merleau-Ponty, 1968, 2002), interpretation of the results of flesh and fleshly brings forth a deeper meaning of flesh and fleshly and hence the body.

Six themes emerged from the interpretation process:

1) Flesh as the corporeal body

2) Flesh as the protective body

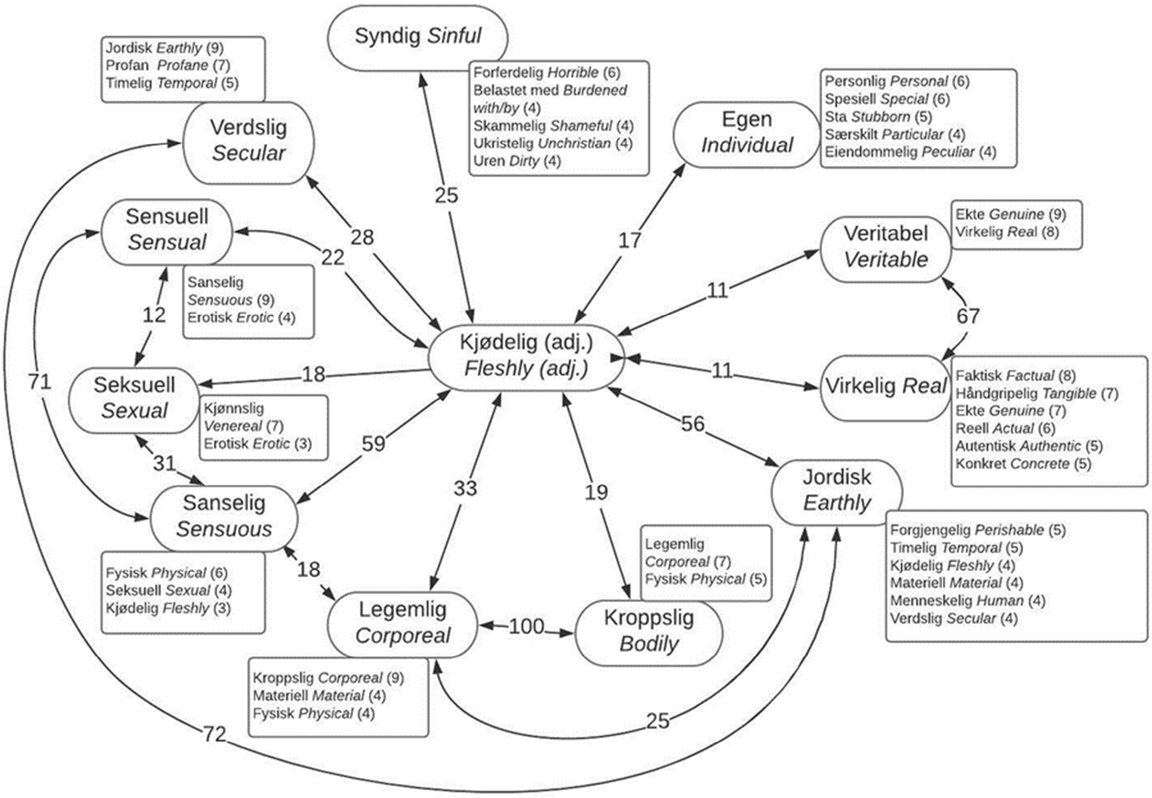
3) Flesh as the temporal body

4) Flesh as the sensuous body

5) Flesh as the shameful body, and

6) Flesh as the vigorous body.

Figure 2. The discrimination paradigm of fleshly.



Flesh as the corporeal body

The physical and material aspects of body are found in the hermeneutic concept analysis of, respectively, fleshly with its synonym corporeal and flesh with its synonym body. The related synonym to body, trunk, is the central part of the human body, which keeps the body in an upright position, and the body is dependent on it for its existence. An empirical study (Lorentsen, Nåden, & Sæteren, 2019) shows how important it is for patients to feel that their physical body still carries them, that they are still able to stand upright despite an advanced cancer diagnosis. When the body is no longer able to carry the person in an upright position, this causes helplessness and vulnerability, reminding the human being of her changed condition due to illness.

Flesh as the protective body

The body as trunk may also be understood as a form of protection while it keeps the body in an upright position and prevents it from falling, and flesh has an element of protection in the description of flesh as soft in the dictionaries. Flesh is also the soft tissue between the body's skin and bones, according to the etymological analysis. These descriptions of flesh evoke the body as something good, protective and restful.

Elements of protection are also found in the characteristics of whales from the etymological analysis. Whales are covered with a thick layer of blubber that insulates against cold and stores energy, which is important to the health of whales and protects them in periods when they do not eat. Blubber is also a related synonym to fat in the semantic analysis of flesh. The other related synonyms to fat: thick and butter, have also characteristics that confirm the element of protection.

These descriptions of goodness and protection, which the body represents, both concretely and metaphorically, may describe the body as the bearer of dignity (Edlund, 2002; Edlund, Lindwall, Post, & Lindström, 2013). However, understanding the body in this sense is problematic when the body is sick and the relative dignity is threatened (Edlund, 2002; Edlund et al., 2013).

Thus, the sick body can illuminate dignity as a value inherent to the human being rather than connected to what the body is able to perform.

Flesh as the temporal body

The dimension of time also becomes evident in the hermeneutic concept analysis of fleshly. The synonym earthly, which has one of the strongest bindings to fleshly, with its related synonyms perishable, material and temporal, shows that flesh is final; it is temporary and fleeting. People are going to die and the body is going to decompose or decay. Secular, with its related synonym temporal, also confirms the temporal dimension of the body. This is further affirmed by Løgstrup (1978) who describes time as irreversible: it is linear, transitory and will not return. Life is always a movement towards death.

However, studies show that time might also have a wider meaning, as timeless time. Timeless time is the moment where time stands still, and one might gain a glimpse of something real and genuine, or a sanctifying infinitude, as Nurminen (2009, 2012) calls it. We did not find this dimension in neither the semantic nor the etymological analysis. However, we might recognize this dimension of time in Merleau-Ponty (1968)'s philosophy of flesh when he claims that flesh is the place where mind, body and world cross. Time as flesh might also be understood, as in Kierkegaard's description of the moment, as the time when temporality and eternity meet (Sæteren, 2006). In this moment of timeless time, people may experience renewal and alleviation.

Flesh as the sensuous body

There are elements of sensitiveness, or rather sensuousness, in the hermeneutic concept analysis of fleshly with the synonyms sensuous and sensual, both strongly related semantically. Even though the synonyms related to the two synonyms sensuous and sensual are of a more sexual and erotic character, the sensuous dimension of the body is important and has the strongest binding to fleshly in the discrimination paradigm. We also found elements of sensitiveness in the descriptions of flesh in the dictionaries, where soft was understood as being touched lightly and as sensitive. The etymological analysis also reveals, especially in a religious setting, flesh as 'sensual appetites' and flesh as 'a sensual person'.

Merleau-Ponty (2002) confirms how the body can gain access to the truth through relating to or affecting the senses rather than the intellect. He claims that sensuousness or perception is our access to the world through our materiality or through our flesh. Corbin (2003) also states that the body speaks to the person through sensations that are anchored in meaning that is derived through experience in the social world.

Flesh as the shameful body

There are elements of shamefulness and dirtiness in the hermeneutic concept analysis of fleshly, where both descriptions were synonyms related to sinful. Other synonyms related to sinful were horrible, burdened with and unchristian. Shame is something that people often hide from others; it is mute and dark and experienced deep inside the human being, exerting a negative influence on the self (Dolezal, 2015; Werkander Harstäde et al., 2012). Living with a hidden and unarticulated suffering or shame, or suffering with no language, leave people unable to articulate who they are (Råholm, 2008).

Flesh as the vigorous body

The results show a number of synonyms with elements of strength. These are descriptions from the dictionaries of flesh as juicy and flesh of the fruit, but also the descriptions of flesh as something succulent and fresh that nourishes the body and provides strength. We also found fat and nourishment as synonyms of flesh in the hermeneutic concept analysis, which may be understood as important sources of energy that provide strength. Flesh is not just a piece of dead meat, but is alive and vital. The etymological analysis also confirms this by showing that flesh relates to an old English word that means the muscular part of the human or animal body. These synonyms confirm the importance of the life-affirming dimension represented by the body.

Methodological considerations

The dictionaries included in this study were from almost every decade (1937-2009) except for the period from 1940-1950s, when there were few relevant dictionaries, possibly because of problems related to World War II (Gabrielsen et al., 2009). This is important in order to have knowledge of the concept's development over time (Koort, 1975; Sivonen et al., 2010), to be able to explore and understand the meaning of constructs. It is also important to have as much width as possible in the family of concepts. This we have also almost achieved, except for the fact that two of the dictionaries have one editor, Guttu (1991, 2005), which may explain why there are many similar synonyms in the two dictionaries.

Semantic analysis is preferably done in the researcher's native language, as the interpretations of the results are presumed to be more valid in one's first language. When translating conceptual meanings into another language, the challenge is to find words that express the same meaning (Sivonen et al., 2010). Still we wanted to translate the Norwegian semantic analysis into English as we found the knowledge generated from the analysis to be of a wider, professional and scientific interest. An authorized translator performed the translations of the Norwegian words.

The choice of method for exploring and understanding the meaning of flesh may seem antagonistic to Merleau-Ponty's belief in language. He claims that things expressed metaphorically are considered to mirror the activity of life more closely than a language that is more semantically resolvable (Sellheim, 2010). Nevertheless, hermeneutic concept analysis is a fruitful method to widen our understanding of the concept because it allows a deeper understanding of the conceptual content when lexicons and thesauruses are used in a new way, not primarily for explanations of words but for exploring the meaning of constructs.

Conclusion and implications for nursing practice

The study reveals insight into the meaning of the ambiguous body. The body is more than the physical body we recognize with our eyes. The descriptions of flesh as corporeal, protective, temporal, sensuous, shameful and vigorous body shed light on dimensions that are important for the human beings' feelings of dignity and health.

It is important that nurses are aware of these meaning dimensions so they may help the patients discover how the body can protect them or how they can feel the strength that the vigorous body represents. Likewise, nurses should take into account that peoples' access to knowledge is through the sensuous body and the importance of being sensitive to underlying shame in order to help the patients regain feelings of dignity and health.

The several meaning dimensions of the body detect nuances of reality and might be a reminder of the complexity of nursing care. However, while part of our understanding of the other is rooted in our body and is less available for our consciousness because it is unarticulated and affective, this study might help us articulate and make visible some of this wordlessness and invisibility, which concern the body. Thus, in order to care for the whole human being and thereby help nurses perform better nursing care, it is important to explore the different meaning dimensions of the body. Likewise, to develop knowledge that the body is more than the visible body, a knowledge which previously has been more or less hidden.

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Article 3

Lorentsen, V.B., Nåden, D. & Sæteren, B. (2019). The paradoxical body: A glimpse of a deeper truth through relatives' stories. *Nursing Ethics*, 26(6), 1611-1622. (Published). DOI: **https://doi.org/10.1177/0969733018768660**

Original Manuscript

Nursing Ethics
2019, Vol. 26(6) 1611–1622

10.1177/0969733018768660
journals.sagepub.com/home/nej

The paradoxical body: A glimpse of a deeper truth through relatives' stories

Vibeke Bruun Lorentsen, Dagfinn Nåden and Berit Sæteren
Oslo and Akershus University College of Applied Sciences, Norway

Abstract

Background: People with progressive cancer experience that their bodies change due to disease and/or treatment. The body is integral to the unity of the human being, a unity that must be perceived as whole if dignity shall be experienced. Relatives are in touch with the suffering bodies of their dear ones, physically, socially, mentally, and existentially, and thus the relatives' experiences of the bodies of their dear ones might yield insight into the concept of dignity.

Aim: The aim of this study is to explore relatives' experiences of the patients' bodily changes from a perspective of dignity.

Research design and method: A total of 12 relatives from a hospice in Norway were interviewed. Gadamer's ontological hermeneutics inspired the interpretation.

Ethical considerations: The principles of voluntariness, confidentiality, withdrawal, and anonymity were respected during the whole research process. The Norwegian Social Science Data Services approved the study.

Results and conclusion: The conversations about the body were conversations about ambivalent or paradoxical matters that shed light on the concept of dignity. The results show that the relatives got in touch with elements that otherwise would have remained tacit and unspoken, and which gave glimpses of a deeper truth, which might reveal the core of dignity. Furthermore, the relatives' confirmation of the ambivalence might be understood as a strong ethical obligation to treat the other with dignity. The confirmation may also reveal the relatives' unselfish love of the other, which can be understood as the core of ethics and ethos. Finally, the results reveal the relatives' limited insight into their dear ones' bodily changes, and we discuss the challenges of truly seeing the other. Body knowledge and the relationship between body and dignity as phenomena cannot be ignored and needs more attention and articulation in clinical nursing practice and in nursing research.

Keywords
Body, dignity, extended family, life experience, palliative care

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Corresponding author: Vibeke Bruun Lorentsen, Department of Nursing and Health Promotion, OsloMet - Oslo Metropolitan University, PB 4, St Olavs plass, 0130 Oslo, Norway.
Email: vibekebl@oslomet.no

Introduction

The body is the center of human experience. It is in continuous dialogue with the world and represents the patient's access to the world and to other people.[1] People with progressive cancer experience that their bodies change due to disease and/or treatment. These changes affect physical, psychological, social, and existential dimensions of life.[2,3]

The bodily changes do affect not only the patients but also their relatives. Several studies[4–6] show that relatives worry and have a difficult time when their dear ones experience severe cancer disease. Relatives have higher levels of anxiety and lower quality of life throughout the period of illness and also after the patients' death. They have to handle both their own worries and take care of the one who has become ill.[4–6] This may be detrimental to the relatives' own health and social functioning.

The concept of dignity is important in the healthcare context, and influences the caregiver's view of humanity and the quality of care. There has been great effort trying to clarify and enhance the understanding of dignity within nursing and caring research.[7–10] For Kant, dignity is an absolute inner value all human beings possess.[11] Edlund,[12] Edlund et al.,[13] and Eriksson et al.[14] refer to it as absolute dignity. Absolute dignity is a value that belongs to every human being simply by virtue of being human and cannot be taken away.[12–14] Relative dignity is influenced by the culture and society that the human being is a part of and can be transformed, torn, and rebuilt.[12–14]

Edlund[12] and Edlund et al.[13] describe the body as bearer of this relative dignity. People experience dignity when they perform actions that are in accordance with the culture's and body's rules and norms of dignity. However, the body is also a source of violation. It holds feelings of independency and freedom, limitations, and dependency. The body also generates feelings of pride and shame, vulnerability, violation, strength, and powerlessness. It is an important part in the unity of the human being, a unity that must be whole if dignity shall be experienced.[12,13]

Merleau-Ponty[15] states that peoples' understanding of the world is based on the body's understanding of its surroundings or situations. Any perception of a thing involves perception of the own body. The body is something we have and something we are. We exist as both body and consciousness, but the two do not exist as separate units. Merleau-Ponty[15] says that self and world are not one but neither are they completely separate. There is an intertwining between self and world, a reversibility that means that there is a folding of the self into world and world into the self. He describes this as that to touch is also to be touched, to see is likewise to be visible. To engage in the world in a sensory way means that we participate in it, are part of it, and flesh signifies this participation or intertwining.[15,16]

The relatives are in touch with the sick bodies of their dear ones physically, socially, existentially, and/or mentally. Since the literature review reveals that the body influences dignity,[12,13] knowledge about the relatives' experiences of their dear ones' bodies might yield knowledge of what the body represents, symbolizes, and means from the perspective of dignity. Thus, this knowledge might give insight into the concept of dignity.

Research studies have explored relatives' experiences of dignity in relation to death, but few studies[17] have examined what relatives consider to promote dignity in a palliative phase. Despite the importance of body from a perspective of dignity, we also found sparse research on the relationship between dignity and body as phenomena from the perspective of caregivers. The research we found was from the perspective of patients.[12,13,18] This study is part of a project where we try to understand more about body and dignity in a cancer context. Another study in this project, a semantic analysis where we seek to explore and understand different dimensions of the body, is in process.

Table 1. Age and relation of the participants.

Relative	Age	Relation
1	63	Friend
2	41	Daughter
3	77	Wife
4	54	Daughter
5	43	Daughter
6	41	Daughter
7	68	Husband
8	73	Husband
9	60	Wife
10	50	Daughter
11	86	Husband
12	68	Wife

Aim

The aim of this study is to explore the relatives' experiences of the patients' bodily changes from a perspective of dignity.

Research questions

- What are the relatives' experiences of the patients' bodily changes?
- How do these experiences give insight into the phenomenon of dignity in a bodily perspective?

Methodology

The study has a hermeneutic approach based on Gadamer's[19] ontological hermeneutics. Gadamer[19] has not developed a method of interpretation but describes how pre-understanding and data can merge into a fusion of horizons where a new understanding appears. This might happen through slow, lingering reading where the text is one of the horizons and the other is the researcher who reads the text. The intention is to seek the truth that lies behind immediate reality.

Setting, sample, and method of data collection

In order to gain insight into the relatives' experiences of dignity, qualitative research interviews were used to collect data.

A total of 12 relatives (Table 1), 3 men and 9 women, aged 41–86 years, from a hospice in Norway, participated in the study, 10 from a hospice day care unit and 2 from a hospice inpatient unit. The relatives were the one the patients felt closest to; spouses, grown-up children, and friends. All participants spoke and understood Norwegian and were mentally aware of time and location. The period of data collection lasted from April to June 2015. One of the head nurses in the unit performed the inclusion of informants.

An interview guide based on the purpose of the study and the theoretical perspective was composed. The interviews were taped and transcribed by the first author (V.B.L.). They lasted between 45 to 75 min. The transcribed interviews and the tape recordings constituted the materials for interpretation. Interviews were read of all in the research group, and the themes were agreed in discussion.

Interpretation

One may ask whether it is problematic to use a hermeneutic design while Merleau-Ponty,[1,15] who is important for understanding the body in this study, represents a phenomenological tradition. Even if it may seem contradictory, we have chosen to use both of them because Gadamer's hermeneutic philosophy is used on a methodological level in order to understand the text, and Merleau-Ponty's philosophy is used on another level to get a deeper understanding of the substance of the body.

Within the Gadamerian approach, our pre-understanding is essential for the understanding of meanings of texts. We discovered, during the interpretation process, that the pre-understanding was too strong and a barrier to what the text was telling us. Thus, it was difficult to formulate questions to pose to the text and to allow the text to speak, as Gadamer[19] describes it. However, we experienced that Gadamer's[19] philosophy of play[20] helped us to creativity and engagement for the text to reveal meaning while we tried to transform his descriptions of the movement of the play into our attitude of interpretation. Gadamer describes the play as a constant movement backward and forward where the movement takes precedence over the consciousness. The movement has no goal that brings it to an end, rather it renews itself in constant repetition and brings into light what is otherwise hidden and withdrawn, and thus the play is a transformation of the truth.[19,20] We intended to have the same attitude during the interpretation process so that we openly could listen to what the text could tell us and not be captured by our pre-understanding.

Even if Gadamer has not outlined a method of interpretation, studies[21,22] have operationalized his hermeneutic philosophy to aid interpretation. We have been inspired by the four steps in Koskinen and Lindström's[22] hermeneutic reading. The hermeneutic process started with a first reading of the interviews in their particularity and otherness. The next step was to separate larger textual units that touched and evoked wonder and extract them from the text. By lingering reading patterns of meaning units were uncovered, which through further interpretation gave new understanding.

Ethical considerations

One of the head nurses in the hospice informed the research participants about the purpose of the study and obtained written consent from the informants before the research study started. The informants were informed of the principles of voluntariness of participation, the duty of confidentiality and anonymity, and the possibility of withdrawal from participation without giving any reasons. The relatives were at a vulnerable stage in their life and this raised special ethical demands for the researcher to be sensitive and protect the relatives' dignity throughout the research process. The Norwegian Social Science Data Services (NSD), reference number 42503, approved the project.

Results

The relatives told stories about the consequences cancer disease had for the bodies and lives of their dear ones, and what these bodily changes meant for the relatives. The relatives were concerned not only about changes to their dear ones' physical bodies but also about the mental and existential changes. In this sense, the body is extensive and involves the whole human being and their life and not only the physical corpus.

Five themes emerged from the hermeneutic interpretation:

Fear of being devoured and the struggle to hold on;
A stranger—not the one I knew, but the same, nevertheless;
The longing for what there was and the wish to lift up what there is;
A gnawing uneasiness—the need to understand and to be invited;
The vulnerable and decaying body appeals to responsibility and loyalty.

Fear of being devoured and the struggle to hold on

Relatives said that they had to stay on the outside of their loved ones' lives because they feared that the tiredness of the patients would paralyze them. The patient's tiredness was quite extensive and devastating and greatly affected the relatives. They struggled to keep going and felt like equilibrists who had to balance on a knife's edge and not take the wrong steps and fall. It was tough to be the patient's crutch, someone said. Others described their life as an earthquake, a "roof slide" and as hanging on by their fingertips. One woman said: "I cannot go down because then I'd give up, and I can't do that. I hope it's enough" (9).

One relative became irritated, angry, and provoked by the tiredness and unwillingness of the patient to fight and defy the fatigue. The muscles and hence life have to be triggered, she said:

> I don't know why I get angry. It is an unreasonable demand; I know. He gets up in the morning, eats his breakfast and brings his coffee into the living room. Then he lies down on the sofa because he is tired. I can tell him to get up and exercise, go for a little walk, bend and stretch his legs. I feel that he doesn't try enough. (3)

A woman also described the tension between the patient's body, paralyzed with fatigue, and her own powerful and strong body. The relative felt that she had to moderate her own activities and enthusiasm in respect for the patient. If she was too enthusiastic and wanted too much, he might see this as demands and expectations that he could not fulfill and become depressed.

A stranger—not the one I knew, but the same, nevertheless

The relatives not only talked about the physical changes of the body but they were just as concerned with the body's psychological, existential, and social changes. A woman described the difficulties of living in a marriage with a person who was totally changed mentally. She felt she did not know him anymore. He had become a stranger that she did not belong to anymore. Their relationship was totally changed. Being together, doing activities that provided good experiences, was important to the relationship between the relatives and their dear ones. The relatives described feelings of loneliness when this was no longer possible because of the patients' illness.

The relatives experienced the changes in personality as more difficult to deal with than the physical changes of the body. It was hard to witness the patients in another reality and not remembering anything. The relatives were particularly concerned with the patients' eyes which they described as having an empty gaze, as being uninhabited, absent, and alien because of the consequences of the severe cancer disease and its treatment:

> Her eyes are like big windows. Her drugged and gazing eyes make her look like she is absent. Not absent, but I can see when she is not with us and has to be brought back to reality. She is a bit empty and scared at the same time. (1)

The relatives also felt a sadness concerning the patients' bodily changes. They described their dear ones becoming perceptibly older, skinnier, feebler, and weaker. They found it depressing and demanding when the patients had become so much thinner as a consequence of the cancer disease and described them as eroded cliffs that wasted away. The eroded, decomposing body reminded the relatives that death was near:

> It is depressing to see a human being so sick and helpless. He has shrunk and there is no chance of recovery. (6)

Another relative said,

> It is hard to see him just fade away. He has become extremely reduced physically. (12)

Even though the relatives told several stories about the consequences of the changing bodies to the patients and themselves, the relatives all said that the physical changes were of no importance to them personally. They expressed that the patients were the same, no matter what, even though they did not have the same strength as before. This is a contrast to the many stories of sorrow, frustration, and anger that the relatives told about their loved ones' bodily changes.

One might ask whether the patients' bodily changes did not at all affect the relatives or whether this statement has to do with a commitment to treat their dear ones with absolute dignity. The expression "He is my husband, no matter what" (9), might imply that.

A husband also said that the illness and thus the bodily changes had made their relationship closer. He was grateful that he had this experience because he had not felt this emotionally involved in any circumstances earlier in life. He felt that the disease had brought them closer together.

The longing for what there was and the wish to lift up what there is

Relatives found it difficult to see the great negative influence the changed bodies had on the patients' self-images. They looked back on the past and on the patient's body as it was when he or she was healthy. They talked about how they missed the time when their loved ones had not yet become ill. Relatives' desires to look back on how the patient was before, remembering how beautiful and vigorous he or she was, might bring back some of the pride and dignity and thus give the relatives strength and power in a difficult time.

A daughter said with pride that her father was so handsome before he got sick and that he had changed as a consequence of the cancer disease:

> I have a nice picture of him when he was young and in the army. He was such a handsome man, very attractive. My father has always been very good looking. I was very proud of him when I was a little girl. He had dark thick hair. There is not much left of it now . . . I prefer to think about him the way he looked earlier, before he got sick. (4)

However, even if there was a longing in the interviews to look back on the past, there was also a wish to lift up and confirm the present, and see the sick body as it is today. To be visible and stand up for oneself are important to all human beings, it is important for the self-image and identity, the relatives claimed. It is easy to become invisible when one is ill. An example of how to become visible appears in the story told by a spouse about her husband who had started drawing pictures. He had done a lot of drawing earlier but had had a long break up until now. She experienced that drawing was good for him. He received positive responses not only from her but also from their friends and other family.

A gnawing uneasiness—the need to understand and to be invited

The relatives described how the sick body sent signals that were more or less easy to understand. The signals were of a physical, mental, or existential character. The relatives described how demanding it might be to see the blurred body and interpret the signals that worried them. It was of great importance to the relatives to understand the patients' situation and they described how difficult it was to live with a gnawing uneasiness most of the time:

> I think he has more pain than we have ever been told and understood. It was a shock to us when he told us that he was in a lot of pain. I would have liked to know . . . (5)

Interestingly, it seems that the physical signals from the body were more silent and less demanding for the relatives to handle than the mental and existential signals. A woman described how she sought to understand what her friend tried to tell her when she was mentally confused. She tried to put all the pieces of the jigsaw together and catch what was missing. It was a troubling and emotionally difficult task.

Some relatives were also especially concerned with how much time the patient had left and when he was going to die:

> I do not know how much time he has left and I do not want to know the exact date for his death. But at the same time I wonder; does he have one year left, half a year . . . ? Can we go away for a holiday? What will the summer be like? Many people have told me that there will be signs when death is approaching, but I do not know what signs I am looking for. (10)

The relatives, especially the grown-up children, also felt that they were not able to understand what the patients were going through because they were always a bit behind both in time and in space:

> I do not see her that often and therefore I am a bit behind and I do not know how her situation is just now. (2)

They received little information and had to use a lot of effort to grasp what was going on. A daughter described how she fought to be invited into the patient's world of suffering. The patient tended to keep her out of her life:

> I feel I have to pull out of her how she feels. Everything is good, she says. And then I suddenly discover that she is in pain. (2)

Despite this, some relatives experienced that they were allowed inside. One described how she was the only one allowed to see her friend naked and undressed. The patient trusted her and invited her in. Another described the sickness as a "we-project." He talked about a deep knowledge and participation in the patient's situation and said "we," not "I," when he talked about their life.

At the same time, the relatives reflected on reasons why some patients did not want to let them in. To be able to carry their bodies with dignity might involve having a private room in themselves where they could be on their own, one daughter said. This might be important to some people.

The vulnerable and decaying body appeals to responsibility and loyalty

The fight to be invited in and the great need for understanding describe the responsibility the relatives felt for their loved ones. The severity of the illness became very clear through the decaying body. It made them worried and anxious and they used all their effort to grasp what was going on.

The relatives described the responsibility in different ways. One relative described being a relative as work, work that was neither hard nor heavy. It was a privilege to live close to the patient and follow his struggle and suffering. However, later in the conversation she also said how exhausted and concerned she was and wondered whether she had enough strength to bear the pain. Another relative said that he would not be without these experiences. They had made him a more compassionate and better human being. He had earlier not been very emotionally involved in situations, but that was different now. He was happy that he had become so emotionally engaged and dependent on his spouse who was sick. He said that if you have a commitment to something or someone you also come to depend on the person or business that is your responsibility.

The vulnerable and decaying bodies also demanded loyalty from the relatives. One cannot pull a drowning man up and then leave him alone, one spouse said. Another relative expressed disgust and contempt for her father's unhealthy body. He lived a life that was so fundamentally different from her own healthy life. She felt that many of his bodily problems were self-inflicted and nothing she wanted to deal with:

> My parent has lived an unhealthy life. This has been demanding because it is so fundamentally different from myself. I like to exercise, I do not smoke, I eat healthy food and I take care of my body. (4)

She also mentioned several situations when she was betrayed, but despite this, she was loyal and would not leave him now when he needed her most. The relatives seemed to tolerate a lot before they let these values go. They felt a great responsibility for their loved ones and endured much despite conflicts and betrayals earlier in life.

Interpretative discussion

The stories about the sick body were stories about how the relatives experienced being relatives. The relatives described what the patients' body did and did not express, how this affected them, which consequences it had for their relationship, and which actions this induced.

In order to get a deeper insight into dignity in a bodily perspective, the relatives' stories have been in a continuing dialogue with the researchers' pre-understanding and the theoretical perspective of the study. Through this dialectical movement back and forth, we asked ourselves what does the bodily in the stories tell us and what does it mean in addition to being the concrete observable body.

The stories revealed a coexistence of opposing and conflicting feelings and experiences. The relatives described these demanding or ambivalent feelings about the other's bodies, what this meant to them, and how they acknowledged or confirmed this ambivalence. The meaning and confirmation of this ambivalence, but also the need and the challenges the relatives expressed to understand their dear ones' blurred body, became important to understand in relation to dignity. Thus, through an overall interpretation and dialogue with the text, four themes emerged:

- The demanding feelings that the body causes—a threat to dignity;
- The meaning of ambivalence and how this discloses aspects of truth;
- Confirmation of ambivalence—act of will to promote dignity;
- The challenges of seeing in order to understand the other's body.

The demanding feelings that the body causes—a threat to dignity

The relatives tell about how their dear ones' bodies bring forth feelings of anger, sorrow, sadness, discouragement, provocation, irritation, and how the sick bodies are described as strangers. They also tell how the sick bodies are demanding, annoying, and cause exhausting tensions. To endure the situation, the relatives keep themselves as much as they can on the outside of the patients' lives.

These negative feelings and experiences of their dear ones' bodies are in great contrast to Edlund's statement of the body as bearer of the external relative dignity.[12,13] They are also in contrast to values such as pride, nobility, position, value, respect, grandiosity, and authority, which are some of the results in Edlund's[12] semantic analysis of dignity.[13]

At first glance, the descriptions of contrasts are contrasts between the sick and the healthy body due to the understanding of the concept of dignity in a bodily perspective, and the healthy body is the bearer of dignity. However, the healthy body is something more than just the external, apparently perfect, body that one might observe if one tries to understand the body according to Merleau-Ponty's[15] philosophy of flesh. Merleau-

Ponty[15] describes the intertwining between the body and the world as a fold where the elements fold back upon themselves.

The intertwining or the reversibility means that the body and the world are mutually dependent on each other and in a continuous dialogue.[15] That might raise the question of whether it is appropriate to distinguish between relative and absolute dignity according to the assumption that the body is bearer of dignity in the way Edlund[12] and Edlund et al.[13] claim. Maybe, it is more fruitful to understand dignity as a unity in a bodily perspective or as a value inherent to the human being[11] and not divide it into internal and external dimensions of the concept.

The meaning of ambivalence and how this discloses aspects of truth

Despite several stories about how the dear ones have changed physically, mentally, socially, and existentially, it seems as a paradox arise in all the interviews as the informants state that the patients are the same despite the bodily changes.

The paradoxes reveal an ambivalence between the relatives' experiences and feelings and the fact that their dear ones are the same or possibly an ambivalence between what they feel and what they think they ought to feel. What the ambivalence concerns might vary from person to person, but Werkander Harstäde et al.[23] refer to Lögstrup who claims that there is an ambiguity in shame and that shame is connected with awkwardness and implies a sensitivity to boundaries that should not be crossed. One might ask whether the ambivalence may represent some of this ambiguity in shame described by Lögstrup in his work.

However, the ambivalence discloses a complexity or intertwining between contraries. The characteristics of intertwining are that something twists together and creates something new. Merleau-Ponty[15] describes that the intertwining of body and the world form a reality that is more real than the individual's visibility. The results showed that encouraging the relatives to tell their stories from a bodily perspective might have helped them to get in contact with matters that otherwise would have remained silent and unspoken.

Confirmation of ambivalence—act of will to promote dignity

The unanimous confirmation that the patients were the same might also be understood as an act of will. The relatives had decided that their dear ones were not changed despite the several stories they told about great bodily changes. The act of will may be the power of control that minds have over their feelings. This mental control might be relatively strong in terms of the strong feelings that the participants described quite thoroughly in the interviews.

The confirmation might also be viewed as a strong ethical commitment by the relatives to not let their loved ones down. The patients' sick bodies appeal to strong ethical obligations to be treated with dignity. The confirmation might also be grounded in the substance of love that is fundamental to being.[24] Agape love is the unconditional and unselfish love toward the other and is the core of ethics and ethos.[24,25] This love may become the duty to act in a caring manner and hold the other's otherness with respect and dignity. Lévinas[26] also describes the ethical obligation of seeing the other's body. He claims that the relationship to the face is immediately ethical. The relationship to the other is asymmetrical and selfless. To take ethical responsibility is to respond to the other's appeal to be cared for.

Even if Merleau-Ponty has not formulated an ethics, it is natural to ask whether the philosophy of flesh and reversibility can be understood as ethics. Aarø[27] claims that Merleau-Ponty's description of reversibility forms a basis for an ethics of being. He refers to an example of a painter where the painter's interaction with the world of perception constitutes a perspective that enjoins the painter to be responsible for that perspective in communication with other individuals, and responsibility is the meaning of ethics according to Levinas.[26,28]

There are also many bodily tensions or struggles in the interviews. The relatives describe their fight and effort to keep themselves going as quite exhausting and demanding strong acts of will. The relatives do not only fight for themselves but also fight for their dear ones and use a lot of strength trying to persuade the patients not to give up. However, the act of will to not allow their dear ones to let go might also evoke feelings in the patients of not having personal freedom, which again may threaten the patients' dignity. The tensions and fights describe bodies that are not in a state of equilibrium, but in a state of imbalance, which is the opposite of the Latin meaning of dignity as equality and credibility.[14] Gadamer[29] also describes the constant movement of bodies between the loss of equilibrium and the search for a new point of stability and thereby health. According to him, we need this balance for our lived environment and for the feeling of being at home in the world.

The challenges of seeing in order to understand the other's body

The relatives are very touched by the vulnerability and suffering of their dear ones due to the bodily changes. However, even though the relatives told several stories about how their dear ones' bodies changed as a consequence of living with severe cancer disease, the interviews did not reveal much of what the bodily changes might mean to, and feel like, for the patients.

Merleau-Ponty[15] describes challenges concerning seeing. He says that even though we might trust that what we see corresponds with what the other sees, no person fully experiences the same as another person. The world that we see is the world as it is for us and what we see is outside the other's body. We may therefore wonder if it is just as much their own suffering the relatives are telling us about as the suffering of the patients. García-Rueda et al.[30] confirm this and imply that much of the knowledge of the experiences of living with advanced-stage cancer are based on reports from caregivers and the perceptions of professionals, and that these reports are not so much about the concerns of the sufferer but rather provide the perspectives of others.

However, Merleau-Ponty[15] argues that even though we all have our private world, we are still in the world "floating in Being with another life" (p. 144). Through perception, there is a folding of self into the world and vice versa that mean that we touch and we are touched, we see, and we become visible.[15] This may imply that the relatives perceived more than they were able to express with words during the interviews. To make this perception meaningful, maybe, relatives need alternative ways of communication that might bring forth what is speechless.

Methodological considerations

The sample of this study consisted of 12 relatives from a hospice day care unit and a hospice inpatient unit, the relative the patient described as being the closest. No sons participated in the study. Maybe the results had been different if it was not a purposive sample, but a sample with more specific criteria. We also found Merleau-Ponty's philosophy of great value for opening new dimensions of the body.

Conclusion and recommendation

The intention of this study has been to explore the relatives' experiences of the patients' bodily changes and how these experiences give insight into the phenomenon of dignity. The relatives describe sorrow, frustration, and anger evoked by the patients' bodily changes. They feel that their dear ones have become strangers. The relatives are worried about being consumed by the difficult situation and have to use all their strength to keep going.

The conversations about the body are conversations about ambivalence or paradoxical and silent matters that might hold a deeper truth than the one immediately discovered. This deeper truth might reveal the core of dignity. Confirmation of the ambivalent or rather paradoxical body is grounded in the fundamental love for being and in an act of responsibility, both important bricks in the concept of dignity. Furthermore, the complexity of the body may make the division between absolute and relative dignity inapplicable when understanding dignity in a bodily perspective.

The study reveals that body knowledge cannot be ignored. The relatives' understanding and experiences of the world are rooted in the body and what the body symbolizes, means, and expresses. This knowledge needs more attention and articulation in clinical nursing practice and among the nursing leadership, while this study reveals that knowledge about the meaning of the body is important in nursing care. Inviting the relatives and the patients to talk about bodily matters should be just as common as inviting them to talk about other basic needs.

Further research is also required in order to explore more about the relationship between body and dignity as phenomena, including the perspectives of patients and nurses, while it has got little attention in nursing research today. The literature review confirms that there is sparse research about the importance of body. Understanding of the body revealed in this study might be a starting point and the first brick in developing a theory about bodily dignity.

Conflict of interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

ORCID iD

Vibeke Bruun Lorentsen https://orcid.org/0000-0002-8145-886X

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Article 4

Lorentsen, V.B., Nåden, D. & Sæteren, B. (2019). The meaning of dignity when the patients' bodies are falling apart. *Nursing Open*, 6(3), 1163-1170. (Published).
DOI: **https://doi.org/10.1002/nop2.301**

Received: 24 January 2019 | Revised: 9 April 2019 | Accepted: 2 May 2019
DOI: 10.1002/nop2.301

WILEY NursingOpen Open Access

RESEARCH ARTICLE

The meaning of dignity when the patients' bodies are falling apart

Vibeke Bruun Lorentsen | **Dagfinn Nåden** | **Berit Sæteren**

Department of Nursing and Health Promotion, OsloMet – Oslo Metropolitan University, Oslo, Norway

Correspondence
Vibeke Bruun Lorentsen, Department of Nursing and Health Promotion, OsloMet – Oslo Metropolitan University (former Oslo and Akershus University College of Applied Sciences), PB 4, St Olavs plass, 0130 Oslo, Norway.
Email: vibekebl@oslomet.no

Abstract

Background: People with advanced cancer disease experience great bodily changes due to disease or treatment. They tend to feel ashamed when their bodies are subjected to such changes and they feel their dignity is threatened.

Aim: To explore the patients' experiences of the bodily changes in relation to dignity.

Design: The study has a hermeneutic qualitative design.

Method: Individual in-depth interviews and participant observations were conducted with 13 patients with advanced cancer disease at a hospice inpatient unit in Norway. Gadamer's ontological hermeneutics inspired the interpretation.

Results and conclusion: The patients' unpredictable, sick bodies forced the patients, or gave them the opportunity, to relate to their bodies in an honest way. The patients, living in interaction between suffering and health, strove to find dignity. The patients had a will to live and they experienced a love in their unruly bodies that both helped alleviate their suffering and give them an experience of enhanced dignity. It is important that nurses have insight into the consequences of bodily changes for the patients' experiences of dignity in health and suffering to provide good, dignified care.

KEYWORDS
body, dignity, life experience, nursing, palliative care, patient

1 | INTRODUCTION

Serious illness leads to a loss of "the destination and map" that previously guided the sick person's life (Frank, 2013). The "map" that changes is, among other things, the body. People with advanced cancer diagnoses experience great bodily changes due to disease and/or treatment. The changes are, among others, emaciation, scars, hair loss, fatigue, ulcers, loss of limb(s), but also invisible changes in bowel, urinary and sexual function (Gobel, Yarbro, & Wujcik, 2011; Price, 2009).

The most frequently reported symptoms occurring in patients with cancer in a palliative phase are fatigue, feeling drowsy, difficulty sleeping and worrying (Stark, Tofthagen, Visovsky, & McMillan, 2012). Pain (Oechsle, Goerth, Bokemeyer, & Mehnert, 2013) and weight loss (Teunissen et al., 2007) are also reported as frequent symptoms.

Research studies also explore how patients experience living with advanced stage cancer and the existential challenges concerning living with the disease at the end of life (García-Rueda, Carvajal Valcárcel, Saracíbar-Razquin, & Arantzamendi Solabarrieta, 2016; Henoch, Danielson, Strang, Browall, & Melin-Johansson, 2013; Sæteren, Lindström, & Nåden, 2011, 2015). Research studies describe a perception of the body as a stranger and as an alien. The body sets boundaries and limits for existence and does not feel like a home anymore, but rather like a prison where battles are fought (Lindwall & Bergbom, 2009; Sekse, Gjengedal, & Råheim, 2013). Even though the bodily changes may seem fundamentally threatening to the human being, few studies have delved deeply into how people with advanced cancer disease experience living in a changed body.

1.1 | Background

The concept of bodily dignity is rarely addressed in research, except dignity as related to identity (Jacobson, 2007; Nordenfelt, 2004). The body is described as the bearer of relative dignity (Edlund, Lindwall, Post, & Lindström, 2013) and people may experience dignity when they perform actions that are in accordance with their culture's and their body's rules and norms for dignity. Embodied dignity is described as when a person affirms the value of his or her carnal nature and a certain comportment, showing both a self-accepted vulnerability and a certain honour in this, is noticeable (Galvin & Todres, 2015).

When the body is sick and weak, bodily dignity cannot be related to the performance of actions that are in accordance with a healthy and strong body. People have to relate to their bodies in a different way: as something they are, rather than something they have (Merleau-Ponty, 2002), when their bodies are more or less falling apart.

The concept of dignity is important in nursing because it says something profound about the status, the sacredness and the uniqueness of the human being (Lorentsen, Nåden, & Sæteren, 2016; Tranvåg, Synnes, & McSherry, 2016). Research studies reveal that dignity is threatened and people feel ashamed when they experience great bodily changes caused by their severe cancer disease (Franklin, Ternestedt, & Nordenfelt, 2006; Lin, Watson, & Tsai, 2013). The body becomes unrecognizable, it smells from wounds that will not heal and the patients experience a lack of control of bodily functions. These bodily changes affect not just the patients' bodies, but their whole life.

Tranvåg and McSherry (2016) claim that nurses have an intuitive understanding of dignity. However, they may lack an in-depth understanding of the underlying components of the concept, an understanding which would have better enabled them to identify and resolve practices that violate dignity. Since the literature review reveals that the body influences dignity (Edlund et al., 2013; Galvin & Todres, 2015), knowledge about the patients' experiences of their bodily changes would probably yield knowledge of some of these underlying components of dignity. Through the patients' stories, we hoped to gain insight into the affective knowledge that requires both mind and body when living with advanced cancer and into how this provides deeper knowledge of the phenomenon of dignity from an inside, bodily perspective. Merleau-Ponty's philosophy of the body, as the basis for consciousness and language (Merleau-Ponty, 1968, 2002), is also important in our effort to understand more about the subject of the study.

2 | AIM

The primary aim of this study is therefore to explore the patients' experiences of bodily changes in relation to dignity.

The secondary aims are as follows:

- What are the patients' experiences of the bodily changes?
- How do the patients' experiences of bodily changes give insight into the phenomenon of dignity?

3 | METHODOLOGY

3.1 | Design

Since the aim of the study is to acquire a deeper understanding of the patients' experiences of the bodily changes in relation to dignity, the study has a hermeneutic qualitative design based on Gadamer's (2004) ontological hermeneutics, where the purpose is to achieve understanding through interpretation. Gadamer (2004) does not offer a special method of interpretation, but has described how new understanding emerges through slow, lingering reading of a text, where pre-understanding and data merge into a fusion of horizon.

3.2 | Setting, sample and method of data collection

Data were collected through individual in-depth interviews and participant observations. Thirteen patients, four men and nine women, aged 53–83, from a hospice inpatient unit in Norway, participated in the study. The patients included had an advanced cancer diagnosis, were at the end of life and experienced bodily changes due to disease and/or treatment (Table 1). All patients spoke and understood Norwegian and were mentally aware of time and location. The period of data collection lasted from January–June 2017. One of the head nurses selected the participants in accordance with the inclusion criteria.

TABLE 1 Age and gender of the patients

Patient	Gender	Age
1	Woman	83
2	Woman	57
3	Woman	60
4	Woman	53
5	Man	60
6	Woman	75
7	Man	77
8	Man	79
9	Woman	56
10	Woman	75
11	Man	70
12	Woman	57
13	Woman	55

3.3 | Qualitative interviews

The first author (V.B.L) conducted the interviews with the patients in the patient room at the hospice inpatient unit. An interview guide was applied (Table 2) and the interviews started with an open-ended question, asking the patients to tell about their bodily experiences of the illness. Other research questions focused on how the body had changed during the illness trajectory and the meaning of those bodily changes for the patient and for relations with other people. The interviews lasted between 35–70 min. Data from the interviews were taped and transcribed by the first author. The research group consisted of three Norwegian researchers who, from previous studies, were familiar with both the subject of the research and the research method.

3.4 | Participant observation

The first author (V.B.L) observed different care situations at the hospice inpatient unit: patients interacting with nurses or doctors, receiving treatment from the physiotherapists, or conversing with the occupational therapists. Since our primary duty as researchers is to treat the patients with respect and caution, we found it ethically proper to follow and observe each patient during a 1-day shift only, while most of the patients had a 14-day stay. For the same reason, the observer did not stay permanently in the patient's room during the whole day shift but went in and out and came in when various health personnel visited the patient. Thus, each patient was observed for a total of approximately 3–4 hr.

The primary purpose of the observations was to give the researchers more background knowledge about the suffering body to gain a deeper and better understanding of the patients' situation. This helped the first author, in the interview situation, gain a deeper insight into what was at stake for the patients. Also, that the researcher spent more time with the patients probably made the patients more familiar with the researcher and more confident and open in the interview situations.

We did not develop an observation guide as we did not want to focus on specific situations but absorb as much as possible in the situations (Nåden, 2010). The first author observed how the patients talked about the illness, their use of body language, the tone of voice, the way they moved their bodies, slow or fast, the cooperation with other health personnel and what was explicitly put into words or left implicit.

TABLE 2 The interview guide

I am concerned about the body. As a result of illness and/or treatment, many patients with advanced cancer disease experience bodily changes
Can you tell me about the bodily experiences you have had in relation to being sick?
- Have you experienced that your body has changed as a result of illness and/or treatment?
Can you say something about how your body has changed throughout the course of the disease?
What do the bodily changes mean to you?
Do the bodily changes affect how you see yourself?
Do the bodily changes have any importance for your relationship with others?
Do you have any thoughts on how we, as nurses, can help you/the patients to have good bodily experiences?

3.5 | Interpretation

Even though Gadamer (2004) did not outline a specific method of interpretation, he offered some key concepts, which have guided our interpretation. These are openness to the text, questions and answers, the hermeneutic circle, parts and whole and fusion of horizons. The texts were read several times to grasp the overall meaning. To search for a deeper meaning and to achieve a movement from the empirical to a generic understanding, three questions were posed to the texts: "What does the text say?", "What does the text mean?" and "What is the deeper meaning in the text?" The questions were organized in a matrix. Throughout the repeated readings of the text, there was a dynamic and inner movement between the steps in the matrix or between the parts of the text and the whole. The researchers' pre-understanding was challenged, and the process continued until consensus was reached in the research group.

3.6 | Ethical considerations

The Norwegian Social Science Data Services, reference number 42503, approved the project. A head nurse in the hospice inpatient unit informed the patients about the purpose of the study. She obtained written consent from the participants before the research study started and informed the participants about the principle of voluntariness of participation, the duty of confidentiality, anonymity and the possibility of withdrawal from participation without giving any reason.

The research raised special ethical issues as the patients were weak and at a vulnerable stage in their life. Thus, the ethical principle to do no harm was important throughout the research project. The first writer was particularly concerned with this during the interviews, but also during the participant observations and strove to be sensitive and to remain aware of the patients' conditions. Thus, the researcher asked the patients frequently if they needed breaks, or wanted to finish the interviews, or if they wanted the researcher to leave the room. The researcher also made sure that the staff would follow-up the patients afterwards if the interviews evoked feelings or reactions that they needed to talk about. However, spending time with the participants throughout the participant observations not only entailed a risk of causing harm; it also could potentially strengthen the patients' confidence and thus have a beneficial effect.

4 | RESULTS

The patients told stories about how their bodies changed due to the advanced cancer disease and what the bodily changes meant to them and their surroundings. Telling their stories helped the patients get in touch with their own vulnerability; they could not trust their bodies in the same way as before. The unpredictable bodies threatened the patients' identity and dignity and they became afraid of losing themselves. However, the bodily changes also revealed a strong desire to live and to feel that their bodies still functioned. Four themes emerged from the hermeneutic interpretation:

- The unruly body – a wreckage that rocks the depth of being.
- The body as conveyor of existential truth.
- The life-affirming will discovered in the wrecked body.
- Moving into new and health-inducing rooms in their sick bodies.

4.1 | The unruly body – a wreckage that rocks the depth of being

The patients had to relate to bodies that were no longer a protection or something they could rely on, but rather caused painful feelings and even fear:

> There is nothing I can do with my body. It is a mystery. Things happen that are outside of my control because I am being eaten up inside. My body is like a horror movie. It looks normal, but there is a lot of bubbling and boiling inside of it. (2)

Several participants cried when we asked them how they experienced their altered body. A man described his body like wreck, shit and a bunch of stuff that was impossible to repair.

The voiced fear of annihilation while still alive also emphasized what was really at stake for the patients. A woman described her fear of whether her dignity would disappear someday, while she gradually felt she lost herself and the more disgusting parts of death would take over.

The impossibility of stopping the life-changing conditions that the illness caused reinforced the threat to dignity, while predictability and control have elements of protection that all human beings long for. A man said:

> After the last operation, new tumours pop up faster than the doctors are able to get rid of the former. They lie near the surface and spring up like small mushrooms. (5)

The uncontrollable body also had consequences for how the patients enjoyed social life. They used a lot of strength to try to control a body that was impossible to handle.

However, despite these stories, several participants confirmed that they were not worried that changes in their appearance would be a threat to their identities:

> In the beginning, I felt sad when I looked at myself in the mirror. I don't feel that anymore. I have seen my body too much for that. It is as it is. The important thing for me now is that my body carries me. (10)

Nevertheless, when observing some of the female patients, the contrasts in their appearance struck us and suggested to us that maybe appearance still had some importance for dignity. A woman had beautiful fingers with red nail polish and earrings that gleamed. She had no hair; her skin was pale and her face was quite oedematous without any make-up. She told us how thoroughly she tried to keep her looks and fix what was possible to fix. Another woman said:

> I try to keep my dignity as long as possible. I comb my hair and try to keep my looks and take care of myself… which many probably forget because they think there is no point. It is of great importance to me to take care of myself. (6)

4.2 | The body as conveyor of existential truth

The altered body was no longer able to cover up or ignore problems the way it did when it was healthy. The sick body was rather a guide that showed and let the patients understand, what was at stake, a conveyor of truth.

A woman described the truth that the body represented as a new stability in her life that made her more honest with herself. Others said that their dependency on others forced them to relate to their surroundings and to themselves in a closer and more honest way. They had to relate to their body or vulnerability to a greater extent than earlier because the previous shelter no longer worked. A woman said:

> I think I have become more humble because I feel I am going to die quite soon. I have also become more dependent on others because I am so weak and miserable. I am probably more honest than before. (12)

The bodily changes were also described as an existential journey. One woman described it as discovering new layers of truth in herself. The patients also said that the bodily changes had forced them to reduce their activities and to understand and give priority to what was important in their lives:

> The problems with my legs help me realize that I cannot do everything anymore, but the most important things I can still do. If I didn't have any pain in my legs, I would probably have gone along and never stopped and I would have been too tired afterwards… The bodily changes have helped me calm down and become aware of what is important in life. (13)

However, the body was not only a conveyor of the good but also of the painful truth. Several participants said they had to move out of their house or apartment, or that they were not able to visit their cottage anymore because of the bodily changes:

> I live on the third floor. I have great problems getting up the stairs to my apartment. So I have to move, probably to the opposite side of the district, because there they have some flats that will suit me. (7)

Being forced to move at the end of life might feel quite dramatic and laborious. The home was, for many participants, not just a house, but also a place of belonging, of memories and feelings that made it difficult to leave.

4.3 | The life-affirming will discovered in the wrecked body

Despite the body being at risk of collapsing, the patients showed a great desire, or a life-affirming will, to keep their body constantly moving, keeping it in an upright position to ensure that it still lived and functioned:

> I try to walk because my legs are beginning to fail. I feel that I have to try to keep the strength I have in my legs by walking. (10)

We also observed the importance of movement in patients who exercised, by squeezing small balls several times a day, despite that they had not experienced any effect yet. The patients showed a resoluteness and persistency when they exercised with the physiotherapists. They seemed to move into another mental state and used all their strength and concentration to accomplish the training.

To be active and involved when the prognosis was severe seemed to be important for the patients' experiences of dignity. One woman confirmed this and described the illness as a tango and said she was the man in the dance, leading the tango and the illness was not.

However, the patients also described it as tough to persistently work and uphold a body that just wanted to kneel and rest. Sometimes it was good just to be left alone with no expectations as to what to do.

4.4 | Moving into new and health-inducing rooms in their sick bodies

The patients also told stories about how they tried to take care of their unruly bodies, not only in a physical way but also in a psychosocial or mental way as well. One woman described how she tried to bring light into her life every day. The light was not anything in particular, but a kind of feeling of something good from the past. Another woman mentioned rituals as an example of light and claimed that the regularity, the firmness, but also the goodness of the rituals helped her to remain rooted when the body crumbled away.

The patients were concerned with exploring and moving into new health-inducing rooms in their bodies as ways to endure their difficult life situation and preserve dignity:

> I have started to think that my body is my house and that I still am situated in my body. I try to imagine nice pictures of my body. A house is a good place where you are happy, safe and taken care of. It is a place filled with warmth and love.... I have started painting. I feel that is important for my identity now... By doing this I feel that I have moved into new rooms deeper in my body. (3)

Imagination and painting helped the patient keep the life-affirming force that love represented in her life, which was important for dignity and health. The will and the way the patients opened up for new and health-inducing rooms in their bodies showed that they were responsible and willing to take care of themselves and make the best of a difficult situation to preserve dignity.

5 | DISCUSSION

The initial interpretation of the results disclosed how the patients experienced their wrecked bodies, what the bodies represented and how the patients felt, related and acted to keep themselves and their bodies whole to preserve dignity. The results were further interpreted through a continuing dialogue with the researchers' pre-understanding, the philosophy of the body, the theory of dignity and other research studies. This resulted in three overarching themes that gave a deeper insight into the phenomenon of dignity.

Themes 1–2 from the results showed how the patients, through their sick and wrecked bodies, were shaken to the depth of their being and thus gained the possibility of being in contact with the existential truth, which gave them insight into dignity from a bodily perspective. Thus, themes 1–2 were merged and the new theme that arose was:

- The unruly body – a possible source of a deeper understanding of dignity.
- The life-affirming will discovered in the wrecked body showed a natural force to achieve health and dignity and the theme that emerged from the interpretation was:
- The life-affirming will – a natural force for achieving health and experiencing dignity.

The patients' movement into new and health-inducing rooms in their sick bodies showed how they rediscovered love, deeply rooted in themselves, as a healing power that alleviated suffering and promoted dignity. The theme that arose was:

- Love, as a healing power in the health-inducing rooms, alleviating suffering and promoting dignity.

These themes will be discussed further.

5.1 | The unruly body – a possible source of a deeper understanding of dignity

The sick bodies forced the patients, or at least gave them a possibility, to deal with their bodies in an honest and natural way. It was difficult to cover up or hide the bodily changes from themselves or from their surroundings, as the results reveal. The sick body and the world were in a continuous movement and interaction with each other and this seemed to make the patients relate to their bodies in a deeper and more truthful way.

Sæteren, Lindström, and Nåden (2011) claim that the human being is composed of extreme opposites like finite and infinite, mortal and immortal, freedom and necessity. The authors refer to Kierkegaard (1964), who says that the ethical demand is to become oneself by growing together with oneself. A process of striving for being and becoming a self (Eriksson, 2007) might take place in the interaction or movement between these apparently opposite life experiences that the patients described in our study. The patients' stories about a new stability and honesty in their life might be an example of such a process of becoming.

Understanding dignity through the lens of ambiguity or interaction between suffering and health means that dignity is not a concept of objective explanations, but rather a concept understood in the continuous movement and interaction between the opposite life experiences. The meaning of trying to understand dignity is therefore not to search for well-defined categories, but rather to reflect on what the good ambiguity means to the human being. Bengtsson (2001) refers to Merleau-Ponty (1968), who describes the good ambiguity as the ambiguity that is in continuous interaction and which is not abolished. Human beings are in this good interaction when they touch the world and further reconcile or acknowledge the uncertainty and possibilities that life gives (Gustafsson, Wiklund-Gustin, & Lindström, 2011), the way the patients in our study did. Gadamer (1996) states that we must recognize and accept the fundamental disposition of anxiety in the face of life and equally of death and he describes this as ontological dignity.

5.2 | The life-affirming will – a natural force for achieving health and experiencing dignity

The patients described a great sensibility to the way their bodies functioned. They told several stories about how important it was to them that their bodies still felt alive and worked despite the descriptions of their bodies as wreckage. Active and vital bodies were important for their experiences of health and dignity and they were willing to push their sick bodies more than they otherwise would have done. This is confirmed by Wickström-Grotell (2016) and Wikström-Grotell and Eriksson (2012), who describe bodily movement as an absolute value related to human dignity and as a sign of life. Bodily movement gives a sense of being present and alive and induces trust and hope for the future.

The patients defied both pain and fatigue to feel and confirm that their bodies were alive. The natural will to feel alive was like an inner force (Gadamer, 1996; Nyholm, 2015), which kept the patients going.

This will becomes more visible in borderline situations when the human being senses life's finitude (Nyholm, 2015). However, this will may also be weakened by suffering, as suffering may prevent or make it difficult for people to listen to their inner will. The patients told quite detailed about their changed bodies. This might imply that they were in contact with and familiar with their bodily changes. The body was not a stranger to them anymore. This may be understood as that the patients had reached the level of becoming in Eriksson's ontological health model (Eriksson, 2006), implying that they were reconciled with their difficult life situations.

Thus, the life-affirming will discovered in bodily movement was a positive force for achieving health and experiencing dignity. When the patients lived in harmony with their inner will, they were no longer operated by external circumstances, but were true to themselves.

5.3 | Love as a healing power in the health-inducing rooms, alleviating suffering and promoting dignity

The patients also described their strong will to discover new, health-inducing rooms in their sick bodies as a way to take care of themselves and preserve their dignity. They told several stories about how they filled their life with goodness and love. Love was a healing power that alleviated suffering and could turn life from destruction to strength and hope. The patients experienced love as fundamental to being. They rediscovered the love deeply rooted in themselves and this helped them endure suffering. The love-affirming will gave the patients strength to live. Thorkildsen, Eriksson, and Råholm (2013) confirm that love is above and beyond suffering and can turn life from destruction and coldness to strength and hope. Further, that no human being can exist without love (Thorkildsen et al.., 2013). Love is a precondition for dignity and a burning force that makes the good happen in each individual (Kaldestad, 2018).

It might seem as a paradox that the patients' awareness of their own death made them so aware of how to fill their life with goodness and love. However, other research studies confirm that when patients confront their own death, they awaken existentially. They strive for a wholeness of body, soul and spirit and for becoming a self, which entail experiencing integrity and dignity in life despite bodily changes (Arman & Rehnsfeldt, 2006; Sæteren et al., 2011; Sæteren, Lindström, & Nåden, 2015). Suffering develops the human being's ontological awareness (Thorkildsen et al., 2013).

5.4 | Methodological considerations

The sample consisted of 13 patients from a hospice inpatient unit. Most participants were women. The results may have been different if more men had participated in the study.

Using observations in the collection of data may provide a richer understanding of the field than using only interviews, even if the observations are short. However, as described earlier, it was not ethically defensible to perform longer observations, as this might cause harm. The short observations helped the researcher develop trust among the patients and formulate better questions in the interviews, as the observations gave deeper insight into the patients' experiences of their vulnerable bodies.

The researchers have experiences and knowledge about the subject of the study, the empirical field, the research method and the study's theoretical perspective from previous work as researchers and teachers in nursing education. Thus, the researchers' pre-understanding and the theoretical foundation of the study have consequences for the whole research process, both as to which results were explored and how the results were interpreted. Therefore, it has been important to ensure that the pre-understanding does not cover up, or blinds us to, what emerges throughout the research process (Alvesson & Sköldberg, 2018). We have tried to keep our minds in a persistent uneasiness by constantly asking ourselves what we do not understand. This has helped us to keep our minds open and not conclude too early.

We also found it reasonable to use Gadamer's hermeneutic philosophy to understand the text, even though Merleau-Ponty, who is important for understanding the body, represents a phenomenological tradition. This is because we use Gadamer and Merleau-Ponty on different levels, the former is related to method and the latter is part of the theoretical foundation of the study.

6 | CONCLUSION AND RECOMMENDATIONS

The patients' experiences of their bodily changes gave insight into the phenomenon of dignity. The sick bodies force the patients, or give them the possibility, to deal with their bodies in an honest way when they can no longer cover up or hide the bodily changes, not from themselves, nor from the surroundings. The patients live in an interaction between health and suffering and reconcile, or acknowledge, the possibilities that life gives. This yields insight into dignity as the good ambiguity.

Secondly, the life-affirming will is discovered as a natural force in the wrecked body, a force that helps the patients achieve health and experience dignity. The patients willingly push their bodies and defy both pain and fatigue to feel and show that they are still alive and that their bodies are still able to carry them. Lastly, love is discovered as a healing power in the new and health-inducing rooms that the patients explore in their sick bodies. A love that alleviates suffering and promotes dignity.

Exploring the concept of dignity through the patients' stories about their sick bodies might develop knowledge of dignity from an inner perspective, a knowledge which may comprise some of the intuitive understanding nurses have of dignity and which needs to be verbalized. Since dignity often is threatened when patients are seriously ill, it is important that the nurses do not abolish the interaction between health and suffering, but encourage and strengthen the patients to live in and relate honestly to, both their suffering and health to become themselves and experience dignity. Likewise, it is essential that the nurses help the patients to find their inner resources to manifest themselves and promote dignity, such as the "will for life" and "love as a healing power" discovered in this study.

Dignity is essential in nursing care and more attention needs to be paid to the concept and its articulation in clinical nursing practice and among nursing leadership to provide good, dignified nursing care.

Further research is also required to explore the relationship between the body and the phenomenon of dignity, including the nurses' perspective, as this little attention is paid to this in nursing research today.

ACKNOWLEDGEMENTS

The authors wish to thank the participants in this study for sharing their experiences. This study has not received any funding.

CONFLICTS OF INTEREST

The authors have declared no conflicts of interest.

ORCID

Vibeke Bruun Lorentsen https://orcid.org/0000-0002-8145-886X

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How to cite this article: Bruun Lorentsen V, Nåden D, Sæteren B. The meaning of dignity when the patients' bodies are falling apart. *Nursing Open*. 2019;6:1163–1170. https://doi.org/10.1002/nop2.301

POSTADRESSE:
OsloMet – storbyuniversitetet
Pilestredet 46
Postboks 4, St. Olavs Plass

0130 Oslo

OsloMet Avhandling 2021 nr 4

ISSN 2535-471X
ISBN 978-82-8364-283-4