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The Challenge of Consolation:

A qualitative study of nurses' experiences with practicing and teaching spiritual and existential care for the dying

PhD Thesis

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"It is in the fearful moments of desolation where there is no meaning left that a brave statement of consolation penetrates the darkness and creates new meaning. This happens on the border where nothing is possible anymore."

(Kierkegaard, cited in Norberg, Bergsten and Lundman, 2001 p.545)

Contents

1. Acknowledgments

Løgstrup (1997) notes that while every person is an independent and responsible individual, he also points out that we are inescapably dependent upon each other, and that we belong to a world in which we hold something of one another's life in our hands. Accordingly, although a PhD thesis is an independent piece of research, it would not have been possible without the contributions, support and encouragement from many others, for which I am extremely grateful.

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2. Abstract

Background: In western countries an increasing proportion of older patients with incurable cancer or other chronic conditions will require palliative care. Responding to the fiscal pressure in the Norwegian healthcare system the Norwegian government implemented a major health care reform in 2012. This *"Coordination Reform"* downsized specialized health care units in the secondary health care sector and transferred more palliative care responsibilities to nursing homes and home care nursing in the primary health care sector, which often lack adequate nursing expertise. As a consequence, less qualified care workers as well as registered nurses increasingly have to provide palliative care, which includes the impeccable assessment and treatment of physical, psychosocial, spiritual and existential pain. However, research shows that spiritual and existential care for the dying is frequently overlooked in most care settings and that nurses and other care workers often feel anxious and uncertain about providing spiritual and existential care for dying patients. This indicates that there is a widespread need for spiritual and existential care competency in palliative care. There is a gap in the literature about how nurses may alleviate dying patients' spiritual and existential suffering in their everyday practice. There is also a gap in the literature about how to train nursing staff to provide spiritual and existential care for the dying.

Aim: The overall aim of this PhD thesis is to illuminate the meaning of registered nurses' experiences with practicing and teaching spiritual and existential care for the dying in different Norwegian health care contexts. The aims in studies I, II and III were:

I: *To describe the meaning of hospice nurses' lived experience with alleviating dying patients' spiritual and existential suffering*

II: *To describe registered nurses' experiences with spiritual and existential care for dying patients in a general hospital*

III: *To illuminate a pioneering Norwegian mobile hospice nurse teaching team's experience with teaching and training care workers in spiritual and existential care for the dying in nursing homes and home care settings*

Methods and design: This is a qualitative study. Study I was based on eight individual narrative interviews with hospice nurses. Study II was based on six individual narrative

interviews with registered nurses in a medical-oncological ward in a general hospital. Study III was based on a narrative focus group interview with the three hospice nurses in the mobile teaching team. A phenomenological hermeneutical method was used to analyze the interview texts.

Main results: Spiritual and existential care was about consoling the dying by unburdening them and facilitating a peaceful death. The nurses conveyed consolation by helping their patients to settle practical issues, reconcile themselves with their loved ones and to find peace with God, and by simply being present with their patients to share the suffering. Conveying consolation proved to be a deeply relational practice, which demanded courage and compassion because it exposed the nurses to their own vulnerability, mortality and helplessness. Practical training programs providing experiential learning opportunities through situated bedside teaching may be efficient to develop care workers' courage and competency to provide spiritual and existential care for the dying. However, the results suggest that such programs should also introduce nursing staff to religious perspectives on suffering and religious reasoning, because the results show that the nurses expressed uncertainty about addressing patients' religious needs due to a lack of formal knowledge.

Conclusions: When nothing else can be done, bearing witness and sharing the patients' suffering may be consoling acts in themselves. Nurses and care workers in end-of-life care confront intractable suffering. Hence, they cannot always expect to be successful in their efforts to alleviate it. Therefore, the study results, which indicate that consolation may be conveyed and sustained through presence and relatedness, are extremely important. A less qualified workforce increasingly dominates nursing homes and homecare nursing at a time of increasing prevalence of complex health concerns. Mobile expert nurse teaching teams in spiritual and existential care, (and other nursing fields) may be an effective means to redress the widening gap between work force quality and the demand for high quality care in the primary health sector.

Keywords: consolation, spiritual and existential care, palliative care, health care reform, phenomenological hermeneutical method, narrative interviews, primary and secondary health care sector

3. List of original papers

The thesis is based on the following papers, which will be referred to in the text by their roman numerals:

I. Tornøe, K. A., Danbolt, L. J., Kvigne, K., & Sørlie, V. (2014). The power of consoling presence-hospice nurses' lived experience with spiritual and existential care for the dying. *BMC Nursing, 13*(1), 25.

II. Tornøe, K. A., Danbolt, L. J., Kvigne, K., & Sørlie, V. (2015). The challenge of consolation: nurses' experiences with spiritual and existential care for the dying-a phenomenological hermeneutical study. *BMC Nursing, 14*(1), 62.

III. Tornøe, K., Danbolt, L. J., Kvigne, K., & Sørlie, V. (2015). A mobile hospice nurse teaching team's experience: training care workers in spiritual and existential care for the dying-a qualitative study. *BMC Palliative Care, 14*(1), 43.

4. Introduction

The overall aim of this PhD thesis is to illuminate the meaning of registered nurses' experiences with practicing and teaching spiritual and existential care for the dying in different Norwegian health care contexts.

4.1 Background

In western countries an increasing proportion of patients are older people living with incurable cancer or other chronic conditions that will require palliative care for shorter or longer periods of time (Haug, Danbolt, Kvigne, & Demarinis, 2014, p. 68; Norwegian Directorate of Health, 2015; Seale, 1999). The evidence on death and dying in Western Europe and the USA suggests that a majority of people die in hospitals (Costello, 2006). In line with this trend, Norwegian palliative care has undergone quite dramatic changes during the last thirty-five years. Moving from its idealistic and social hospice origins, Norwegian palliative care has been integrated in the public healthcare system which is well organized within two main sectors: the primary health and long-term care sector (nursing homes and homecare nursing), and the secondary health care sector, involving hospital and specialist services (Romoren, Torjesen, & Landmark, 2011). Specialist palliative care services, including hospices, are organized within the level of secondary health care in somatic hospitals (Bollig, Rosland, & Husby, 2013; Haug et al., 2014; Norwegian Directorate of Health, 2015; Strømskag, 2012).

However, the Norwegian health care system is straining under fiscal pressure, following the international trend of cutting health care costs and downsizing specialized hospital units in secondary health care (Euclid Network, 2012; Norwegian Ministry of Health and Care Services, 2012 ; World Health Organization, 2002). Responding to the economic challenges in the healthcare system, the Norwegian government implemented a major health care reform in 2012: *"The Coordination reform"* (Norwegian Ministry of Health and Care Services, 2012). The aim was to alleviate pressure on the secondary health care sector by upgrading the primary health care sector and by transferring more palliative care responsibilities to nursing homes and home care nursing (Bollig et al., 2013; Norwegian Ministry of Health and Care Services, 2012). Henceforth, nursing

homes and home care settings are becoming the hospices of the future (Abbey, Froggatt, Parker, & Abbey, 2006). As a consequence, less qualified care workers (such as unregulated nursing assistants) as well as registered nurses will increasingly have to provide palliative care in nursing homes and home care nursing (Annear, Lea, & Robinson, 2014; Colombo, Llena-Nozal, Mercier, & Tjadens, 2011; Leclerc et al., 2014). In Norway nearly 50 % of the dying are residents in nursing homes, with underpowered budgets and often lacking adequate expertise (Bollig et al., 2013).

The World Health Organization (World Health Organization, 2002) maintains that palliative care includes the impeccable assessment and treatment of physical, psychosocial and spiritual pain. A growing body of international palliative care research indicates that spiritual and existential care is an integral component of holistic, compassionate care for the dying (Bachner, O'Rourke, & Carmel, 2011; Nolan, 2011; Steinhauser et al., 2000). One of the key goals of palliative care is to alleviate dying patients' suffering (Delgado-Guay et al., 2011). Eric Cassel (1991a) states that although suffering often is related to acute pain or other bodily symptoms, it extends beyond the physical. "Most generally, suffering can be defined as the state of severe distress associated with events that threaten the intactness of person" (Cassell, 1991a, p. 33). Dying patients literally experience a threat to their "intactness of person", and as such are prone to experience suffering. Existential and spiritual suffering are among the most debilitating conditions in dying patients. Henceforth, there is a great need for palliative spiritual and existential care competency in the primary as well as the secondary levels of the Norwegian health care sector (Boston, Bruce, & Schreiber, 2011).

Yet, research reveals that spiritual and existential care is frequently overlooked in palliative care. There is a growing awareness that most care settings fail to provide optimal spiritual care to those with serious illness and those at the end of life (Puchalski et al., 2009). Patients with advanced illnesses report that their medical caregivers infrequently provide spiritual care (Balboni et al., 2013; Sæteren, Lindström, & Nåden, 2011). According to Udo (2014) several studies reveal that many patients are dissatisfied with the emotional and existential support they are given, even if they are satisfied with their medical and physical care. This is supported by Groenvold, Pedersen, Jensen, Faber, and Johnsen (2006) who found that a significant number of dying patients

long for adequate spiritual or existential care and counseling. In spite of this, seriously ill patients often refrain from discussing their spiritual and existential thoughts with nurses because they do not feel that nurses acknowledge this need (Udo, 2014). Research shows that registered nurses and care workers often feel inadequately prepared to provide spiritual and existential care for the dying, and that this makes them anxious and uncertain (Christensen, 2008; McSherry & Jamieson, 2013; Noble & Jones, 2010; Pesut, Fowler, Taylor, Reimer-Kirkham, & Sawatzky, 2008; Udo, 2014). Several studies indicate that a lack of skills in psychosocial and spiritual care may result in high levels of moral distress, grief and burnout (Back, Bauer-Wu, Rushton, & Halifax, 2009; Bosma, Apland, & Kazanjian, 2010; Noble & Jones, 2010; Rushton et al., 2009; Vivat, 2008). Studies also indicate that there is a widespread need for training in all aspects of spiritual and existential care for the dying (Balboni et al., 2013; Holloway, Adamson, McSherry, & Swinton, 2011). According to the literature, nurses' and care workers' discomfort related to providing spiritual and existential care for the dying may lead to unmet spiritual and existential needs possibly leading to increased patient suffering (Back et al., 2009; Bosma et al., 2010; Noble & Jones, 2010; Rushton et al., 2009; Vivat, 2008).

There is a gap in the research literature about how patients' existential wellbeing may be best supported by nurses and other health care providers in everyday practice (Henoch & Danielson, 2009). In 2014 Pesut et al. conducted a scoping review to summarize the available evidence concerning palliative care education for nurses and other nursing care providers (Pesut et al., 2014). None of the references in their review explicitly mentioned training care workers in spiritual and existential care for the dying. This suggests that there is a gap in the literature concerning this issue. This thesis, which is an empirical study of registered nurses' experiences with practicing and teaching spiritual and existential care for the dying, will hopefully contribute to bridge these important gaps.

Nursing research in spiritual care has until recently been dominated by Anglo-American studies. Although this research yields valuable insights, it cannot be directly applied to Scandinavian contexts, due to the differences in spiritual and religious climates in these societies (Lundmark, 2006). On the grounds of different surveys Sørensen (2012) notes

that religion is a more pervasive and diverse phenomenon in the USA, than in the Scandinavian countries where large numbers of the population belong to the protestant/Lutheran majority churches. (Sørensen, 2012), In Norway approximately 73 % of the population belong to the Church of Norway (Statistisk Sentralbyrå (Central Bureau of Statistics in Norway), 2015). However, in spite of the large church membership, Scandinavian societies are quite secularized and religious and spiritual thoughts and practices are largely regarded as private matters. However, this does not mean that the majority has turned away or is hostile to religion (DeMarinis, 2008; la Cour, 2008; la Cour & Hvidt, 2010). Although the interest in traditional religion is declining, Norway is gradually becoming a more multicultural and religiously diverse society (Ulland & DeMarinis, 2014), and a growing number of Scandinavians consider themselves to be "spiritual but not religious". Dismissing dogmatic truths, their religiosity and religious participation is mainly rooted in emotions and human experience, as a means to search for and express "authentic self-hood" (Botvar & Schmidt, 2010; DeMarinis, 2008). This form for spirituality or "worldview construction" is related to "existential meaning making", which may or may not include a transcendent dimension (DeMarinis, 2008; Schnell, 2009, 2010; Schnell & Keenan, 2011).

Despite the "privatized attitudes" towards religion and spirituality in the Scandinavian countries, recent years have yielded a growing number of Scandinavian nursing studies in spiritual and existential care (Ilkjær, 2012; Sæteren et al., 2011; Torskenæs & Kalfoss, 2013; Torskenæs, Kalfoss, & Sæteren, 2015; Ødbehr, 2015) which draw on the emerging body of research within the field of psychology of religion, spirituality and health (Haug, 2015; Koenig, King, & Carson, 2012; Masters & Hooker, 2013; Sørensen, 2012; Sørensen, Lien, Landheim, & Danbolt, 2015). This PhD. thesis is to be viewed as a Norwegian contribution to the emerging field of Scandinavian nursing research in spiritual and existential care.

4.1.1 Conceptual clarifications

Spirituality is an international term which is used by nurse academics (Narayanasamy, 2014; Paley, 2008; Pesut, 2008b; Swinton & Pattison, 2010) as well as by academics in other fields such as practical theology (Bueckert & Schipani, 2006; Swinton & Mowat,

2006) and in psychology of religion (Koenig et al., 2012; Paloutzian & Park, 2013). However, Northern European and Scandinavian contexts tend to be more familiar with terms such as *view of life, worldview, religion, meaning-making, existentiality* and *existential questions* (Stifoss-Hanssen, 1999; Stifoss-Hanssen & Kallenberg, 1998; Ulland & DeMarinis, 2014). (See for example Karlsson, Friberg, Wallengren and Öhlén's (2014) and Strang, Henoch, Danielson, Browall and Melin - Johansson's (2014) Swedish studies about dying patients' existential issues.) Accordingly, "it is not to be assumed that Norwegians use the term spirituality in clinical practice" (Ulland & DeMarinis, 2014, p. 4). Taking this into account, the nurses in this study were asked to narrate about their experiences with practicing and teaching spiritual and existential care in order to capture as much in-depth data as possible. In light of Ulland and DeMarinis (2014) it is interesting to note that the nurses did not discern between spiritual and existential care during the interviews. Considering the nurses' use of the terms, and the fact that these terms often are used synonymously in the nursing literature, (Boston et al., 2011; Boston & Mount, 2006; Henoch & Danielson, 2009) the term "spiritual and existential care" will be used throughout this thesis. However, it is important to note that the use of these terms vary in the literature, which is cited. For the sake of academic rigour the researchers' use of the terms will be quoted. (Swinton and Pattison (2010) for instance use only the terms "spirituality", and "spiritual care".)

4.2 Spiritual and existential care: The study's theoretical position

Spirituality is a highly debated concept due to the many variations which emerge from the nursing literature (Paley, 2008; Pesut, 2008a). Several researchers point out that since there seems to be no single agreed definition in the nursing literature, the term" spiritual care" is open to interpretation (Kalish, 2012; Noble & Jones, 2010; Pesut et al., 2008; Reimer-Kirkham, 2009; Swinton & Pattison, 2010). It is therefore important to clarify this study's theoretical standpoint.

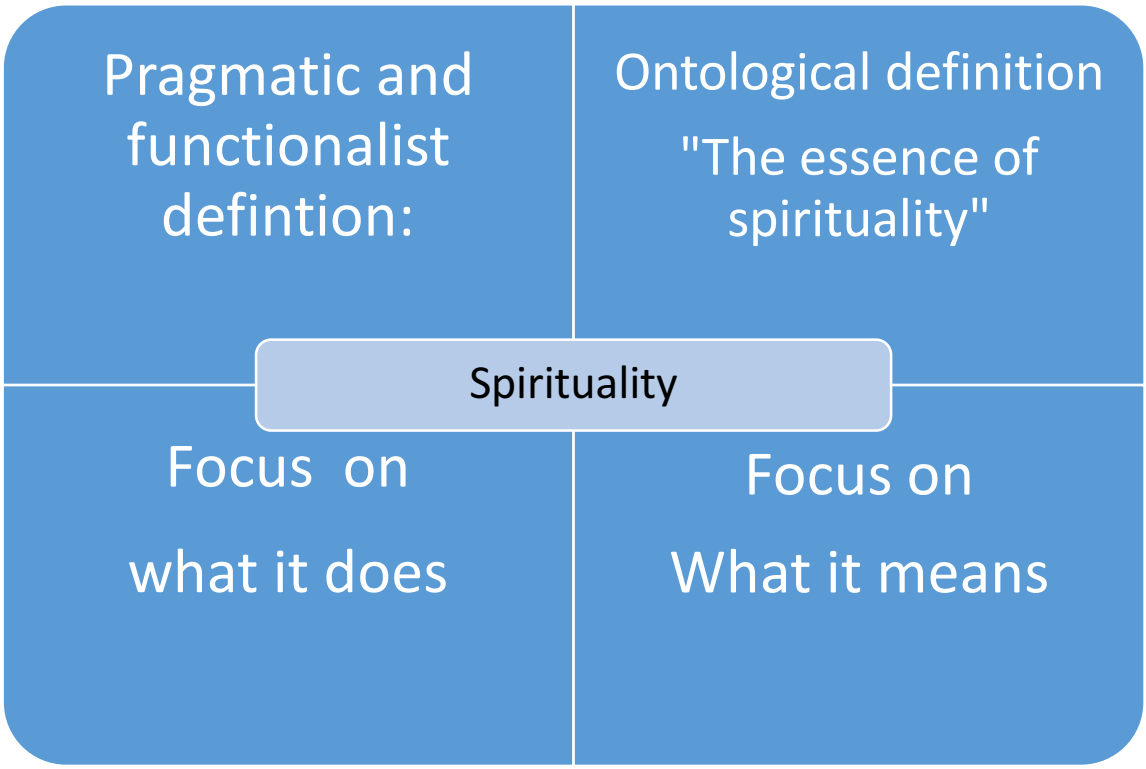
My preunderstanding of spiritual and existential care is shaped by several years of experience as a registered nurse, caring for dying patients in cancer wards and nursing homes, my background as an ordained deacon in the Norwegian Lutheran Church, a

master's degree in theology, (with a thesis on spiritual and existential end-of-life care based on narrative theology) and my book about spiritual and existential care for the dying, based on my master's thesis (Tornøe, 1996). As a nurse educator and researcher, I find that Swinton and Pattison's (2010) pragmatic and functional understanding of spirituality in nursing care resonates with my own viewpoints which have evolved through my own spiritual and existential care experiences in end-of-life care and my educational background. I have therefore chosen to ground this study in their understanding of spirituality because it fits the study's aim which is to illuminate the meaning of registered nurses' experiences with practicing and teaching spiritual and existential care, rather than clarifying the ontological and conceptual questions about how to define spiritual and existential care in the research literature (Reimer-Kirkham, 2009). This will be elaborated in the following:

While Paley (2008) argues that the wide range of spirituality definitions renders the concept meaningless and insignificant, Swinton and Pattison (2010) claim that the concept's strength lays in its vagueness, and that it cannot be dismissed just because it does not fit with a strict empiricist view of reality. While hard positivists may argue that concepts in language which do not correspond with events or things in the material world should not be attended to, Swinton and Pattison (2010) state that not all concepts are simply referential and they still accord value within the social world. Drawing on Wittgenstein, they (2010) point out that words are performative and expressive as well as referential. Accordingly, words are not essentialist in their meaning. Rather than deliberating over the lexicographical meanings of spirituality, they advocate that it is more useful to develop "a thin, vague and functional understanding of what this word and its cognates might do in the world of health care". (Swinton & Pattison, 2010, p. 227)

Henceforth, they make it clear that defining spirituality for health care purposes is not the same as claiming any direct ontological status (Swinton & Pattison, 2010). According to Swinton (2014), any definition of spirituality in healthcare is a pragmatic, rather than an ontologic description, which means that the focus is on what the concept "<u>does</u>" (in terms of its effect on health care practice), rather than what it "<u>is</u>" (in terms of essential definitions). This is illustrated in figure 1.

Figure 1: Spirituality in Nursing: Two major theoretical positions (Swinton, 2014; Swinton & Pattison, 2010)



Swinton and Pattison (2010) argue that spirituality, like any other concept has always been and inevitably will be a social construction. But that is not to say that it is nothing but a social construct. While spirituality may well have an ontology it is clear that it has been interpreted in various ways and that the contexts where these interpretative actions take place are significant. Swinton and Pattison (2010) point out that spirituality is constructed in different ways by various religious traditions, spiritual movements, belief systems, cultures and context, and not least by particular individuals in specific circumstances. Accordingly, the meaning of spirituality is necessarily emergent and dialectical; it is shaped and formed by the context within which spiritual language is expressed (Swinton & Pattison, 2010). Since life, death and illness is messy and chaotic, it is unreasonable to expect that practices and concepts associated with the emergent term of spirituality will be consistent, coherent and universally valid. Rather, the value of the languages that deploy spirituality and its practical and theoretical values lay in their contingent, evolutionary and contextual usage (Swinton & Pattison, 2010). Furthermore, Swinton and Pattison (2010) note that many of the key terms that are used within health care (including health care itself!) are similarly emergent,

constructed and changing. The terms “community”, “care”, “love” and “friendship” for instance, are equally vague, contested and multi- or polyvalent, as spirituality but nonetheless important and necessary. Thus, there is no inherent reason why a lack of clarity should denote a lack of significance. Rather, multiple definitions may be indicative of the necessity and the flexibility of the term to meet particular needs that would otherwise go unmet (Swinton & Pattison, 2010). As Swinton (2014, p. 163) points out: “Spirituality is unabashedly a fluid and deeply pragmatic concept that shifts and changes according to the context with which it is constructed and the needs it is attempting to meet.”

According to Swinton and Pattison (2010), in a western secularized health care system an emphasis on spirituality attempts to capture something of the phenomenology of illness (the lived experience of being ill) which has been underplayed by highly medicalized modes of healthcare strategy and delivery. Spirituality in a highly secularized healthcare context seeks to recapture those dimensions of the human person that were once expressed in religious language and that are not captured effectively by biomedical discourse, such as “the importance of meaning, purpose, hope, love, God and relatedness” (Swinton & Pattison, 2010, p. 232). Swinton and Pattison (2010) point out that such issues often come to vital prominence during the experience of being ill. According to them (2010), spiritual care cannot be understood as a single task, or even a discrete series of tasks. Rather, it denotes the multifarious, disparate and pluriform skills and perspectives that nurses and care workers need to learn in order to cater well for certain aspects of the experience of illness as it is lived out within particular health care contexts.

Swinton and Pattison (2010) note that the term spirituality and the discourse that surrounds it, can at its best, function as a sensitizing concept that draws our attention to such issues as meaning, purpose, relationality, hope, value, love, God and transcendence, areas, which well may be overlooked in health care, without this sensitizing function. According to them (2010), spirituality is not perceivable as a single thing, but rather as a response to a variety of human quests, which often are activated in times of illness and duress. Thus, if one aspect of functional spirituality is the human search for meaning, then carers will need to develop approaches and methods which enable them to deal

with the existential quests of people in times of illness. If spirituality denotes a quest for hope, the desire for relationships or the construction of purpose, various approaches and techniques will be required to enable nurses to care well for this aspect of people's lived experience of illness. If spirituality is a search for God and the transcendent, then facilitating that quest requires a particular set of skills and knowledge of religious traditions, theology, religious practices or at least an ability to recognize the need and to refer to appropriate persons (Swinton & Pattison, 2010).

For the purpose of this study, Swinton and Pattison's (2010, p. 229) three most important points are:

1. In times of illness, what might loosely be called spiritual, meaning, identity and purpose issues may come to the fore, even when religion and spirituality formally defined have not previously been of significance for the patient. "It is in such situations in the 'everydayness' of their lives that people are most likely to think about 'spiritual' issues or to have 'spiritual needs' however inchoate or ill-articulated". (Swinton & Pattison, 2010, p. 229)

2. It seems to be the case that ordinary people, patients, carers and professional healthcare workers seem to find the language of spirituality to be functional, helpful and meaningful especially during times of illness and duress (WHO, 1998), despite the lack of clear definitions of what spirituality might mean in referential terms. There is evidence to suggest that the voices, habits and perceptions of ordinary people should be closely attended to in any aspect of health care, and especially when it appears to relate closely to issues of purpose, identity and the self, as the language of spirituality often does.

3. If ill people and their carers are using the concept of spirituality - "and using it with earnestness and serious intent, *prima facie,* their views should be taken seriously by academics and health care providers". (Swinton & Pattison, 2010, p. 229) (However, as noted in section 4.1.1, it is important to be aware that in Northern European and Scandinavian contexts, patients and nurses tend to be more familiar with terms such

as *view of life, worldview, religion, meaning-making, existentiality* and *existential questions*.)

In line with Swinton and Pattison (2010), the objective of this study is not to question the validity of the nurses' language or definitions of spirituality but to listen to them in order to explore the meaning of their lived experiences with practicing and teaching spiritual and existential care.

4.3 Why research lived experience?

Over many years the scientific method has become the most important means of generating evidence about the world and human society, and considerable effort has been devoted to implement evidence based practice in nursing (EBP) (Avis & Freshwater, 2006). However, Benner (2000a), drawing on Merlau-Ponty (1962) points out that scientific language which omits our embodied experience of illness, recovery and health also leaves out perceptual capacities that enable reasoning and acting as moral agents in particular lifeworlds. Solvoll and Lindseth (2015) note that phenomenologically speaking, we understand "experiences" as a series of significant events that constitute the world and a bodily self. The body and awareness find their places in this flow rather than preceding it. According to Solvoll and Lindseth (2015) practitioners' professional knowledge can be "observed" through their narratives about their experiences. While each narrative is unique, in the sense that it is based on the practitioner's personal experience, one practitioner's experience may be representative of other practitioners who work in the same field of care. Accordingly, gleaning knowledge from one example may be a form of analogical reasoning, which can be transferable and thus contribute to significant learning for other practitioners. Therefore, exploring nurses' lived experience with practicing and teaching spiritual and existential care may be a useful means to uncover essential embodied, tacit and practical knowledge, which may be transferable and useful for others in end-of life care (Aadland, 1997).

5. The aim of the study

The overall aim of this PhD thesis is to illuminate the meaning of registered nurses' experiences with practicing and teaching spiritual and existential care for dying patients in different Norwegian health care contexts.

5.1 The specific aims

Paper I: To describe the meaning of hospice nurses' lived experience with alleviating dying patients spiritual and existential suffering

Paper II: To describe registered nurses' experiences with spiritual and existential care for dying patients in a general hospital

Paper III: To illuminate a pioneering Norwegian mobile hospice nurse teaching team's experience with teaching and training care workers in spiritual and existential care for the dying in nursing homes and home care settings

5.2 The research questions

Paper I: What are the hospice nurses' experiences with alleviating dying patients' spiritual and existential suffering?

Paper II: What are the registered nurses' experiences with alleviating dying patients' spiritual and existential suffering?

Paper III: What are the mobile hospice nurse teaching team's experiences with teaching and training care workers in homecare and nursing homes in spiritual and existential care for the dying?

6. Methodological Framework Phenomenological Hermeneutics

While *methodology* has to do with the overall approach to a particular research field, implying a family of methods that share particular philosophical and epistemological assumptions, *methods* are specific techniques that are used for data collection and analysis. Henceforth, the choice of techniques (- or methods) used in a study, must be consistent with its methodological framework (Swinton & Mowat, 2006). The study's methodological framework will now be presented.

The overall aim of this study is to illuminate the meaning of nurses' experiences with practicing and teaching spiritual and existential care for dying patients in different Norwegian healthcare contexts. This determined the choice to anchor the study in the tradition of *phenomenological hermeneutics* (Gadamer, 2004; Heidegger, 1962; Ricoeur, 1976, 1981, 1984, 1992, 2008) with special emphasis on Ricoeur's (1976) interpretation theory. Following Ricoeur's (1976) line of thought, one person's experience cannot directly become another's:

> An event belonging to one stream of consciousness cannot be transferred as such into another stream of consciousness. Yet, nevertheless, something passes from me to you. This something is not the experience as experienced, but its meaning. Here is the miracle. The experience as experienced as lived, remains private but its sense, its meaning becomes public. (Ricoeur, 1976, pp. 15-16)

Drawing on Ricoeur, the overall aim of this study is to interpret and "make public" the meaning of the nurses' spiritual and existential care experiences.

Phenomenological hermeneutics, being the process of interpreting and describing human experience to understand the meaning of that experience is well positioned as a suitable methodology for human science research. It is not a research method as such, but rather both a theoretical perspective and methodology that lies behind the methods employed in a particular study (Tan, Wilson, & Olver, 2009; Van Manen, 2014). Increasingly phenomenological hermeneutics is the philosophical underpinning of choice in qualitative healthcare research and is frequently used in nursing research

(Lindseth & Norberg, 2004; Sørlie, 2001; Tan et al., 2009; Torjuul, 2009; Ødbehr, Kvigne, Hauge, & Danbolt, 2014).

The tradition of phenomenological hermeneutics will now be outlined, drawing on the works of Husserl, Heidegger, Gadamer and Ricoeur. This will be followed by an explanation of how Ricoeur's (1976) phenomenological hermeneutical interpretation theory informed and guided the choice of methods that were used in the study.

6.1 Edmund Husserl

Edmund Husserl (1859 -1938) is generally regarded as the intellectual founder of phenomenological philosophy (Van Manen, 1990, 2014). According to Porter and Robinson (2011) Husserl's philosophical research is not hermeneutics. It is not even hermeneutically inclined in its methodology because he avoids taking an "interpretive" stance in many respects, focusing instead on things (phenomena) and our consciousness or experience of them. Nonetheless, Husserl's phenomenology is of invaluable significance for hermeneutics indirectly, and for the development of "phenomenological hermeneutics" directly. His influence is particularly pronounced in the hermeneutical developments of Martin Heidegger (1889 -1976), Hans-Georg Gadamer (1900-2002) and Paul Ricoeur (1913-2005), all of whom have taken up and expanded their own form of phenomenology (Porter & Robinson, 2011). Henceforth, this outline of phenomenological hermeneutical thought will begin with a brief description of Husserlian phenomenology.

For Husserl phenomenology is a discipline that endeavors to describe how the world is constituted and experienced through conscious acts (Van Manen, 1990). Husserl's phrase "Zu den Sachen" (back to the things) has become a watchword in phenomenology (Van Manen, 2014, p. 92). Generally, "to the things" seem to mean "to the issues that matter". Husserl defines phenomenology as a descriptive philosophy of the essences of pure experiences. He aims to capture experiences in its primordial origin without interpreting, explaining or theorizing. For Husserl, the essences which phenomenology concerns itself with are "*Erlebniswesen"*, essences of lived experiences. Only knowledge that is derived from immediate experiential evidence can be accepted

(Van Manen, 2014, p. 89). In his last and posthumously published text "*The crisis of European Sciences and Transcendental Phenomenology"* (Husserl, 1970), cited in Van Manen (1990, p. 182), Husserl developed the idea of *the life world* and described it as "already there", "pregiven", the world as experienced in the "natural primordial attitude" that of "original natural life" (Husserl, 1970, pp. 103 - 186) cited in Van Manen (1990, p. 182). Husserl reserved the notion of the *"natural attitude*" to the "taken-for-grantedness" of everyday thinking and acting (Van Manen, 2014). This "natural attitude" manifests itself in our natural inclination to believe that the world exists out there, independent of our personal existence. Husserlian phenomenology does not deny the external existence of the world. But it emphasizes the importance of being able to shift from "a natural to a phenomenological attitude" in order to perceive things as they give themselves in lived through experience – not as externally real or eternally existent, but as an openness that invites us to see them as if for the first time (Van Manen, 2014).

In order to shift from a natural to a phenomenological attitude, Husserl proposes two main methods (Porter & Robinson, 2011, p. 54). Husserl's first method, the *epoché reduction* is the attempt to describe phenomena as immediately apparent in experience. This reduction involves *bracketing* or suspending one's subjective or private feelings, preferences, inclinations, or expectations that would prevent one from coming to terms with a phenomenon or experience as it is lived through (Porter & Robinson, 2011, pp. 54-55). In addition, one also needs to strip away the theories or scientific conceptions and thematizations that overlay the phenomenon one wishes to study, and which prevents one from seeing the phenomenon in a non-abstracting manner (Van Manen, 1990, p. 185).

Husserl's second method is called the *eidetic reduction* (Porter & Robinson, 2011). In the eidetic reduction one needs to see past or through the particularity of lived experience towards the universal essence or *eidos* that lies on the other side of the concreteness of lived meaning (Van Manen, 1990,p.185). The bracketing procedure is often referred to as the *transcendental reduction*. It is what makes the eidetic reduction possible. However, the epoché reduction is not meant to reduce something to its basic or most fundamental principles but to allow access to the phenomenon in the least prejudiced or corrupted way (Porter & Robinson, 2011, pp. 54-55).

6.2 Martin Heidegger

Husserl had hoped for a continuation of his philosophy through his former assistant and successor, Martin Heidegger (Porter & Robinson, 2011). However, Heidegger made a decisive break with Husserl's transcendental phenomenology through his first major work *"Being and Time"* (Heidegger, 1962). The key points in Heidegger's phenomenology will now be outlined, based on Porter and Robinson's (2011) work. In contrast to Husserl, Heidegger is not interested in the structures of consciousness, essences or even knowledge *per se*, but in an investigation into the meaning of being, (*"Dasein")*. Heidegger claims that phenomenology cannot merely investigate pure consciousness but must take into account the totality of the human situation, due to the fact that we are, each and every one of us, already "being-in the world".

With Heidegger phenomenology becomes a radically interpretive enterprise. He claims that human existence has a hermeneutical structure which underlies all our interpretations including those of the ontic or natural sciences; that is, both scientific and cultural knowledge must be derived from the structure of being (Porter & Robinson, 2011). Accordingly, there is no neutral or unbiased starting place from which one may begin to understand. We are thrown into a world in which language, culture and institutions of life already are given. So no matter where or when we find ourselves, we will always be conditioned by our own historical situatedness. Henceforth, Heidegger argues that we cannot possibly bracket the world in order to understand our selves and that judgment about actually existent things cannot be suspended. Heidegger states that the meaning of things is known in the context of our relationships to them within the world. He argues that we understand life from out of life itself. Understanding begins with our situatedness as *being-in-the world*. Through hermeneutics we are making understanding explicit and disclosing the nature of being, - or Dasein to ourselves. However, Heidegger points out that understanding may never be self-evident as if it were corresponding to facts in the world, for Dasein has no single object or fact to first comprehend. Instead understanding is inherently circular or hermeneutical (Porter & Robinson, 2011).

Heidegger's *hermeneutical circle* is best characterized in terms of *preunderstanding* and *temporality* (Porter & Robinson, 2011). Structures of understanding involve a fore-structure that constantly projects upon that which is already understood and evident. It is an anticipatory structure or preliminary awareness of meaning. As historical beings, we have anticipations and expectations of the future and its possibilities as well as conditioned understanding from previous understanding. Hence, all existence is interpretive and all meaning takes place within a context of interpretation mediated by culture and language. What remains in interpretation is to work out "the things themselves" instead of allowing our pre-understanding to be guided by mistaken assumptions and illusions (Porter & Robinson, 2011, p. 68). Even so this working out is not a technique or method meant to achieve understanding. Rather, it is meant as a description of how understanding emerges as we constantly respond to our fore-projection and prejudgments. Understanding happens prior to our reflection because we are already participating, and therefore understanding, from a specific orientation and awareness about our situation and context (Porter & Robinson, 2011).

Accordingly, for Heidegger, Dasein is an event, an occurrence wherein understanding is "to be" in the world which is always to be understood interpretively. Heidegger's existential and phenomenological analysis redefines what it means to understand (Porter & Robinson, 2011). What is needed Heidegger proposes, is an existential analysis that inquires into the meaning of "to be" that is present to us, yet remains to be drawn out. This meaning will only be disclosed when we stop attempting to grasp essences, facts and abstractions and begin to live life without trying to manipulate it. Knowledge in the scientific sense may only be supplemental to our distinct way of existence. Heidegger's analysis rests upon a distinction between the ontological and the ontic. The ontic or ontical is the factual world understood by the sciences, such as chemistry and biology. While Dasein has ontic qualities, as an animal in the factual world, "Dasein" (he, she we) is also unique, for Dasein alone is concerned with the question of being and what it means, "to be". None of the other animals inhabiting the earth are concerned with the meaning of being. For Heidegger the question of being represents our decision to let the question be a question for us. It is a turn or a decision, an event of recognizing a wedge between being and being – an ontic- ontological difference. We are the beings who ask the questions of who we are. We alone are able to

interrogate the nature of what it means to be. Heidegger's ontological phenomenology can be characterized as a hermeneutics of life or what he calls "hermeneutics of facticity". Hermeneutics in this sense is an interpretation of the conditions and circumstances that determine or limit one's possibilities of being-in-the-world (Porter & Robinson, 2011).

6.3 Hans-Georg Gadamer

Hans-Georg Gadamer is one of the foremost representatives of hermeneutical phenomenology (Van Manen, 2014). As a former student of Heidegger, Hans-Georg Gadamer shares his notion that all understanding is hermeneutic and that the hermeneutic function is actually our basic mode of being-in- the world (Porter & Robinson, 2011). The task of hermeneutics, according to Hans-Georg Gadamer, is to clarify the conditions in which understanding and interpretation take place (Gadamer, 2004).

The historical strands of Friedrich Schleiermacher (1768-1834) and Wilhelm Dilthey's (1833 -1911) pioneering hermeneutics, the phenomenological description of Edmund Husserl (1859 – 1938) and the ontological analysis of Martin Heidegger (1889 -1976) all come together in Gadamer's seminal work *"Wahrheit und Methode: Gründzüge einer philosophischen Hermeneutik"* (1960) translated to the English version as *"Truth and Method"* in 1975 (Porter & Robinson, 2011).

In this magnum opus Gadamer (2004) explicates in a phenomenological manner, the hermeneutic method as it had been originally developed by Friedrich Schleiermacher and subsequently by Wilhelm Dilthey and Heidegger himself (Van Manen, 2014). Schleiermacher applied hermeneutics to the interpretation of texts, and emphasized the importance of considering the historical temporality and rationality of the text. For Schleiermacher, hermeneutics deals with reconstructing the past (Van Manen, 2014).

While Gadamer (2004) agreed about the necessity of approaching texts with openness and sensitivity to their historical traditions and interpretive horizons, he also argued that it was impossible to place oneself in the original reconstructed historical context.

In contrast to Schleiermacher's search for the authorial intent of a text, Gadamer argues that ancient texts must be interpreted in the context of one's own social historical existence (van Manen 2014). According to Gadamer (2004) there exists:

> an insuperable difference between the interpreter and the author that is created by historical distance …..The real meaning of a text, as it speaks to the interpreter, does not depend on the contingencies of the author and his original audience. It certainly is not identical with them, for it is always co-determined also by the historical situation of the interpreter, and hence by the totality of the objective course of history. (Gadamer, 2004, p. 296)

For Gadamer (2004), hermeneutic understanding is achieved through a circular interpretation process, where one moves back and forth between the text as a whole and its individual parts. As such, construing the meaning of the whole involves making sense of the parts and grasping the meaning of the parts is dependent on having some sense of the whole: "Thus the movement of understanding is constantly from the whole to the part and back to the whole. Our task is to expand the unity of the understood meaning centrifugally". (Gadamer, 2004, p. 291)

Gadamer emphasizes that the hermeneutic circle is not a "methodological circle", rather it describes an element of the ontological structure of understanding (Gadamer, 2004, p. 294). The basic model of understanding that Gadamer finally arrives at in 1960 in "*Truth and Method"* (Gadamer, 2004), is conversation and dialogue (Malpas, 2015). Conversation always takes place in language and similarly Gadamer views understanding as always linguistically mediated. For Gadamer, understanding is a matter of negotiation between oneself and one's partner in a hermeneutical dialogue. Henceforth, the process of understanding can be seen as a matter of coming to an "agreement" about the matter at hand. For Gadamer (2004), interpretation and understanding always occur from within a particular "horizon" that is determined by our historically determined situatedness. Accordingly, coming to an agreement, means establishing a common framework or "horizon". Gadamer thus takes understanding to be a process that involves a "fusion of both party's horizons" or "*horizontverschmelzung"* (Malpas, 2015).

Inasmuch as understanding is taken to involve a "fusion of "horizons" it also involves the formation of a new context of meaning that enables integration of what is otherwise unfamiliar, strange or anomalous. In this respect all understanding involves a process of mediation and dialogue between what is familiar and what is alien, in which neither remains unaffected (Malpas, 2015). Gadamer (2004) points out that in the dialogue of understanding our prejudices come to the fore. He claims that our prejudices play a crucial role in opening up what is to be understood, inasmuch as they themselves become evident in that process. As our prejudices thereby become apparent to us, they can also become the focus of questioning in their own return:

> The essence of the question is to open up possibilities and keep them open…. In fact, our own prejudice is properly brought into play by being put at risk. Only by being given full play is it able to experience the other's claim to truth and make it possible for him to have full play himself. (Gadamer, 2004, pp. 298-299)

Not surprisingly, one of Gadamer's (2004) most controversial moves is his defense of the importance of prejudice in interpretation. For Gadamer, understanding requires presuppositions and assumptions that enable understanding as well as misunderstanding (Porter & Robinson, 2011). Gadamer (2004) maintains that we always bring our finite and historically conditioned awareness with us when we encounter something. This means that we must allow our traditions and long held assumptions to be challenged and tested. There may be no new experience and understanding otherwise. Authentic experience shakes us awake and opens our eyes to the new and unexpected, that which lies beyond our personal horizon. Gadamer (2004) points out that within every understanding, truth is partially relative to the interpreter's own horizon though never entirely consumed by it. Just like our living relationship to the truth of a text, our whole experience of life reflects the same universal hermeneutical dynamics. Gadamer's (2004) description of hermeneutics in terms of what it means to understand is not only a matter of how we know classical and philosophical texts, works of art and the like. Rather, Gadamerian hermeneutics is a way of disclosing what it means to have an experience of understanding universally (Porter & Robinson, 2011).

6.4 Paul Ricoeur

Paul Ricoeur more than any other, cemented the connection and mutual affinity between hermeneutics and phenomenology (Ricoeur, 1981, 2008; Tan et al., 2009). In his landmark essay *"Phenomenology and hermeneutics",* Ricoeur (1981) confronts the question of what remains of Edward Husserl's phenomenological program in the wake of Heidegger and Gadamer's devastating critique of phenomenology. In line with the hermeneutics of Heidegger and Gadamer, Ricoeur discusses our embeddedness in the world of language and social relationships and the inescapable historicity of all understanding (Finlay, 2012; Ricoeur, 1981). Ricoeur convincingly demonstrates that what succumbs to the hermeneutical critique is not phenomenology as such, but rather phenomenology in its most idealistic Husserlian form (Ricoeur, 1981).

While Husserl argued that phenomenology consists of describing what appears in consciousness, Ricoeur (1981, p. 137) shows that according to Husserl's own accounts, whatever appears in consciousness is already the work of the constituting ego. And in this constitution process, the interpretive is already at work (Van Manen, 2014). Ricoeur (1981) points out that beyond the simple opposition between phenomenology and hermeneutics there exists a mutual belonging between them. On the one hand, hermeneutics is erected on the basis of phenomenology, and thus preserves something of the philosophy from which it differs. On the other hand, phenomenology cannot constitute itself without a hermeneutical presupposition:

> … beyond the critique of Husserlian idealism, phenomenology remains the unsurpassable presupposition of hermeneutics; and on the other hand, that phenomenology cannot carry out its programme of constitution without constituting itself in the interpretation of the experience of the ego. (Ricoeur, 1981, p. 114)

This brings us to the main tenets of Ricoeur's (1976) phenomenological hermeneutical interpretation theory, which have informed and guided this thesis. For Ricoeur (1976), interpretation is the hinge between language and lived experience (Geanellos, 2000). In his famous interpretation theory, Ricoeur attempted to graft the hermeneutical problem of interpretation to contemporary insights in phenomenology (Ricoeur, 1999).

6.4.1 Text understood as human action

Although Ricoeur (1976) originally formulated his interpretation theory with respect to texts, he also points out that human action can be understood as discourse and interpreted as text, when it has been objectified and fixated through writing. Accordingly, his interpretation theory can be extended into the sphere of the social sciences (Ricoeur, 1981). In light of this, Ricoeur's (1976) interpretation theory is applicable to interpret nurses' narratives about their experiences with spiritual and existential care. This will be elaborated on in the methods section.

6.4.2 Distanciation and appropriation

Writing renders the text autonomous with respect to the author's intention. When spoken discourse is written down, (i.e. like the research interviews in this study), the fixated discourse and its meaning becomes distanced from the speech event. Through this distanciation, the text becomes "decontextualized" from the speech event and its social and historical conditions, thus opening itself up to an unlimited series of readings (Ricoeur, 1976, 1981, 2008). Distanciation creates a need to recontextualize and *appropriate* the text, - to familiarize ourselves with the text and make it our own (Ricoeur, 1976). Ricoeur (1976, p. 43) points out that:

> reading is the *pharmakon* the "remedy" by which the meaning of the text is "rescued" from the estrangement of distanciation and put in a new proximity, a proximity which suppresses and preserves the cultural distance and includes the otherness within the owness.

Accordingly, there exists a dialectic relationship between distanciation and appropriation in the interpretation process: "To make one's own what was previously foreign remains the ultimate aim of all hermeneutics… This goal is achieved insofar as interpretation actualizes the meaning of the text for the present reader". (Ricoeur, 1976, pp. 91-92)

Methodologically distanciation and appropriation allow researchers to move beyond the notion that only the research participants' understanding is meaningful and or correct. It also allows the interpreters to interpret the same text faithfully, yet somewhat differently because it is acknowledged that texts have many meanings (Geanellos, 2000).

6.4.3 Explanation and understanding

Interpreting a text involves moving beyond understanding what the text says (*its sense*) to understanding what it talks about (*its reference*) (Ricoeur, 1976, p. 88). As such, the text's sense and its reference embodies the two stages of Ricoeur's interpretation theory: (i) explanation, - or what the text says and (ii) understanding, or what the text talks about (Geanellos, 2000). While explanation is directed toward analysis of the internal relations of the text (the parts) understanding is directed toward grasping the meanings the text discloses (the whole in relation to the parts) In this way, interpretive understanding goes forward in a continual movement between the parts and the whole allowing understanding to be enlarged and deepened (Geanellos, 2000). "Ultimately the correlation between explanation and understanding, between understanding and explanation is 'the hermeneutic circle'." (Ricoeur, 2008, p. 163) Hence, the sense of a text is not behind the text, but in front of it. It is not something hidden, but something disclosed:

> What has to be understood is not the initial situation of discourse, but what points to a possible world. The text speaks of a possible world and of a possible way of orientating oneself within it. The dimensions of this world are properly opened up and disclosed by the text. (Ricoeur, 1976, pp. 87-88)

6.4.4 Guessing and validation

All interpretive activity involves a dialectic between guessing and validating (Ricoeur, 2008). We make an educated guess about the meaning of a part and check it against the whole and vice versa. In the same way, we begin by guessing about the meaning of the whole as determining the relative importance of several parts. Throughout this process of guess and validation we can come to an end when we say this is how we understand things. But there is no definite outcome (Dauenhauer & Pellauer, 2014, p. 154).

It is always possible to relate sentences, or actions to one another in more than one way: “This plurivocity is typical of the text considered as a whole, open to several readings and to several constructions” (Ricoeur, 2008, p. 154). Although a text may have several interpretations, some interpretations are more probable than others. It is therefore necessary to validate our guesses. Validating guesses is closer to a logic of probability, than to a logic of empirical verification. We validate an interpretation by vindicating it against competing interpretations. Thus, validation is not verification (Ricoeur, 2008). Rather, it is an “argumentative discipline comparable to the judicial procedures of legal interpretation. It is a logic of uncertainty and of qualitative probability.” (Ricoeur, 2008, p. 155) Guess and validation are circularly related as subjective and objective approaches to the text. Although there is always more than one interpretation, all interpretations are not equal. One must therefore try to find the most probable interpretation. Ricoeur points out that:

> The text is a limited field of possible constructions. The logic of validation allows us to move between the two limits of dogmatism and skepticism. It is always possible to argue against an interpretation, to confront interpretations, to arbitrate between them and to seek for an agreement, even if this agreement remains beyond our reach. (Ricoeur, 2008, p. 155)

As mentioned in the beginning of this chapter, the researcher’s choice of methods to carry out a study must be consistent with the study’s methodological framework (Swinton & Mowat, 2006). The link between this study’s philosophical underpinnings and the methods used in the study (Van Manen, 2014) will therefore be explicated in the following chapter.

7. The methods

Data were collected through narrative interviews (Mishler, 1986) and a phenomenological hermeneutical interpretation method (Lindseth & Norberg, 2004) was chosen to analyze the data.

7.1 Data collection: Narrative interviews

Open-ended narrative interviews (Mishler, 1986) were used to collect the data in all three studies. The narrative interviews in paper I and II were conducted as individual interviews, while the narrative interview in paper III was conducted as a focus group meeting with the mobile hospice nurse teaching team.

Ricoeur's (2008) theory of narratives states that life has a prenarrative quality and that action can be looked upon as a potential narrative (Vandervelde, 2008). Ricoeur notes that:

> Life is lived; history is recounted…. In remaining bound to time and to change, history remains tied to action. …. Ultimately history cannot make a complete break with narrative because it cannot break with action, which itself implies agents, aims and circumstances, interactions and results both intended and unintended. (Ricoeur, 2008, p. 5)

Ricoeur maintains that action and life are structured or organized in their being by narrative-like features, so that telling the story is not an after-the fact reorganization of what took place, but the making explicit of what was already implicit in action and in life. Accordingly, understanding takes the form of narratives and is permeated by a cultural world that is itself made of narratives. An inchoate narrative structure lies at the heart of people, things and events. Narratives are thus not mere descriptions of something that would be otherwise available independently of description, but are ontological layers, part and parcel of the past of actions and experiences (Ricoeur, 2008; Vandervelde, 2008, p. 141).

Drawing on Ricoeur's argument about the interconnection between narrative and human experience (Ivic, 2009) it seemed reasonable to believe that the narrative

interview (Mishler, 1986) would be a suitable method to gain access to the participants' experiences with practicing and teaching spiritual and existential care for the dying. This was based on the presupposition that the interviewees' perspectives would be best revealed in narratives where they use their spontaneous language to talk about their experiences (Mishler, 1986; Van Manen, 1990). According to Mishler (1986, p. 68) "there is a wide recognition of the special importance of narrative as a mode through which individuals express their understanding of events and experiences". Mishler (1986) points out that: "we are more likely to find stories reported in studies "using relatively unstructured interviews where respondents are invited to speak in their own voices, allowed to control the introduction and flow of topics, and encouraged to extend their responses". (Mishler, 1986, p. 69) The narrative interviews were conducted, using one open-ended question. Clarifying follow-up questions were used when necessary.

As discussed in Chapter 4.2, spiritual care is a highly debated concept due to the many variations which emerge from the nursing literature. The authors chose not to present any of these variations during the interviews. They also avoided defining *palliative* and *terminal* care, since these terms are in common and sometime interchangeable use (Clark & Seymour, 1999) and the moment when a patient transitions from "palliative" to "terminal" care is debated in the literature (Clark & Seymour, 1999; Harlos, 2010). Accordingly, the authors chose an open approach to ensure that the nurses felt they could narrate freely about their experiences with spiritual and existential care for the dying. The authors presumed that this would give them the best chance to collect as many rich narratives as possible.

The hospice nurses in paper I, and the nurses in paper II were asked the question: *"What are your experiences with providing spiritual and existential care to dying patients?"*

In paper III the mobile spiritual and existential care teaching team was asked the question: "*What are your experiences with teaching and supervising care workers in existential and spiritual care for the dying*?"

7.1.1 The narrative focus group interview

The narrative interview in the last part of the study (paper III) was conducted as a focus group meeting because the authors wanted to collect narratives about the group's experience as a unique pioneer mobile spiritual and existential care teaching team. Belzile and Öberg (2012) point out that focus groups are useful to study the perceptions, feelings, meanings or ways of thinking that are held by a group who share in a particular intersubjective reality. The focus group is an efficient way to obtain data from participants who work together daily: "…colleagues can relate to each other's comments to incidents in their daily shared lives. They may even challenge each other on contradictions between what they profess to believe and how they actually behave". (Kitzinger, 1995, p. 300)

7.2 Data analysis: Interpreting the interview texts

Drawing on the works of Heidegger, Gadamer and Ricoeur, Lindseth and Norberg (2004) underline that *essential meaning* is something that humans are familiar with in the practices of life and that this familiarity is expressed through actions, narratives and reflections. However, in order to study the essential meaning of research participants lived experience, their narratives must be written down and interpreted. It is important to note that when Lindseth and Norberg (2004) use the term essential meaning, their method does not involve a "pure" Husserlian" phenomenological search for meaning that is uncontaminated by interpretation. Nor does it involve a "pure" hermeneutical text interpretation, since the aim of the interpretation is to transcend the meaning of the text in order to reveal essential traits of our life world: "Thus we see that phenomenology must be phenomenological hermeneutics. Essential meaning must be studied and revealed in the interpretation of text" (Lindseth & Norberg, 2004, p. 147).

In Lindseth and Norberg's (2004) interpretation method, each interview is looked upon as a text. The interpretation method implies a dialectic movement between the text as a whole and parts of the text. The method consists of three practical steps involving:
1. Naïve reading, 2. Structural analysis, 3. Comprehensive understanding.

7.2.1 The naïve reading

The aim of the naive reading is to grasp an overall impression of the text and to gain access to the participants' lived experience. During the naïve reading, the researcher must strive to avoid making judgments about the factual in the narratives. Rather, the researcher must keep an open mind, allowing herself to be touched and moved by the narratives. To do this, the researcher must shift from a "natural" to a "phenomenological attitude" or in other words, accomplish "epoché" or "bracketing" (Lindseth & Norberg, 2004, p. 147). It is important to note that when Lindseth and Norberg (2004) use the Husserlian concepts of "essential meaning", "epoché" and "bracketing" they do not mean that researchers should give up their preunderstandings in order to arrive at a pure un-interpreted and uncontaminated essential meaning. This is neither possible nor desirable. Researchers should instead strive to bracket their eagerness to classify the participants' stories into categories, explanations and models in order to let the participants leave an impression on them (Lindseth & Norberg, 2004). By encountering the participants with openness and receptivity, a space of attention opens up. When the participant's "expression can make an impression, something fundamental happens... A space of attention opens up, in which what has been said can show itself with greater clarity" (Lindseth, 2015, p. 51).

Striving to keep an open mind, the authors reread the interview texts several times. The process of rereading drove the analysis towards a phenomenological world, which allowed the authors to be touched by the narratives. The naïve understanding of the text revealed the direction for the structural analyses (Lindseth & Norberg, 2004; Ricoeur, 1976, 1981, 1984). The results from the naïve readings were discussed between the authors. The naïve reading guided the structural analysis, which was the second step in the interpretation process.

7.2.2 The structural analysis

The structural analysis includes various examinations of the parts of the text in order to understand and explain what it says and how it is said. The structural analysis can be viewed as a stage between a naïve and a comprehensive interpretation, or between a

surface and a deep interpretation. The objective of the structural analysis was to explain what the text was saying (Lindseth & Norberg, 2004; Torjuul, 2009). The authors reread the transcripts several times to look for meaningful parts and patterns that could be divided into narrative meaning units. A meaning unit could consist of one sentence, parts of a sentence or a whole paragraph with related meaning. The meaning units were then condensed, compared and reflected upon to identify the spiritual and existential care themes and subthemes that penetrated the whole or parts of the text. A theme may be regarded as a thread of meaning that permeates the texts as a whole or parts of it (Lindseth & Norberg, 2004; Torjuul, 2009). The meaning units, themes and subthemes were discussed and reflected upon by the authors. The process of reading, identifying and discussing the themes and subthemes were repeated until the authors reached an interpretative agreement, were they felt that the themes corresponded to their text interpretations. Lindseth and Norberg (2004), the objective of the structural analysis is to explain what the text is saying. Hence, the structural analysis can be viewed as the methodic or "objective" part of the interpretation process, since the meaning units are decontextualized from the individual accounts and the text as a whole (in other words: the parts and meaning units are considered independently from their context in the interview texts (Lindseth & Norberg, 2004)). To recontextualize the text, the meaning units were grouped together to create tentative themes according to the authors' naïve reading. The authors validated the structural analysis, by checking their interpretations, rereading the text and comparing the themes and meaning units with their naïve understanding of the text as a whole.

7.2.3 Comprehensive understanding (Interpreted whole)

In the third and last step of the interpretation process, a comprehensive understanding was developed. The comprehensive interpretation is developed through a merging of the researchers' pre-understanding, naïve reading, the structural analysis, previous research and relevant theory (Lindseth & Norberg, 2004; Sørlie, 2001; Ødbehr et al., 2014). To develop a comprehensive understanding, the researchers must reflect on the themes in relation to the research question and the context of the study (Lindseth & Norberg, 2004). The aim of this step is to gain a deeper understanding of the interviews as a whole, - in Ricoeur's terms to recontextualize the text (Ricoeur, 1976). Methodically,

interpretation allows actualizations of the meanings of the text. For Ricoeur (1976) this occurs through *"appropriating the text*"; i.e. to make one's own what was previously foreign in the text (Ricoeur, 1976, pp. 91-92). When the world of the text is appropriated, the horizon of the researcher is expanded. This opens up the possibility of seeing things differently and orienting oneself differently in the world. It is this link between understanding, experience and self-understanding that grounds Ricoeur's theory in existence (Geanellos, 2000; Ricoeur, 1976; Torjuul, 2009). While the structural analysis is characterized as *the methodic or objective pole* of this interpretation method, Lindseth and Norberg (2004) state that the development of a comprehensive understanding can be looked upon as the method's *non methodic pole of understanding* and they point out that imagination is important because it is not possible to follow strict methodological rules in the process of recontextualizing the text. Accordingly, Lindseth and Norberg emphasize that their phenomenological hermeneutical interpretation method lies between art and science: "We use our artistic talents to formulate the naïve understanding, our scientific talents to perform the structural analysis and our critical talents to arrive at a comprehensive understanding" (Lindseth & Norberg, 2004, p. 152).

To develop a comprehensive understanding, the themes from the structural analysis in paper I, II, III and the main results in the thesis are discussed in light of relevant theoretical perspectives such as Norberg, Bergsten and Lundman's (2001) model of consolation. The comprehensive understanding in each individual study is presented in the discussion section in each paper, while the comprehensive understanding of the main results from the entire study is presented in chapter 10 in this thesis.

7.3 Methodological considerations

What constitutes quality in qualitative research and the means to determine or enhance it has been a subject of debate and controversy in recent years (Cho & Trent, 2006; Golafshani, 2003; Morse, Barrett, Mayan, Olson, & Spiers, 2008; Onwuegbuzie & Leech, 2007; Torjuul, 2009). The matters of dispute have primarily evolved around issues concerning *reliability* and *validity*. However, to this date none of the definitions of these

concepts represent a hegemony in qualitative research (Cho & Trent, 2006; Golafshani, 2003; Morse et al., 2008; Onwuegbuzie & Leech, 2007; Torjuul, 2009). The array of criteria and terminology used make this discourse problematic and rather complicated. Moreover, there exists no single set of philosophical and methodological presuppositions that can underpin a qualitative paradigm. In addition, there exists no uncontested collection of methods and standards for reporting and evaluating qualitative research in the literature (Cho & Trent, 2006; Golafshani, 2003; Kvale & Brinkmann, 2008; Morse et al., 2008; Onwuegbuzie & Leech, 2007; Torjuul, 2009).

Nevertheless, qualitative researchers agree that a study's credibility or trustworthiness has to be warranted by conforming to some generally accepted scientific standards. Such standards include methodological congruence, auditability, or rigour in documenting and explaining the research process, ethical rigour and the credibility or fittingness of the data interpretation (Cho & Trent, 2006; Golafshani, 2003; Morse et al., 2008; Onwuegbuzie & Leech, 2007; Torjuul, 2009).

Drawing on Lincoln and Guba (1985), Seale (1999) states that establishing trustworthiness of a research report lies at the heart of issues conventionally discussed as validity and reliability. According to Kvale and Brinkman (2008) reliability pertains to the consistency and trustworthiness of research findings, while validity pertains to the degree that a method investigates what it is intended to investigate. Validation consists of a consistent quality control throughout every stage of knowledge production, rather than an inspection at the end of the production line (Kvale & Brinkmann, 2008). Following Kvale and Brinkman (2008), an attempt to establish methodological congruence has already been conducted in the description of the study's methodological framework and methods. In order to strengthen the credibility of the study, the rest of this chapter will discuss methodological trustworthiness related to data collection, data analysis, study limitations and the first author's preunderstanding.

7.3.1 The trustworthiness of the data collection

The narrative interview method was used to collect as many rich narratives as possible in order to achieve the study's overall aim, of illuminating the nurses' lived experience.

The authors' ambition was to capture as many features and dimensions of the nurses' experiences as possible in order to ensure authenticity and to avoid superficial data (Lindseth & Norberg, 2004; Torjuul, 2009). However, as Appleton (1995) and Mishler (1986) emphasize, the quality of the data generated through narrative interviews is largely dependent on the skills and expertise of the interviewer.

In order to promote trustworthiness, the authors strove to create a permissive and non-judging climate, encouraging the nurses to use their own words and to narrate as openly and honestly as possible about their experiences during the interviews (Appleton, 1995; Mishler, 1986). No definitions of spiritual and existential care were introduced, in order to allow the nurses to talk freely about what they considered as spiritual and existential care. Care was taken to avoid interrupting the nurses' narrative flow and reflection in order to give them enough time and space to follow their own thoughts and work out their own stories. This required the ability to be patient and endure moments of silence. The authors followed up on the themes that the nurses focused on during the interview in order to obtain the meaning of their narratives (Gadamer, 2004). This was done by tying questions and comments to the narratives and repeating the nurses' words whenever possible (Riessman, 1993). Occasionally the authors would use probing questions, such as "What happened then?" or "Could you please tell me more about…?" to encourage the nurses' narrative flow. However, it was necessary to be sensitive to their responses and reactions in order to avoid probing too much (at the risk of invading the nurses) and probing too little (at the risk of missing out on important stories). In order to increase trustworthiness, the authors also strove to clarify unclear questions and unclear answers in order to reduce potential misunderstandings with the nurses.

In spite of these precautions, one can never avoid that some research participants might not be willing to, or dare to tell stories, while others may not remember, or find it difficult to express their thoughts and feelings. This challenges the researcher to pay attention to cues that could suggest that the nurses might have more to say (Lindseth & Norberg, 2004; Torjuul, 2009).

The act of telling a story must take place after the actual event took place: "Life is lived history is recounted" (Ricoeur, 2008, p. 5). As such, participants' narratives are stories

about past experiences. Hence, narratives are not stories concerning factual truths; rather, they are a synthesis between a person's experienced events and incidents. Accordingly, a recounted story is always more than the actual sum of the single events (Benzein, 1999; Polkinghorne, 1988; Ricoeur, 2008; Sørlie, 2001). One of the problems with retrospective interviews is that participants may reconstruct the past with a framework that they have learned later. On the other hand, narrative interviews give participants the opportunity to speak about what is important for them from their memory (Sørlie, 2001). As such, the narrative interview method is an important way to obtain information about participants' experiences.

Nevertheless, the research interview is also a situation where participants enact their identities through talking, wanting to present themselves as experienced, moral and knowledgeable. They may therefore be tempted to withhold experiences that might prove otherwise (Gullestad, 1996; Jordens & Little, 2004; Ricoeur, 1992; Torjuul, 2009). However, the study results did not give this impression. In several touching narratives, the nurses told about their uncertainty; ambiguity and vulnerability related to alleviating dying patients' spiritual and existential suffering. As the authors did not know the nurses personally, this may have helped them to express themselves freely.

7.3.2 The trustworthiness of the data analysis

The trustworthiness of the data analysis can be judged if the researcher is open about how the steps in the analysis were carried out (Benzein, 1999). In all three papers, care was taken to describe the steps in the phenomenological hermeneutical analysis to allow the reader to follow the process from the naïve reading (step 1) through the structural analysis (step 2) towards the comprehensive understanding (step 3) (Lindseth & Norberg, 2004).

Since the aim of the phenomenological hermeneutical analysis is to obtain the meaning that is opened up in front of the interview text, - not to search for the participants' meanings or *authorial intent* (Lindseth & Norberg, 2004; Ricoeur, 1976), the researchers' interpretations cannot be returned to the participants for validation in order to increase the trustworthiness of the interpretation (Riessman, 1993;

Sandelowski, 1993). Instead, validation is accomplished through the structural analysis, where the results from the structural analysis are compared with the initial interpretations stemming from the naïve readings in step 1. The structural analysis is the objective part of the interpretation (Lindseth & Norberg, 2004; Ricoeur, 1976, pp. 82-88).

It is important to note that an interpretive construction relies on clues contained within the text that point to their meaning. These clues permit an interpretation because the clues either make sense or inhibit an interpretation because they do not fit (Ricoeur, 1976). Ricoeur (1976, 2008) emphasizes that a text has multiple interpretations, and that all interpretations are not equal. Because there are multiple possible meanings within a text, the interpreters must make choices about competing interpretations and the different possibilities of naming and framing them (Torjuul, 2009). Following Ricoeur, researchers need to appreciate that no single interpretation can ever exhaust the meaning of a text. Every interpretation is therefore an approximation. Accordingly, it is the researchers' task to argue for their interpretation (Benzein, 1999; Geanellos, 2000).

In order to arrive at the most plausible of competing interpretations, all of the authors read the interviews, followed the paths in the analysis and discussed possible interpretations until a consensus was reached. This kind of researcher cooperation is called analyst triangulation (Benzein, 1999; Patton, 1990). Analyst triangulation is aimed at reducing the potential bias, which may occur when a single researcher collects and interprets the data. Analyst triangulation provides a means of more directly assessing the reliability and validity of the results (Benzein, 1999). The authors' cooperation and critical discussions gave them a wider frame of reference (horizon) to interpret the texts, since it enabled them to question each other's interpretations.

Lindseth and Norberg (2004) emphasize that the researcher must check whether the results from the structural analysis validate or invalidate the initial naïve understanding. If the structural analysis invalidates the naïve understanding, the whole text must be reread to develop a new naïve understanding. The new naïve reading must then be checked by a new structural analysis. The researcher must repeat the process until s/he

experiences that the naïve understanding is validated by the structural analysis (Lindseth & Norberg, 2004). The authors checked the themes from the structural analysis in relation to their naïve readings, which were found to be consistent with their initial naïve understanding. This strengthened the trustworthiness of their interpretations. The themes are presented in the Results section in the three papers. Some nurse researchers claim that using a phenomenological hermeneutical method to analyze focus group interviews is a controversial choice. Critics state that phenomenology's emphasis on individual, lived experience is inconsistent with group approaches (Webb, 2003; Webb & Kevern, 2001). This controversy has been thoroughly discussed in paper I where the authors argue that the focus group approach does not exclude individual perspectives and that subjecting focus group interviews to phenomenological hermeneutical analysis is consistent with Ricoeur's (1976) interpretation theory because the aim of the phenomenological hermeneutical analysis is to interpret *the meaning of the interview text*, rather than the experience of individual participants (Lindseth & Norberg, 2004; Ricoeur, 1976). The first author, who conducted the interview, made sure that all of the team members were heard and encouraged the less vociferous to talk about their experiences in order to capture the whole group's experience as a teaching team.

7.3.3 Rationale for conducting a phenomenological hermeneutical data analysis

Different epistemological perspectives and pluralism have created an array of qualitative approaches, such as grounded theory, various forms for phenomenology, ethnography, action research and qualitative content analysis. There is a considerable overlap among available approaches in terms of methods, procedures and techniques. It can therefore be challenging for researchers to determine which approach is most suitable to answer their research questions (Vaismoradi, Turunen, & Bondas, 2013).

In this study we chose to apply a phenomenological hermeneutical method (Lindseth & Norberg, 2004) to analyze the interview texts. It could also have been possible to use qualitative content analysis (Graneheim & Lundman, 2004). Initially, this method focused on analyzing the *manifest content*, - what the interview text says, its visible, obvious components (Graneheim & Lundman, 2004, p. 106). - or in Ricoeur's terms "its

sense" (Ricoeur, 1976, pp. 19-23). However, over time, qualitative content analysis has expanded to include interpretations of what the text talks about, - its *latent content* (Graneheim & Lundman, 2004, p. 106), - or in Ricoeur's terms "the text's reference" (Ricoeur, 1976, pp. 19-23). As such, phenomenological hermeneutical analysis (Lindseth & Norberg, 2004) and qualitative content analysis (Graneheim & Lundman, 2004) seem to share a common aim of analyzing narrative materials by breaking them into relatively small units of content and submitting them to descriptive and interpretative treatment. However, according to Sandelowski and Barroso's (2003) typology of qualitative studies, qualitative content analysis employs a lower level of interpretation than phenomenological hermeneutical approaches. The authors therefore judged that it would be more suitable to apply a phenomenological hermeneutical method to analyze the interview texts because the study's overall aim to *"illuminate the meaning of registered nurses' experiences with practicing and teaching spiritual and existential care for the dying"* demanded a method which employs a high level of interpretive complexity. As van Manen (2014, p. 226) notes:" The phenomenological study of lived or existential meanings attempts to describe and interpret these meanings to a certain degree of depth and richness."

Using Lindseth and Norberg's (2004) phenomenological hermeneutical method to interpret the narrative interviews proved to be a good choice for this study, because it enabled the authors to interpret the nurses' lived experience. The interpretations provided a fruitful departure point to develop a comprehensive understanding about the meaning of the nurses' experiences with practicing and teaching spiritual and existential care for the dying.

However, as mentioned earlier, phenomenological hermeneutical researchers must "bracket" their judgments about the factual in narrative interview texts in order to disclose the texts' essential meaning. It is important to note that bracketing one's judgment is not the same as bracketing one's preunderstanding (Lindseth & Norberg, 2004). Drawing on Ricoeur (1976), Lindseth and Norberg (2004) point out that every human being has an implicit preunderstanding of life which they cannot free themselves from and that researchers can only understand and interpret their informants' narratives in relation to their own preunderstandings. Accordingly, to strengthen a

phenomenological hermeneutical study's trustworthiness, researchers must reflect critically and document how their preunderstandings have influenced the research process and the data interpretation. This will be presented in the following:

7.3.4 My preunderstanding

As mentioned in Chapter 4.2, when I began my research, I had a preunderstanding of spiritual and existential care, which had evolved through my own nursing experience in palliative care and my theoretical frame of reference in nursing and narrative theology. In retrospect, I see that this background has had its advantages as well as disadvantages.

On the one hand, being a nurse with palliative spiritual and existential care experience gave me an asset as a researcher, because it enabled me to establish trust and rapport with the nurses. Coming from the same background, helped me to communicate with them. I experienced that the nurses opened up and talked quite frankly with me about their challenges and struggles because I was "one of them". (I informed them briefly about my background when I presented myself at the beginning of each interview.) However, being viewed as "one of them", also had its challenges. When the nurses told me moving stories, I often felt that they appealed to me for recognition, when they held my gaze and said things like: *"... - you know what I mean...!!?"* This was especially challenging during my first interviews, because I was new to the role as the researcher. I quickly discovered that I was tempted to respond spontaneously to their appeals as a fellow nurse, and I experienced that I had to make a conscious effort to inhibit my reactions in order to maintain my role as a researcher. Resisting the temptation to confirm that I *"absolutely understood them"* as a fellow nurse, I made an effort to settle back and encourage the nurses to tell me more about their experiences. Aiming to be faithful to Lindseth and Norberg's (2004) method, I strove to bracket my thoughts and feelings as much as possible, in order to refrain from judging or comparing the nurses' stories with my own nursing background (during the interviews and throughout the interpretation process). I experienced that this was absolutely necessary in order to listen actively and focus on the meaning of the nurses' experiences. This could be especially challenging when their stories evoked some of my own memories about dying patients who had touched me deeply (Tornøe, 1996).

During my first interpretation attempts, I discovered that I tended to overlay the interpretations with my own nursing experience and theoretical preunderstandings. However, as I gained proficiency in the interpretation method, I was gradually able to let go of my natural attitude (already "knowing" in light of my preunderstanding) to cultivate a more open phenomenological attitude (Lindseth, 2015; Lindseth & Norberg, 2004). I experienced that the dialectical process of comparing my structural analyses with my initial naïve readings expanded my interpretative horizon. I believe this reduced the impact of my preunderstandings and helped me to explore and interpret the essential meanings in the interview transcripts.

7.3.5 Study limitations

As this is a qualitative study, it is not reasonable to discuss the concepts of validity, reliability and generalizability in their traditional senses. The number of informants in qualitative research projects is not sufficient to allow for generalized conclusions. However, they do insure strength and representativity in relation to transferability, as they permit an in-depth insight into the phenomena under study. Qualitative projects can therefore be stated to show a high content validity. This means that there is a high degree of detail in the data (Dehlholm-Lambertsen & Maunsbach, 1997). Three to five informants are sufficient to achieve a high content validity (Kvale & Brinkmann, 2008; Mishler, 1986). Our decision about the sample size was guided by the need to ensure a variety of in-depth experiences. Since qualitative studies are not designed to be representative in terms of statistical generability, they may gain little from expanding sample size except a more cumbersome data set, allowing for less depth and richness to be extracted from the material (Carlsen & Glenton, 2011; Pope, Ziebland, & Mays, 2000).

Even though the results in this study cannot be generalized, the results are deemed as credible or trustworthy if people with similar experiences can recognize the results of the study (Benzein, 1999; Sandelowski, 1993; Sørlie, 2001). In conclusion however, one can argue for and against the interpretation of this particular phenomenological hermeneutical study, as the results that are presented are only one of several possible interpretations:

> An interpretation must not only be probable, but more probable than another interpretation… It is always possible to argue for or against an interpretation, to confront interpretations, to arbitrate between them and to seek agreement, even if this agreement remains beyond our immediate reach. (Ricoeur, 1976, p. 79)

Although the hospice nurses in the first paper mentioned that they sometimes had Muslim patients and that they were sensitive to these patients' spiritual and existential needs, they had limited experience with spiritual and existential care for patients from different ethnic backgrounds and/ or religious traditions (paper I). The study in paper II was conducted in a small rural Norwegian town where the majority of the population consisted of ethnic Norwegians. None of the participants in paper II and III mentioned that they had provided spiritual and existential care to patients from other ethnic groups or religious faiths. The participants in all three papers were ethnic Norwegians.

Due to the study's geographical and cultural context the study is limited to the participants' experiences with providing spiritual and existential care to ethnic Norwegian patients. Although Norway is becoming an increasingly pluralistic and multicultural society (Botvar & Schmidt, 2010; Aadnanes, 2008), approximately 73 % of the population have an affiliation to the Church of Norway (Statistisk Sentralbyrå (Central Bureau of Statistics in Norway), 2015). Henceforth, the results from this study are still relevant in spite of these limitations.

8. The study

According to Halcomb, Gholizadeh, DiGiacomo, Phillips, and Davidson (2007), it is important to select potential participants that are able to provide insight into and information about the research topic and that they are able to articulate their perspective on relevant issues.

Paper I and paper II explore hospice nurses' and registered nurses' spiritual and existential care experiences within the *specialized levels* of care, while **paper III** explores a mobile hospice nurse teaching team's experiences with teaching and supervising care workers in spiritual and existential care within the *primary levels of care*. These healthcare contexts were chosen to capture a broadest possible range of nursing experiences related to practicing and teaching spiritual and existential care for the dying.

For the first part of the study (paper I), eight experienced hospice nurses from a leading Norwegian hospice in a major city were recruited. Since hospice nurses work with dying patients, it seemed reasonable that these nurses would be able to provide rich narratives about their experiences with spiritual and existential care for the dying.

For the second part of the study (paper II) six registered nurses from a medical and oncological ward in a general hospital were recruited. In contrast to hospice nurses, hospital nurses must maintain curative responsibilities for patients while at the same time caring for the dying as part of their daily work (Costello, 2006). In this ward, eight beds were especially designated for patients with advanced stages of cancer. The authors assumed that these nurses would have experienced the tension between managing curative responsibilities and providing spiritual and existential care for the dying.

For the third part of the study (paper III) three hospice nurses in a mobile spiritual and existential care teaching team were recruited. The fourth author was familiar with the mobile teaching team from previous research projects at the hospice and knew that they were able and willing to participate in research. As Norway's first and only mobile spiritual and existential care teaching team, these hospice nurses possessed a unique

experience with training care workers in spiritual and existential care for the dying in nursing homes and home care.

An overview of the study, participants and papers comprising this thesis is shown in table 1.

Table 1: Overview of the study, participants and papers

The Study	Participants	Data collection	Interpretation Method	Papers	Focus
The Hospice	Eight hospice nurses	Individual narrative interviews	Phenomenological hermeneutical	**Paper I**	Experiences with practicing spiritual and existential care for the dying
Medical and oncological ward in a general hospital	Six registered nurses	Individual narrative interviews	Phenomenological hermeneutical	**Paper II**	Experiences with practicing spiritual and existential care for the dying
The mobile hospice nurse teaching team	Three hospice nurses	Narrative focus group interview	Phenomenological hermeneutical	**Paper III**	Experiences with training care workers in spiritual and existential care for the dying

8.1 The setting

The first and third parts of the study (paper I and paper III) were conducted with hospice nurses who were employed in the same leading hospice in a major Norwegian city. The hospice was an integrated unit in a somatic hospital. The hospice nurses in paper I performed bedside nursing in the hospice, while the hospice nurses in paper III, worked outside the hospice, ambulating between the city's nursing homes and home care settings to teach and train care workers in spiritual and existential care. The second part of the study (paper II) was conducted with registered nurses who worked in a medical and oncological ward in a general hospital. The hospital was situated in a rural Norwegian town.

8.2 Recruitment strategy

A purposive sampling strategy (Devers & Frankel, 2000; Patton, 2002) was applied to recruit key informants from the chosen healthcare contexts in order to fulfill the overall aim of the thesis. The inclusion criteria were that the nurses were interested in palliative care and that they had a wide variety of experiences with spiritual and existential care for dying patients. In addition, the nurses in the third part of the study also needed to be experienced teachers and supervisors in spiritual and existential care for the dying.

For the first and third part of the study (paper I, and paper III), the authors contacted the hospice leader and obtained her permission to carry out the research. She assisted in recruiting participants by informing the hospice nurses about the study and forwarded the authors' information sheet and formal written request to participate in the study. The first eight hospice nurses that signed up for the study were interviewed. To recruit participants for the last part of the study (paper III), the hospice leader asked the three hospice nurses in the mobile spiritual and existential care teaching team if they wanted to participate in the study and she forwarded the authors' information sheet and formal written request to participate in the study. To recruit nurses for the second part of the study (paper II), the authors contacted the head nurse in the medical and oncological hospital ward and obtained her permission to carry out the research. She assisted in recruiting participants by telling the nurses about the study and she forwarded the authors' written information and formal request to participate in the study. The first six nurses that signed up for the study were interviewed.

8.3 The sample

The eight participants in paper I were experienced hospice nurses between the ages of forty-one and sixty-one years, with eight to thirty-five years of nursing experience. Everyone held nursing degrees especially relevant for palliative care, such as palliative care and oncology nursing.

The six participants in paper II were experienced registered nurses between the ages of thirty-seven and sixty-one years with nine to twenty years of nursing experience. Four of them had degrees in oncology nursing and palliative care.

The three participants in paper III were experienced hospice nurses with several years of experience as clinical supervisors in end of life care. They were between the ages of fifty- five and sixty-one years old, with five to fifteen years of hospice nurse experience. All of them held nursing degrees in fields that were relevant for palliative care, such as palliative care and oncology nursing.

Table 2: Overview of the participants

The Settings	Participants	Age	Education	Nursing experience
Paper I The Hospice	Eight hospice nurses	41-61 years	The hospice nurses held nursing degrees in such fields as palliative care or oncology nursing	8 - 35 years
Paper II Medical oncological ward in a general hospital	Six registered nurses	37-61 years	4 registered nurses had degrees in oncology nursing and palliative care	9-20 years
Paper III The hospice	Three hospice nurses in the mobile teaching team	55-61 years	All hospice nurses held nursing degrees in such fields as palliative care or oncology nursing	5-15 years

8.4 Conducting the interviews

The first and fourth author participated in the first and second interviews in paper I. The first author conducted the rest of the interviews in paper I, and all of the interviews in paper II. The first and fourth author participated in the focus group interview in paper III. The first author conducted the interview while the fourth author acted as secretary, taking field notes to comment on situational aspects, language and interaction (Malterud, 2011).

Before each interview, the authors introduced themselves and repeated the information about the study's aim, the interview procedure, their roles as interviewers, and what they expected from the nurses, who were encouraged to ask questions about the study

and the interview procedure. Personal information about each nurse was obtained and written down, and the nurses gave their written consent.

The interviews with the hospice nurses in paper I and paper III took place in 2012 and were held in the hospice meeting room. The interviews with registered nurses in paper II took place in 2014 and were held in a meeting room outside the nurses' medical-oncological ward. The individual interviews in paper I and paper II lasted approximately one hour. The focus group interview in paper III lasted 80 minutes. All of the interviews took place during the nurses' working hours. The interviews were recorded and transcribed verbatim by the first author.

8.5 Ethical considerations

The study was conducted according to the Helsinki declaration (World Medical Association, 2001). Approval was obtained from the Norwegian Center for Research, (Norsk samfunnsvitenskapelig datatjeneste), project number 29973. The ethical considerations throughout the research process was informed by the Helsinki declaration (World Medical Association, 2001) and the Norwegian Center for Research Data's policy and guidelines (NSD, 2016).

The authors distributed a formal written request and a short information sheet about the study to the nurses. The information sheet described the study's aim and background and explained that the interviews would be recorded and transcribed verbatim. Measures to ensure confidentiality and anonymity were also described. The information sheet also stated that the nurses were free to withdraw their consent at any given time, during or after the interview. The information was repeated before each interview started. Measures to ensure confidentiality and anonymity related to publication were repeated and emphasized. All of the nurses gave their written, informed consent to participate in the study.

The Helsinki declaration's ethical guidelines for health care research (World Medical Association, 2001) emphasize the researcher's duty to protect the participants' life, health, privacy, dignity and respect. It also stresses the importance of safeguarding

vulnerable and disadvantaged individuals from the potential risks of the study and the discomfort it may entail. The nurses in this study did not belong to a vulnerable or underprivileged group in society, nor can they be said to need special protection from the researcher. However, patients and their loved ones played an important role in the nurses' narratives and were at risk of being exposed. This did not cause any ethical problems because the nurses made an effort to preserve patients', family members' and colleagues' confidentiality and anonymity when they talked about their spiritual and existential care experiences. The nurses did not disclose any names in the interviews and they occasionally omitted details from their stories to safeguard anonymity and confidentiality.

In Scandinavian countries, spirituality, religion and existential issues are considered to be private and sensitive fields of enquiry (Botvar & Schmidt, 2010; DeMarinis, 2008; la Cour, 2008; Aadnanes, 2008). It was therefore important to be sensitive to this during the interviews because of the asymmetry of power in the interviewee – interviewer relationship (Mishler, 1986). Choosing the narrative interview method was a way to rebalance the power structure between the researcher and the nurses, because when a researcher encourages interviewees to narrate about their experiences, s/he is also encouraging them to find and speak in their own voice (Mishler, 1986).

9. Main results in Papers I-III

9.1 Paper I

The nurses described their patients' suffering as a kind of "total pain", which included emotional, spiritual and existential distress and physical pain. They told that this made it difficult to sort out spiritual and existential suffering. Alleviating physical symptoms was important, since unchecked physical pain would drain the patients' energy to focus on spiritual and/or existential concerns. The nurses said that they needed a good sense of timing, situational understanding and the ability to "sense and tune in on" patients' verbal and non-verbal cues during nursing care, in order to pick up each patient's existential and/or spiritual distress and to respond adequately to their needs.

According to the nurses "being there" for their patients lied at the heart of their spiritual and existential care practice. "Being there" was about conveying consolation through silent presencing, companionship, deep existential and religious conversations, and by supporting patients' expressions of faith and rituals. The nurses expressed that building trusting relationships, easing suffering, and helping patients and their families to find peace, acceptance of death and reconciliation, was deeply meaningful and rewarding.

The nurses saw that patients who were unable to express their thoughts and feelings about death could become stuck in states of anxiety and denial. It was the nurses' impression that patients who voiced their distress died more peacefully than those who "bottled everything up, and they described an ethical dilemma between their wish to help patients find peace by "nudging them to open up" and accepting that some of them would not or could not share their suffering (p.3). The nurses were concerned about the risk of violating their patients' autonomy and integrity, and they stressed that they were bound by their professional ethics to respect their patients' choices. The nurses expressed that it was deeply painful when they were unable to reach in to their patients. Bearing witness to dying patients' suffering and pain, in spite of their consolation efforts was emotionally challenging because it made the nurses feel helpless and vulnerable. They therefore placed great importance on debriefing and support from their colleagues in order to endure the emotional demands of being with the dying.

9.2 Paper II

The nurses experienced that dying patients' spiritual and existential suffering emerged as subtle and elusive entanglements of physical, emotional, relational, spiritual and existential pain. The nurses told that spiritual and existential suffering (which did not always include religious aspects) could emerge spontaneously, for example during physical care. The ability to zoom in on fleeting moments, when patients wanted and needed to talk was therefore viewed as an essential skill.

The nurses strove to convey consolation by unburdening their patients to facilitate a peaceful and harmonious death. They told that this could involve helping patients to resolve practical worries, (i.e. completing a home renovation), as well as helping them to make peace with their past, their loved ones and with God (p.6). The nurses felt they had been able to convey consolation when they saw that their efforts had helped patients to experience a good, peaceful and harmonious death. Witnessing the peaceful passing of a patient was described as a special moment that filled them with reverence and awe. This was experienced as very rewarding and fulfilling. The nurses were deeply moved and amazed when patients shared their trust and openness: "Sometimes I'm really astonished that they choose to share their troubles and worries with me! Even though I'm their nurse, I'm still a stranger!" (p.7)

The nurses expressed that they had an important function as "emotional containers" when they listened and encouraged dying patients to vent their feelings. "It doesn't do any harm if people start to cry. I usually tell my patients that they don't have to feel ashamed of their tears. Tears are only melting ice!" (p. 8). However, the nurses also stated that bearing witness to patients' spiritual and existential distress could be challenging because it exposed them to their own feelings of finitude and vulnerability. Bearing witness to unconsolable patients proved to be the nurses' greatest emotional challenge. Being unable to help patients towards a peaceful death could make them feel professionally inadequate and helpless and they felt that they had not done a good enough job. However, the nurses also emphasized that, what patients needed most, were nurses who showed that they were willing to stand by their patients, and would not abandon them in their time of need.

9.3 Paper III

According to the mobile hospice nurse teaching team, care workers frequently expressed that they were reluctant to address dying patients' existential and spiritual suffering. The team experienced that care workers could be quite afraid of talking with patients about their existential and spiritual concerns. The team expressed that many of them were afraid of silence and "just being with" the patient "in the room of death" (p. 4-5). The team therefore stressed the importance of helping the care workers develop their courage and competency to provide spiritual and existential care. The team believed that the care workers' fear and uncertainty stemmed from personal insecurity as well as insufficient communication and listening skills. They therefore placed great emphasis on the relational aspect of spiritual and existential care when they taught the care workers to "work from the heart".

The team taught care workers to identify patients' spiritual and existential suffering, initiate existential and spiritual conversations and to convey consolation through silent presencing and active listening. The team transferred their personal spiritual and existential care knowledge by participating actively in patient care together with the care workers, and by providing supervision and feedback related to these situations. This was called "bedside teaching", which could take place during many different kinds of patient encounters, such as giving physical care, doing nursing procedures, or just taking part in conversations with patients. The team emphasized that critical reflection was an important part of bedside "learning by doing". The team therefore placed great weight on conducting reflective dialogues with the care workers about their challenges and experiences before and after the patient encounter (p.5).

Drawing on care worker feedback and their own observations, the team considered that situated "bed-side teaching" had proven to be an important tool to develop care workers' courage and competency to provide spiritual and existential care for the dying. The team observed that care workers became more involved and willing to expose themselves to their patients' spiritual and existential suffering. The team thought this indicated that the care workers had become more courageous: "I see that they dare to involve themselves more in these situations, exposing their vulnerability. I see that they have become braver." (p.6)

10. Discussion

In this study the nurses narrated about their lived experience with practicing and teaching spiritual and existential care for dying patients in three different Norwegian health care contexts.

Three themes emerged through the comprehensive understanding, (discussion) of the results in paper I-III: *Conveying consolation, Vulnerability and helplessness, Compassion and courage.* To develop this last step in the analysis, the papers were read as a whole, taking into account the author's preunderstanding, previous research and relevant theory. Although consolation did not emerge as an explicit theme in paper III, the mobile hospice teaching team's situated bedside teaching (p. 3) proved to be consistent with the consolation theme, which emerged in paper I (p. 3- 5) and paper II (p. 7 - 8).

10.1 Conveying consolation

Conveying consolation proved to be an overarching theme in the study. According to Klass (2014), *"solace"* is understood as a sense of soothing which can involve pleasure, enjoyment or delight in the midst of sorrow, hopelessness and despair, hence to be consoled is to be comforted. The etymology of the word *comfort*, carries the sense of intersubjectivity because it is derived from the Latin *fortis*, which means strong or powerful and the prefix *com*, which means *with* (Klass, 2014). Accordingly, to console or comfort another means to strengthen or to find strength together (Klass, 2014, p. 7).

The results show that the nurses conveyed consolation through active presencing and relationship maintaining activities, which could involve gentle hand or foot massages, using a caring touch and listening and communicating emphatically with their patients during physical care, or by just being with them in shared silence. The nurses strove to create a trusting relational haven, where the dying could feel safe enough to open themselves and express their spiritual and existential distress (paper I p. 3-5 and paper II p. 6-7).

The nurses in paper I and II and the mobile hospice nurse teaching team in paper III emphasized the importance of seizing "the fleeting moments" when patients needed and wanted to talk about their suffering. The nurses stressed that this demanded a "fine tuned antenna" (paper II p.5), and that "If you do things properly and show that you care, existential or spiritual distress eventually surfaces if it's there" (paper I p.5). Striving to "get it right" the nurses tried "to tune in on" the individual patient, paying attention to their energy levels and emotional states, neither forcing nor avoiding spiritual and existential conversations (paper I p. 3). The mobile hospice nurse teaching team in paper III placed great emphasis on showing the care workers how to use natural opportunities during physical care to assess spiritual and existential needs and to integrate appropriate interventions. According to the teaching team, teaching the care workers to ask patients the simple question: "How are you?" could be enough to "open the door to meaningful and safe dialogues with patients about their thoughts and feelings" (paper III p. 5). The teaching team taught the care workers to listen attentively and to pay attention to their patients' facial expressions and body language. (paper III p. 5)

These results suggest that consolation cannot be planned, prescribed or imposed on patients through procedural rules and/or guidelines. Rather, conveying consolation seems to be a deeply personal and spontaneous activity, which depends on the nurses' and care workers' ability to apply their relational competence, creativity and compassionate perceptiveness in order to tune in to the particular patient's circumstances. This is supported by several Swedish consolation studies, (Norberg et al., 2001; Roxberg, Eriksson, Rehnsfeldt, & Fridlund, 2008; Söderberg, Gilje, & Norberg, 1999; Talseth, Gilje, & Norberg, 2003), which indicate that consolation can only be conveyed through communion and dialogue in trusting nurse-patient relationships. When the suffering patient becomes open and expresses suffering, and when the nurse mediating consolation becomes open and listens in an emphatic and non-judgmental manner, they are in communion and dialogue. During these moments, the nurse and the patient may experience mutual consolation. The suffering patient draws consolation from the nurse's presence and the nurse draws consolation from observing that the patient's distressed and anguished state moves towards peace and tranquility (Norberg et al., 2001).

10.1.1 The hermeneutics of consolation

According to Norberg et al. (2001, p. 551), "the important prerequisite for communion is a shared affective state, rather than a shared cognitive interpretation of the situation."

However, drawing on the works of Gadamer (2004) and Ricoeur (1976, 2008) it can be argued that sharing the patient's suffering also requires an interpretational dialogue about the meaning of the patient's suffering. Henceforth, conveying consolation through communion and dialogue can also be viewed as a hermeneutical activity. This will be explicated in the following.

In Norberg et al.'s (2001) consolation model, communion and dialogue is linked to two domains, - the patient's experience of his or her suffering and the nurse's experience of the patient's suffering. Henceforth, sharing their experience of the patient's suffering requires more than just sharing an affective state, because the patient's experience cannot directly become the nurse's experience, and vice versa:

> …. what is experienced by one person cannot be transferred whole as such and such experience to someone else. My experience cannot directly become your experience. An event belonging to one stream of consciousness cannot be transferred as such into another stream of consciousness. (Ricoeur, 1976, p. 16)

However, Ricoeur (1976) maintains that something is transferred from one sphere of life to another. "That something" is not the experience as experienced, but *its meaning.* Henceforth, experience as lived, remains private, but its sense, its meaning becomes public (Ricoeur, 1976). In Ricoeur's words: "…. communication in this way is the overcoming of the radical non-communicability of the lived experience as lived" (Ricoeur, 1976, p. 16). Henceforth, the nurse can only interpret the meaning of the patient's suffering through communion and dialogue, in which she experiences the patient as suffering or not (Kahn & Steeves, 1986). As Gadamer (2004, p. 292) points out: "The task of hermeneutics is to clarify the miracle of understanding, which is not a mysterious communion of souls, but sharing a common meaning". Henceforth, drawing on Gadamer (2004) and Ricoeur (1976, 2008) conveying consolation through

communion and dialogue (Norberg et al., 2001) can be understood as a kind of *clinical hermeneutics* (Kahn & Steeves, 1986). Human actions are like a text which awaits fresh interpretations that decide their meaning (Ricoeur, 2008). Thus, all significant events and deeds of human action are open to a kind of practical interpretation, which is open to anybody who can read (Ricoeur, 2008, p. 151). Following Ricoeur's (1976, 2008) phenomenological hermeneutical line of thought, the interpretation of the patient's suffering depends on the dialogic interaction of three elements: *the text, the reader and the context*: The patient's experience of suffering can be understood as the text which the reader–nurse must interpret, and vice versa (Kahn & Steeves, 1986). As the nurse "reads" the patient, the story, and the body, so also the patient always engages in a *reverse hermeneutics* where the patient "reads" and interprets the nurse, and judges his or her interest and care for the patient as a unique person (Schei, 2006).
Cultural, spiritual and existential meanings that the nurse and the patient share or do not share about suffering inducing events will also influence how they interpret the meaning of the patient's suffering. In addition, contextual factors within the particular health care setting, such as physical, psychological and sociocultural environmental features, also impact on how the nurse and the patient "read and interpret" the meaning of the patient's suffering (DeMarinis, Ulland, & Karlsen, 2011; Kahn & Steeves, 1986; Ulland & DeMarinis, 2014).

The results reveal that the nurses' own life experiences and personal beliefs influenced how they felt about providing consolation, especially related to the patients' religious issues. Although the nurses acknowledged that they had a professional obligation to support the patients' sources of faith, meaning and hope, regardless of their own beliefs, some of them had mixed feelings about this because they were not:

> very religious or "very Christian" as they put it: "Actually, I feel a bit uncomfortable when patients tell me that they place their life in God's hands. I think it's probably because I'm not a believer. I'm very skeptical towards the Bible and the Christian faith". (paper I p. 4)

In general, the nurses viewed religion as a very private and personal matter, which made them wary of imposing themselves on their patients (paper II p. 5-6). Some also said that they preferred to refer patients to the hospice or hospital chaplain for religious

support because they felt uncertain and insecure about addressing patients' religious concerns (paper I p.4, paper II p. 5, paper III p.4-5). Two of the nurses in paper I had pursued theological studies prior to nursing. Their colleagues regarded them as valuable resources because they were able to help patients with their spiritual and existential distress by combining their personal faith with theological knowledge and pastoral counseling skills. (paper I p.4) However, in spite of their ambivalence, the study shows that the nurses thought it was important to alleviating their dying patients' spiritual and existential suffering and they strove to console them as best they could within their limited time and resources. (paper II p.6)

10.1.2 The relational dimension in the nurses' consolation narratives

Schei (2006) points out that a therapeutic alliance between the clinician and the patient emerges through reciprocal interpretation and projection where gestures, facial expressions, intonation, pauses and eye movements typically convey more information than mere words. As such, meaning is transmitted on several levels simultaneously; compassion and understanding may be expressed through the look in the nurse's eyes or the timbre of voice, or the speed of talking while factual business is carried out in the explicit verbal lane. Both participants in a dialogue monitor themselves, and the other, including the other's apparent interpretations of one's own utterances, in complex recursive interplay. Thus, the dialogue continually produces new meanings, based on what has already happened in the conversation and in the nurse-patient relationship.

Important lessons may be gleaned from these considerations (Schei, 2006). To the extent that patients with or without serious disease, also suffer, i.e. experience mental imbalance, isolation, grief, fear and other feelings commonly associated with illness, pain and existential loss, the research literature suggests that becoming a part of a therapeutic alliance may in itself be conducive to healing and adaptation (Eells, 1999; Schei, 2006). Moreover, Schei (2006) asserts that this may be especially true – and valuable when medical technology has little to offer in the way of further diagnostic or therapeutic procedures. Henceforth, receiving consolation through communion and dialogue with the nurse (Norberg et al., 2001) may be of therapeutic value for the dying. This will be discussed in light of three of the study's consolation narratives.

1. Breaking the boil

In the first narrative, a dying young cancer patient "just wanted to float away in a drug daze." (paper I p.4) The nurse described the patients' spiritual and existential pain as "a large festering boil. "I'm not sure how we managed to puncture it because we had tried a lot of things." One day, the doctor spontaneously asked the patient if she was bitter because she was dying so young. The doctor's outburst seemed to snap the patient out of her drug daze because she retorted that she was not bitter since her illness had "helped her to grow and mature in ways she couldn't imagine even if she had lived to a ripe old age". According to the nurse, this conversation broke open the boil of suffering, which seemed to create a turning point in the patient's life, because she rose from her deathbed, reconnected with her sister and mother, and went home to her flat one last time to set her affairs in order. (paper I p. 4) And the nurse thought to herself: "Yes! Exactly that question shifted something because now we had a girl taking back her life!"

2. Disappearing into a black hole

In the second narrative (paper II p. 6), the nurse told about a woman who was dying of lung cancer. Sensing her anxiety, the nurse asked what she thought about death. The patient feared that she would just "disappear into a big black hole" when she died. "Isn't there anything more afterwards?" she asked the nurse. The nurse was able to relieve the patient's anxiety by sharing her personal belief that she would be reunited with her loved ones when she passed away. According to the nurse, the patient seemed to draw consolation from the hope of reuniting with her deceased father: "Perhaps he's standing there waiting for me!" she exclaimed. Although the patient seemed calmer, she was still worried about not being able to finish renovating her family's home. To ease her worries, the nurse contacted the social worker who organized her family and friends to complete the job.

3. A punishment from God

The third and last narrative, which will be mentioned here, is a narrative about a dying elderly woman who refused to receive morphine because she believed that God was punishing her through her pain. In this case the nurse had to deal with the patient's religious issues before she was permitted to relieve the patient's physical pain.

Desperately searching for a way to reach in to the patient it suddenly dawned on the nurse that she could use prayer "to turn the situation around" as she put it. (paper II p. 6) So the nurse asked the patient if she wanted to say "The Lord's Prayer" with her. According to the nurse, sharing the prayer helped her to connect with the patient, which opened up a natural opportunity to talk with her about her picture of a punishing and vengeful God. Although the nurse claimed that she was not "very religious" she shared her believe in a trusting and loving God: "The God I believe in loves us and wants to help us! And now I can help you to take your pain away, -at least some of it! – If you'll let me!" (paper II p.7) The nurse thought that the patient seemed to draw consolation from the prayer and the conversation, because she accepted to receive morphine regularly after that, and according to the nurse, the patient died pain free and at peace with God.

In these narratives the patients' spiritual and existential suffering seemed to evolve around their disconnected relationships with self, family members and with God. The nurses therefore strove to help the patients to reconnect and restore their relationships by:

- Challenging the patient to face her suffering, instead of escaping in a drug daze, which stimulated the patient to take charge of her life, settle her affairs and reconnect with her sister and mother (narrative 1)
- Helping the patient to overcome her existential fear and loneliness related to dying, by conveying a hope of reconnecting with her loved ones in the "here after" (narrative 2)
- Helping the patient to maintain her family ties and responsibilities related to completing the renovation of her family home (narrative 2)
- Helping the patient to connect with God and to shift her perception of God from vengeful and punishing to caring and loving (narrative 3)

In the following these results will be reflected on in light of Sulmasy's (2002) relational perspective on suffering. According to Sulmasy (2002), illness disturbs relationships both inside and outside the body. In spite of this, contemporary scientific healing has until recently been limited to restoring the physiological homeostatic relationships within the patient's body, (such as restoring a diabetes patient's blood sugar balance in relation to other biochemical processes). Illness however, disturbs more than the

relationships inside the human organism. It contributes to suffering because it disrupts families and workplaces. It shatters preexisting patterns of coping, and it raises questions about one's relationship with the transcendent (Sulmasy, 2002). Accordingly, illness disturbs the relationship between the individual patient and his or her environment, including the familial and social nexus of relationships, which surround the patient and it disturbs the relationship between the patient and the transcendent (Sulmasy, 2002). This is supported by Cassel's (1991b) work, which shows that suffering generates existential loneliness, because it alienates the sufferer from his or her relationships with others, from the world and from his or her transcendent source of meaning. According to Sulmasy (2002) healing implies that genuine holistic health care attends to all of the disturbed relationships of the ill person as a whole, restoring those that can be restored, even if the person is not completely restored to perfect wholeness. This means that at the end of life where the patient's health no longer can be restored, healing is still possible (Sulmasy, 2002). Following Sulmasy (2002) the consolation narratives can be understood as healing since they involve restoring the patients' significant relationships to self, others and the transcendent. The results suggest that appropriate consolation requires attention to the restoration of all the intrapersonal and extrapersonal relationships that can still be addressed even at the end of life (Sulmasy, 2002).

10.1.3 Conveying consolation in relation to Spiritual/ Existential and Psychosocial care

Given the nurses' strong focus on helping their patients to restore disconnected relationships it can be discussed whether the consolation narratives primarily are concerned with psychosocial care. Within the palliative care context, psychosocial care has been defined as concern with the psychological and emotional wellbeing of the patient and their family/carers, including issues of self-esteem, insight into and adaptation to illness and its consequences, communication, social functioning and relationships (Tan, Wilson, Olver, & Barton, 2011). There exists a thin divide between spiritual/existential and psychosocial care in the palliative care literature, because the importance of relationships is emphasized in both domains (Sinclair & Chochinov, 2012; Tan et al., 2011). It is therefore understandable that psychosocial and spiritual/ existential issues tended to overlap in the nurses' consolation narratives: "She still

worried about her family because she was going to die from her kids, so in this case unburdening her with the practical stuff was an important part of spiritual care" (narrative 2, paper II p. 6). This is supported by other studies, which suggest that in clinical practice the spiritual domain coalesces with other domains and may therefore be addressed through both psychological and spiritual modalities (Sinclair & Chochinov, 2012, p. 73). It is therefore interesting to note that the relational dimension in the consolation narratives also resonate with several definitions that express spirituality in relational and transcendental terms. Puchalski et al. (2009) for instance, define spirituality as: "the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred" (Puchalski et al., 2009, p. 887).

This is in line with Pargament (2013), who points out that the relational dimension of spirituality becomes especially apparent during *sacred moments* which are characterized by a deep sense of interconnectedness and caring. He (2013) maintains that sacred moments are extraordinary moments when nurses can see into who their patients are and they can see into who the nurses are. During these moments, the nurse and the patient touch and are touched by each other. As such, sacred moments are moments of profound interconnectedness (Pargament, 2013). This corresponds to Norberg et al.'s (2001) point of view. According to them, consolation gives a feeling of meaning, homecoming and contact with the sacred dimension (transcendence). When the nurse participates in the patient's pain, communion emerges. Norberg et al. (2001) maintain that communion is a deep connection that touches *the sacred dimension* which is akin to a connection with such phenomena as beauty, joy and goodness. Following Pargament (2013) and Norberg et al. (2001), the nurses' consolation narratives can be understood as descriptions of such sacred moments. It is important to note that Pargament (2013) uses the term "sacred" in a psychological rather than a theological sense. According to him (2013) "sacred" refers to human perceptions of qualities often associated with the divine or higher powers. He also points out that these perceptions do not refer one way or the other to the ontological reality of the sacred, higher powers or God. Rather, they reflect on human character and human relationships (Pargament, 2013). From this perspective, it can be argued that nurses may experience sacred

moments in their work whether they consider themselves to be religious or not. Henceforth it seems reasonable to interpret the nurses' consolation narratives as "sacred moments" in Pargament's psychological sense of the term, although some of the nurses expressed that they did not experience themselves as very "religious or Christian" (paper I p. 4, paper II p. 6).

Rumbold (2003, p. S12), drawing on Lartey (1997), describes spirituality as the web of relationships that give coherence to our lives and that religion may or may not be a part of such a web. Rumbold (2003) points out that often people only become aware of strands in the web when they are stretched or broken, which may happen during life-changing events like a diagnosis of serious illness in oneself or loved ones. According to Lartey (1997) cited in Rumbold (2003), this web of relationships involves relationships with places and things, with ourselves, with significant others, with groups or communities and with transcendence. These relationships form a unique pattern for each of us, and each of us needs that pattern to be largely intact in order to feel whole. This is consistent with Sulmasy's (2002) relational understanding of healing. Lartey (1997), cited in Rumbold (2003). maintains that: "Our web of key relationships defines who we are, and when those relationships are disrupted, we feel vulnerable." Klass (1999) cited in Rumbold (2003) maintains that a good way to think about spiritual life is to look for those moments when we feel most deeply connected to our world. When we feel least isolated inside our usual ego boundaries, we feel a part of something larger than ourselves, and the rest of the world makes sense (Klass, 1999).

10.1.4 Consolation through Existential meaning making

Drawing on Frankl (1969), Park (2013) points out that meaning is widely regarded as central to human experience. If fundamental relations or conditions in life are broken, sources of meaning are used to restore the balance between the individual's expectations of life and the reality as it is experienced here and now. Such reappraisal and usage of sources of meaning are essential when one is confronted with demanding life situations (Sørensen et al., 2015). Norberg et al. (2001) point out that people who suffer, experience a loss of meaning and integrity because "everything falls apart". Inspired by the existential philosopher Søren Kierkegaard, they (2001) state that it is "in

the fearful moments of desolation where there is no meaning left that a brave statement of consolation penetrates the darkness and creates new meaning. This happens on the border where nothing is possible anymore" (Norberg et al., 2001, p. 545). Henceforth, assisting patients in their existential meaning making, which according to Schnell's (2009), research may or may not involve a transcendent dimension, is also an important part of conveying consolation.

Schnell (2009) defines meaningfulness as a fundamental sense of meaning, based on an appraisal of one's life as coherent, significant, directed and belonging, and she (2009) categorizes sources of meaning in the following groups: S*elf-transcendence*, which concerns one's commitment to objectives beyond one's immediate needs. V*ertical self-transcendence,* which consists of religion and spirituality, that is orientated towards an immaterial cosmic power. *Horizontal self-transcendence*, which is linked to taking responsibility for (worldly) affairs beyond one's immediate concerns. S*elf-actualization* refers to employing, challenging and fostering one's capacities. *Order* is linked to holding on to values, practicality, decency and the tried and tested. The last of Schnell's (2009) sources of meaning is categorized as *wellbeing and relatedness*, which involves cultivating and enjoying life's pleasures in privacy and company.

Schnell's (2009) research on existential meaning making takes a secular European context into account (la Cour, 2008; la Cour & Hvidt, 2010), which makes it especially relevant for the study's Norwegian health care context, where a majority of the population either define themselves as "*secular"* or "*spiritual but not religious"* (Botvar & Schmidt, 2010; Aadnanes, 2008). In the following, Schnell's (2009) sources of meaning will therefore be applied to interpret the consolation narratives.

In the first narrative (paper I p.4), the patient wished to withdraw from her existential suffering in a daze of Morphine and Stesolid. In her conversation with the patient, the doctor asked the patient if she was bitter because she was going to die so young. By confronting the patient with her vulnerability, the doctor literally "held up a mirror" which challenged the patient to reflect on the meaning of her suffering. According to the nurse, the patient looked the doctor squarely in the eye and exclaimed that she was not bitter because her years of illness had contributed to growth and maturity beyond her

age (paper I p.4). The nurse believed that this conversation generated a shift in the patient's way of dealing with her situation because she went home to set her affairs in order and she reconnected with her mother and sister. This suggests that the doctor stimulated the patient's process of existential meaning making related to horizontal forms of self-transcendence: self-actualization, order, wellbeing and relatedness (Schnell, 2009).

In the second narrative (paper II p. 6), the patient's need for meaning seemed to be related to order (wishing to complete the family home renovation before she died) and horizontal self-transcendence, since fixing up the family home also involved the patient's need for meaning by taking responsibility for (worldly) affairs beyond her immediate concern (Schnell, 2009). The patient's need for meaning was also related to wellbeing and relatedness (Schnell, 2009), because she was afraid that she would cease to exist after death, and that this would cut her off from her loved ones. According to the nurse, the patient seemed to draw consolation from the possibility of reuniting with her loved ones in the hereafter.

In the last narrative (paper II p.6-7), the patient's need for meaning was linked to vertical self-transcendence, wellbeing and relatedness (Schnell, 2009). The patient suffered from physical and spiritual pain, because she thought she had to endure her pain as God's punishment for her sins. By praying with the patient and talking with her about why she thought God was punishing her, the nurse was able to help the patient to find peace with God. This allowed the patient to accept morphine from the nurse, which alleviated her physical suffering.

To summarize the results of this interpretation in Schnell's (2009) terms: Conveying consolation was about assisting patients in their existential meaning making related to *the horizontal relational dimension*: - helping patients to repair and maintain their relationships with family members (narrative 1 and 2). It also involved assisting patients in their existential meaning making related to the *vertical relational dimension*: - helping the patient to find peace with God (narrative 3).

This is in line with Reed's (1992) understanding of spirituality. According to her (1992), spirituality specifically refers to the propensity to make meaning through a sense of relatedness to dimensions that transcend the self in such a way that empowers and does not devalue the individual. Reed (1992) points out that this relatedness may be experienced intra-personally (as a connectedness with oneself), interpersonally (in the context of others and the natural environment), and trans-personally (referring to a sense of relatedness to the unseen, God or power greater than the self and ordinary sources which implies an expansion of boundaries, inward, outward and upward: "Spirituality then is manifested through these various patterns of connectedness, in which one steps beyond the structures of everyday existence to endow the ordinary with extra-ordinary meaning". (Reed, 1992, p. 350)

The nurses' consolation efforts which evolved around enabling their patients to regain and maintain their relatedness to self, significant others and to God correspond with Schnell's (2009) concept of existential meaning making and Reed's (1992) transcendental and relational understanding of spirituality.

10.1.5 The Power of Consoling presence

Although the nurses experienced that they managed to console their patients when they were able to help them find meaning in their suffering, the results also show that this was not always possible. The nurses expressed that: "There is such a thing as pointless suffering!" and that they sometimes just had to accept that: "Things don't always have a deeper meaning" (paper II p.8). In these situations, the nurses felt that conveying consolation by "just being there" to share the patient's suffering was more important than trying to resolve their spiritual and existential issues. The nurses experienced that embracing the silence together with their patients could have a powerful consoling effect, and they expressed that this demanded a mental shift from focusing on "doing something for the patient" to "being with the patient" (paper I p. 3, paper II p. 8, paper III p.5). The nurses experienced that they had an important function as "emotional containers" when they just stood by their patients, listening and encouraging them to vent their thoughts and feelings which could involve tears, grief and sorrow as well as anger and frustration: "It doesn't do any harm if people start to cry. I usually tell my

patients that they don't have to feel ashamed of their tears. Tears are only melting ice." (paper II p.8) The nurses also pointed out that some patients could be too tired to talk needing the nurse's consoling presence. Eventually there would come a point in time when it was too late for words, and in some cases words lost all meaning due to the brevity of the situation: "When they are so sick that they are vomiting their own fecal matter, the only thing you can do is to be there, holding them, comforting them and warming them". (paper I p. 3)

According to the nurses, what patients needed most, were nurses who were willing to endure and stand by their patients, containing the patients' emotions and showing them that they would not be abandoned in their time of need (paper I p.3, paper II p. 8) "- just being there sharing the pain and letting them talk, if that's what they need, sometimes that's all you can do" (paper I p. 3). This is supported by Rushton et.al. (2009, p. 407), who define presence as the capacity to "be fully there with a quality of attention and authenticity that informs relationships and actions". According to them (2009), modern medicine's emphasis on "curing, fixing and doing" (which may no longer be appropriate when people are dying) must be balanced with the quality of being present with those who are suffering, and they point out that being present with the dying and bearing witness to their suffering are healing acts in themselves and are often "enough" (Rushton et al., 2009).

10.1.6 Consolation understood as a moral responsibility

According to Nortvedt (1998), "to encounter a patient's pain and understanding that pain as suffering is to be struck by the other's agony as a moral reality" (Nortvedt, 1998, p. 387). Hence, Nortvedt (1998) maintains that nurses have a moral responsibility to be answerable for the patients' condition, pain, suffering and vulnerability. Following Nortvedt (1998), it can be argued that nurses have a responsibility to convey consolation as a means to ease their patients' spiritual and existential suffering.

This will be explicated in light of the Norwegian nursing philosopher Kari Martinsen's *philosophy of care* (Martinsen, 1993, 2000, 2006) and the Danish philosopher and theologian K. E. Løgstrup's relational ethics (Lindseth, 1992, pp. 102-103) , with special

reference to *"The Ethical Demand"* (Løgstrup, 1956, 1997)[1]. These thinkers were chosen, because their relational perspectives are consistent with the nurses' emphasis on the relational dimension of consolation. Martinsen (1993, 2000, 2006) anchors her philosophy of care in Løgstrup's ideas about "*the ethical demand"*(Løgstrup, 1997) and *the sovereign expressions of life* (Løgstrup, 2007)[2]. As these ideas are decisive to understand Martinsen's philosophy of care (Delmar, 2012) they will be outlined briefly before we proceed to Martinsen's thoughts on care.

"The Ethical Demand"

In The *Ethical Demand*, Løgstrup (1997) maintains that human beings are always already entangled or intertwined with, and in the life of others, and that this is a basic ontological fact of human existence, which is prior to our constitution as individuals. For Løgstrup (1997), to exist as human beings is to exist with others. Although we may tend to view another person's world as separate from our own, Løgstrup points out that this is not so. On the contrary: "We are each other's world and each other's destiny" (Løgstrup, 1997, p. 16) and Løgstrup is very clear about the consequences of this mutual entanglement. For him, the ethical demand is implied "by the very fact that a person belongs to the world in which the other person holds something of that person's life in his or her hands, it is therefore a demand to take care of that person's life" (Løgstrup, 1997, p. 22). The ethical demand is silent in that it is unspoken, unarticulated and merely implicit. Moreover, it is not identical with any demand that the other person lays on you. Rather, it demands that you, to the best of your knowledge, do what will benefit the other person. In addition, the ethical demand is radical, unconditional and absolute, which means that you must act exclusively and unselfishly for the sake of the other, regardless of who the other person is or your relationship to that person (Løgstrup, 1997, pp. 44-46).

[1] *The Ethical Demand (Den Etiske fordring),* (Løgstrup, 1956)) was translated from the original Danish in 1997.

[2] Løgstrup elaborated on his conception of "the sovereign expressions of life" in *Opgør med Kierkegaard* (Løgstrup, 1968) and several later ethical works (van Kooten Niekerk, 2007). Major excerpts from these Løgstrup texts were translated from Danish in *Beyond the Ethical Demand* (Løgstrup, 2007).

Løgstrup (2007) maintains that we are bound to the world through *such sovereign expressions of life as trust, openness of speech, hope* and *mercy.* These expressions belong to the very basics of life and they are given by life itself. They are relationally lived and experienced and they appear spontaneously through our engagements with one another. They make claims on us through our embeddedness in the world, which according to Løgstrup (2007), subjects us to the radical demand to care for others. As ways of taking care of others, the sovereign expressions of life fulfill the ethical demand, - before the demand has even made itself felt. However, the ethical demand does not make itself felt until the sovereign expressions of life fail. Løgstrup (2007) states that the aspect of duty and morality sets in when we are tempted to pass by a person who is in need of our help. When the drive to perform an act of mercy stems from our moral deliberations, our act is reduced from a spontaneous life expression to duty for duty's sake. As Løgstrup (2007, p. 76) points out: "Duty enters when I am trying to wriggle out of the situation". As soon as openness of speech, hope and mercy are instrumentalized their spontaneity is broken, which destroys them and turns them into their opposite. If mercy for instance, is made to serve oneself or a third party, it is no longer mercy but unmercifulness. Accordingly, the sovereign expressions of life defy being made a means to other goals than their own, which is the immediate service to one's neighbor (Løgstrup, 2007). However, Løgstrup does not provide specific rules and guidelines about how to act. Rather, he asserts that it is up to each individual to use his or her insight, understanding and imagination to figure out what the demand requires (Løgstrup, 1997, p. 22).

Drawing on *The Ethical Demand* (Løgstrup, 1997), Kari Martinsen's caring philosophy (Martinsen, 1993, 2000, 2006) takes on a relational perspective (Delmar, 2012). Using Løgstrup's terms (Løgstrup, 1997, 2007), Martinsen (1993, 2000, 2006) maintains that the patient understood as *"the other",* makes a physical impression on the nurse through his or her senses, which generates an "appeal to look after the other's life" (Martinsen, 1993, p. 19). According to Martinsen (1993, 2000, 2006), the appeal to care for the patient is powered by the ethical demand (Løgstrup, 1997), which challenges us to act in the best interest of "the other" and "to take care of the life which trust has placed in our hands" (Løgstrup, 1997, p. 18). Being moved and touched by the ethical appeal from the patient compels the nurse to care for him or her. Accordingly, something about the

patient must appeal to the nurse to create an awareness of the patients' plight (Martinsen, 2000, 2006). Following Løgstrup (Løgstrup, 1997, 2007) and Martinsen's (2000, 2006) line of thought, the nurses' spontaneous and compassionate reactions to their patients' suffering suggests an implicit acceptance of their moral responsibility to be answerable to the ethical demand. As Martinsen (2006, p. 89) points out: "Perceiving the other is already being in an ethical relationship to him."

"*The Mastery of Seeing"*

However, Martinsen (2000, p. 17) also notes that people respond differently to the suffering of others, and that how they respond, depends entirely on their ability "to see". Accordingly, to respond to the patients' ethical appeal, Martinsen (2000, 2006) asserts that nurses must engage in "a mastery of seeing". Drawing on Løgstrup's (1971) interpretation of the parable about the Good Samaritan, in The New Testament, Luke 10: 25-37 (Biblegateway, 2011), Martinsen (2000, 2006) reflects on what it means, "to see". In the parable Jesus tells about the reactions of a priest, a Levite and a Samaritan when they discovered a half dead waylaid man. When the priest and the Levite saw the victim, the parable states that they passed him by on the other side of the road, leaving the victim to his own devices: "But a Samaritan, as he traveled, came where the man was; and when he saw him, he took pity on him*"* (Luke 10:33, Biblegateway, 2011).

Martinsen (2000, 2006) emphasizes that it was *the sight* of the battered and bleeding man that generated the Samaritan's pity for him. Coming over to the half dead man the Samaritan did not stand there analyzing the situation. Rather, the sight of the victim's bodily pain, struck the Samaritan with a gut wrenching force, which propelled him into action. As Martinsen points out: "The open and receptive eyes of the Samaritan were struck by the other and the situation he was in, and with pity and great pain he could do nothing but nurse and dress the victim's wounds" (Martinsen, 2006, p. 84). Martinsen (2000, 2006) emphasizes that the Samaritan "saw with his whole body" through his senses and was touched. According to her, the Samaritan "saw with his "heart's eye", because his attention was drawn to the suffering victim instead of his own painful feelings and self-pity, which were induced by the sight of the battered man (Martinsen, 2000, 2006). As the situation became clear to him he experienced an immediate

identification with the wounded man, - that "the other" like himself was a fellow human being, while at the same time, "the other" was also different from him, as a victim in need of help. Martinsen (2000, 2006) asserts that like the Samaritan, nurses must also see through their "heart's eye" in order to perceive the ethical appeal from the patient. The nurse must identify with the patient as a fellow human being, while at the same time being aware of their differentness, because the patient is in need of the nurse's help.

Thusly, drawing on Løgstrup (1971, 1997), Martinsen (2000, 2006) asserts that "Seeing with the heart's eye" implies that the professional nurse must dare to be a human being who is open to his or her emotions, while at the same time holding them back to allow the patient to emerge in order to find out what serves him best. Martinsen (2000, 2006) maintains that deciding on the right and best care requires a "friendly interaction" between the nurses' spontaneous, sensory-based and pre-reflective impression of the patient (we are touched and moved before we understand) and her reflective understanding of the patient's illness, (which is based on her professional judgment). While the nurse is spontaneously moved to care for the patient by her immediate impression, her reflective professional judgment enables her to act in the best interest of the patient.

The results reveal that it could be challenging to get a grip on what really troubled the patient. The nurses experienced that the patients' spiritual and existential suffering was frequently embedded and entangled in a web of psychosocial and physical pain, which made it difficult to sort out (paper I p. 5, paper II p. 5, paper III p. 5). They therefore needed to use their clinical judgment to reflect on their immediate emotional impressions to decide on the right course of action to alleviate their patients' suffering. This is illustrated in the following quotes:

> I remember one man who was terribly restless and anxious. He couldn't sleep. No matter how I asked him he just said that he hurt all over. But it must have been more than the physical pain because he was receiving strong analgesics through two different pumps. I often wonder if we could have done more for him. I got the impression of a very sad and lonely man. (paper I p.5)

> There was this young woman with Cancer of the pancreas. She was constantly craving Morphine and Stesolid. It seemed like she wished to float away from all her existential pain, but it was still there, underneath the drug daze. (paper I p.4)

In the nurses' experience, such "never ending" requests for extra pain medication or tranquilizers usually suggested some kind of underlying distress which needed further looking into and they had therefore developed a keen eye to pick up implicit clues, and to exercise their clinical judgment to find the sources for the patient's suffering and to decide on the appropriate interventions.

The "Ethical Demand" and the "seductive pull" of helping

As mentioned earlier, Løgstrup (1997) maintains, the ethical demand and "the sovereign expressions of life defy being made a means to other goals than their own, which is the immediate service to one's neighbor. This implies that any other motivational drive to convey consolation whether overt or covert corrupts the sovereign expressions of life in the nurse-patient relationship. However, it is important to note that the familiarity and trust which develops between a nurse and a patient, coupled with the seductive pull of helping, the complexity of the patient's treatment needs, and a potential lack of understanding of the patient's boundaries can threaten the integrity of the nurse's relationship with her patients. This may ultimately lead to a violation of patient autonomy (Peternelj-Taylor & Yonge, 2003). Paradoxically, being deeply moved and touched by a patient's suffering may put nurses at risk of overstepping their professional boundaries (Peternelj-Taylor & Yonge, 2003). Martinsen (2000, 2006) takes this into consideration in her crucial distinction between "emotionality" and "seeing emotions". According to Martinsen (2000, 2006) when a nurse is stricken and stuck in "emotionality" the nurse circles around her own needs and emotions, "and limits the other to being drawn into her own horizon", whereas in the perceptive, "seeing emotions" the nurse centers her attention on the patient's experience of suffering because the patient is perceived as "the other" which concerns and appeals to the nurse (Martinsen, 2006, pp. 74-75). In light of "the ethical demand" (Løgstrup, 1997), this implies that the patient must be met where he or she is spiritually and existentially situated at the moment.

It is therefore important to keep in mind that there exists a power differential between the nurse and the patient, which cannot be overlooked. By its very nature the therapeutic nurse-patient relationship is asymmetrical. The patient by virtue of needing help is automatically placed in a position of vulnerability; while the nurse on the other hand assumes a position of power through the role of the helper (Martinsen, 2000, 2006; Peternelj-Taylor & Yonge, 2003). Peternejl -Taylor and Yonge (2003) point out that nurses embrace many roles in their personal and professional lives, and are involved in "the dance of relationships". If nurses forget which "dance they are dancing" or which role they are assuming, their own needs can become most important to the relationship. Henceforth, there is a need for caution and ethical awareness, in order to avoid intrusiveness and violation of patient autonomy (Peternelj-Taylor & Yonge, 2003).

This is echoed in the results of the study, which show that the nurses reflected on their ethical challenges related to encouraging patients to share their suffering. While the nurses experienced that patients who were able to express their feelings often died more peacefully than those who "bottled everything up," (paper I p.3, paper II p.7), they also stressed that they had to put aside their own views and personal needs to reach in to patients who were unwilling or unable to share their suffering. The nurses emphasized that they were professionally and ethically obliged to respect the patients' choice. "Who are we to judge what is best for them", they reflected (paper I p.3) and they pointed out that there are no easy answers because every patient is different (paper I p. 4). It was therefore crucial to sense the turning points, when patients became ready to share their suffering and receive consolation. According to the nurses this demanded a good sense of timing, situational understanding and the ability to "tune in on" patients' verbal and nonverbal cues whilst performing nursing care (paper I p. 5, paper II p. 5, paper III p.7).

This resonates with Løgstrup's (1997, p. 15) emphasis on tuning in to listen to "the note, which is struck". According to Løgstrup (1997) this is essential in every conversation, because we deliver ourselves over into the hand of another in the speech relationship, which demands basic trust: "That all speech takes place in such fundamental trust is evident in the fact that the most casual comment takes on a false note if one believes that

it is not accepted in the sense that is intended". (Løgstrup, 1997, p. 15) Thusly, if a nurse ignores or does not hear the note in what the patient says, then that nurse is at risk of violating her patient's integrity, which in turn will violate the patients' basic trust in her. Inspired by Løgstrup (1997), Martinsen (2006, p. 60) asserts that "the tone"[3] points to a common world and provides a context of interpretation for what is going on in the situation, and she emphasizes that the nurse and the patient together must find "the tone" in the situation which enables both parties, - nurse and patient – each in their own way, to dare to come forth.

10.2 Vulnerability and helplessness

When the nurses were asked to narrate about their experiences with spiritual and existential care, their consolation narratives evolved around their efforts to help their patients to find peace and harmony during the final stages of dying (paper I and II). The results show that the nurses felt they had been successful when they were able to unburden some of the patients' most pressing sources of anxiety and distress (paper II p.12). This is illustrated in the three consolation narratives, in section 10.1.2, which show that the nurses managed to help their patients to restore their *intra, inter and transpersonal relationships,* -their relationship with, self, loved ones and with God (Reed, 1992). Regaining these relationships enabled the patients to transcend the isolating spiritual and existential loneliness of dying. As such, these consolation narratives can be characterized as "successful" consolation narratives.

However, the nurses also narrated about "unsuccessful" consolation experiences, which could make them feel professionally inadequate and helpless. Although the nurses acknowledged that suffering and dying are facts of life, which cannot be completely alleviated, they found it difficult to accept that they could not alleviate their dying patients distress (paper I p.6, paper II 7-8). This is highlighted in the following quote:

> A young cancer patient anxiously battled death till the bitter end. All of us thought it was terrible the way he died! We really tried, but nobody could help him find peace, because **he simply refused to die**! We sat there holding his hand, listening to him. But he was completely inconsolable! It was very, very

[3] (or in Løgstrup's (1997) terms "the note")

> challenging and frustrating even though we know that we probably did all we could! (paper II p.7)

Bearing witness to patients who continued to radiate anguish, protest and despair in spite of the nurses' consolation efforts was experienced as emotionally challenging and draining. The "unconsolable patients" were looked upon as problematic, forming the focus of peer support and debriefing (paper I p.6 -7, paper II p.7-8). In addition, the nurses found it challenging to bear witness to the dying patients' suffering because it exposed them to their own latent fears of mortality and vulnerability (paper I p.6, paper II p.8). As one nurse pointed out:" You have to come to terms with your own thoughts and feelings about your own vulnerability to endure working here over time. It's a demanding job! Not all nurses are cut out to care for the dying" (paper II p. 8).

In paper III the mobile hospice nurse teaching team stated that the care workers' main obstacle to engage in spiritual and existential care was their fear and uncertainty of facing dying patients' suffering (paper III p.4 - 6). It seems reasonable to assume that like the nurses in paper I and II, the care workers' reluctance to be with the dying stemmed from their fear of relating to their own mortality and vulnerability.

While vulnerability and suffering are ontological conditions of life, which are experienced by all humans (Heidegger, 1962; Turner & Dumas, 2013), working on the edge between life and death poses daily psychosocial challenges which force nurses and care workers to become acutely aware of the fragility of life (Najjar, Davis, Beck-Coon, & Doebbeling, 2009). Research shows that the emotional stressors related to caring for patients who are suffering and/or dying, place nurses and care workers in a unique position of vulnerability (Gjengedal et al., 2013). Recent research indicates that emotions are felt in the body (Back, Rushton, Kaszniak, & Halifax, 2015). This resonates with the results in this study, which show that the nurses' spontaneous impressions of their patients' suffering could be so strong that they described it in terms of physical sensations in their own bodies:

> We feel the fear and desperation the moment we enter the room even though it isn't ours. I have entered rooms I just have to get out of. The atmosphere is so loaded with sorrow. **It's like a physical sensation. The grief just hits you like a wall!** How do you deal with that? (paper I p.5)

> I can become very overwhelmed when patients share their innermost thoughts and feelings about life and death! **It almost knocks me out sometimes!** (paper II p.7)
>
> Their emotional anguish can be so strong. It's often worse than the physical pain! **It's like their hearts are being torn out!** How do you relieve that kind of pain? (paper I p. 3)
>
> You become quite fond of the patients! Sometimes **they just leap into your heart**! (paper I p. 6)

According to Benner & Wrubel (1989), cited in Raingruber & Kent (2003), bodily responses are stronger when one is deeply involved with and concerned about a situation. Furthermore, Benner (2000a) points out that the empirical research of cognitive scientists and neurobiologists (Damasio, 1999; Lakoff & Johnson, 1999; Rosch, 1981) reveals that emotions and embodied feelings, sensori-motor perceptions and skills shape rational thought and knowing and that the social, sentient, sensori-motor body plays a key role in thought and action. Hence, when a nurse feels that her patient is suffering so much that "it seems like his heart is being torn out" (paper I p.3)" and she becomes so fond of the patient that he "leaps right into her heart" (paper I p.6) it seems reasonable that the patients' pain will resonate in the nurse's "own heart". This was especially the case when the nurses cared for patients who reminded them of themselves: "One of my patients had a little baby. That was really tough because I am a mother myself!" (paper II p.7).

10.2.1 Vulnerability and embodied engagement

After a brief return to Kari Martinsen's caring philosophy (Martinsen, 2000, 2006), the nurses' physical reactions to their patients' suffering will be discussed in light of Merleau-Ponty's (1962) concept of *embodied engagement*. As mentioned in section 10.1.6, Martinsen (2000, 2006) points out that in order to respond to the ethical appeal from the patient the nurse must dare to *"see with her heart's eye"*. This implies that the nurse is willing to take in the patient's suffering through her open and receptive eyes and that this compels her to alleviate the patients' suffering. Martinsen (2000, 2006) points out that for the Samaritan, the bodily pain of the waylaid man struck him close, without distance: "The Samaritan saw with his heart's eye, with his whole body which

was painfully open and receptive, turned towards the other, attentively trying to understand with thought and will as well, what is at stake" (Martinsen, 2006, p. 86).

According to Martinsen (2006, p. 89):

> The openness of perception can be terrifying. In the eyes of the Samaritan the pain of the other struck into his body. He stood receptive and open but did not know what he was looking for. He only felt it, that the pain of the other concerned him.

Both the Samaritan's and the nurses' physical reactions which stemmed from "seeing the sufferer" through their "heart's eye" (Martinsen, 2006) can be understood in light of Merleau-Ponty's (1962) concept of embodied engagement.

Merleau-Ponty (1962), cited in Ray (2006), conceptualized the body as catching, comprehending and spontaneously responding to the communications of another person, which he defined as embodied engagement. According to Merleau-Ponty (1962), cited in Ray (2006), embodiment reflects how we live in and experience the world through our bodies, especially through perception, emotion, language, movement in space, time and sexuality. Merleau-Ponty (1962), cited in Ray (2006), maintains that existence can only be known in and through the body because the phenomenal body is the only means of being in the world. In the nursing context illness, pain, and disability are essentially constituted as embodied experiences (McDonald & McIntyre, 2001). Hence, to be engaged with the patient, the nurse must be engaged with the patient's existential, subjective and embodied being: "It is the patient's body as both object and subject that calls out for our ministerings" (Hess, 2003, p. 145).

Drawing on Løgstrup (1997), Merleau-Ponty, Dreyfus, and Dreyfus (1964) and Martinsen (1997), Benner (2000a), maintains that good nursing practice relies on the human backdrop of embodiment and our embodied capacities to experience "the spontaneous sovereign expressions of life" (Løgstrup, 1997), which include trust, mercy, openness of speech, and our common human condition of finitude, dependency and interdependence. In light of Løgstrup (1997), she (2000a) also points out that it is the immediate experience of embodiment, which enables the nurse to respond spontaneously with mercy, with no additional thought or calculation. Nevertheless,

bearing witness to suffering can be agonizing. According to Malone (2000), witnessing, - or in Martinsen's (2000, 2006) terms seeing with "the heart's eye" is qualitatively distinct from mere looking; witnessing *engages* the nurse as a bearer of truth that the suffering person cannot tell. Malone (2000) maintains that this aspect of nursing practice is largely unacknowledged, and that the vulnerability it requires nurses to experience is rarely addressed. Two notions of vulnerability dominate in the nursing literature according to Malone (2000). One, which might be called a public health model of vulnerability, equates vulnerability to the susceptibility to particular harmful agents, conditions or circumstances. As such, vulnerability is something to be avoided or resisted. The other view regards vulnerability as the common condition of all sentient beings. According to this perspective, vulnerability is a constant condition of human experience, a commonality that we share by virtue of our embodied existence and our finitude. As such vulnerability gives access to understanding aspects of the patients' experiences and is regarded positively (Malone, 2000).

Acknowledging their own as well as their patients' vulnerability, sharpens the nurses' sensitivity, which enables them to open themselves to their patient's situation (Norberg, 2001; Sarvimäki & Stenbock-Hult, 2014). As embodied and vulnerable beings, nurses can experience their patients' world and engage in the ill persons' embodied experience (Hess, 2003). This enables nurses to understand more than what is being said and observed, because their impression of the patients' condition manifests itself as embodied sensations and physical responses before the nurses can understand these impressions intellectually (Martinsen, 2000, 2006; Raingruber & Kent, 2003).

10.2.2 Compassion fatigue

Research shows that being deeply engaged in patients' suffering over prolonged periods of time exposes healthcare providers to various forms for occupational stress. (Back et al., 2009; Hardiman & Simmonds, 2013; Sabo, 2008, 2011a, 2011b; Sandgren, Thulesius, Fridlund, & Petersson, 2006; Smart et al., 2014). The concepts of *compassion fatigue, vicarious traumatization, secondary traumatic stress* and *burnout* have been compared and used interchangeably within the literature. Although these concepts, have

significant similarities they also have significant differences (Najjar et al., 2009; Smart et al., 2014).

For the purpose of this study it will suffice to discuss the results in light of the concept of *compassion fatigue* which has received considerable attention as a potential form for occupational stress during recent years (Sabo, 2011a). Compassion fatigue has been described as "the natural consequent behaviors and emotions resulting from knowing about a traumatizing event experienced by a significant other – the result from helping or wanting to help a traumatized or suffering person" (Figley, 1995, p. 7), cited in Sabo (2011a).

According to Sabo (2011a), several studies suggest that compassion fatigue is connected to the therapeutic relationship between healthcare providers and patients, in that the traumatic or suffering experience of the patient triggers a response on multiple levels in the health care provider. In particular, an individual's capacity for empathy and ability to engage, or enter into a therapeutic relationship is considered to be central to compassion fatigue. Providing assistance to individuals experiencing pain, suffering or trauma, the professional may experience adverse effects similar to their clients. Coetzee and Klopper (2010) claim that compassion fatigue is the final result of a progressive and cumulative process, which is caused by prolonged, continuous, and intense contact with patients, the use of the self and exposure to stress. The physical effects of compassion fatigue include weariness, loss of strength, reduced output, diminished performance, loss of endurance and increased physical complaint. The emotional effects include lessened enthusiasm, desensitization, diminished ability, irritability and being emotionally overwhelmed. The social effects include an inability to aid and share in the suffering of patients. Compassion fatigue is said to occur when health care providers closely identify with their patients and personally absorb the patients' trauma or pain. It results from giving high levels of energy and compassion over a prolonged period of time, particularly when nurses do not experience the positive outcomes of seeing patients get better (Najjar et al., 2009). In light of the afore-cited literature, it seems reasonable that the nurses were at risk of developing compassion fatigue because of their deep relationships with patients, and their emotional and embodied reactions to their patients' suffering.

However, Sabo's (2011a) study of the HSCT nurses' psychosocial health, found that *compassionate presencing* and involvement in the nurse-patient relationship may actually provide a potential buffering against the adverse effects of caring for the seriously ill and dying, whereas distancing or disengagement through *emotional survival strategies* such as *emotional shielding, emotional processing* and *emotional postponing* (Sandgren et al., 2006) may increase the risk of experiencing compassion fatigue and other types of occupational stress.

According to Sabo (2011a), there exists a significant difference between "compassionate presencing" and "emotional survival strategies". Where compassionate presence reflects the notion of: "being with", - a living out of the caring nature of nursing through connections and relationships, emotional survival generally attends to strategies or methods to address a problem, "in essence to "avoid being with" (Sabo, 2011a, p. 109). Sabo (2011a) maintains that compassionate presence conveys a positive tone, where connection or relationships carry benefits, while emotional survival (Sandgren et al., 2006), suggests that caring may lead to negative effects, which nurses may postpone by employing various avoidance strategies. However, Sabo (2011a) does not claim that the potential risk for psychological /emotional pain as a result of caring relationships is non-existent if one is "compassionately present" rather she points out that caring should be perceived as a double-edged sword and that the potential for adverse psychosocial effects such as compassion fatigue may be reduced if nurses are able to be compassionately present. According to Sabo's(2011a) study, the HSCT nurses needed to remain vigilant about whose pain and suffering was being shared. A failure to establish clear boundaries between the personal and professional could place the nurse at risk for adverse effects. Sabo's (2011a) results are consistent with the results in this thesis, which show that the nurses strove to strike a balance between disengaging and over-engaging in their patients' suffering. This aspect has been thoroughly discussed in paper II p. 10.

Sabo (2011a) points out that "compassionate presence" is a way of being and connecting, which requires the nurse to be authentic/ genuine, open and available to share in the ethical-moral moments of their patients and families. Compassionate presence is a reflection of holistic nursing practice embracing the physical,

psychological, emotional and spiritual domains. This bears close resemblance to the nurses' emphasis on sharing their patients' suffering through consoling presence and relationship maintaining activities (paper I p. 3-5 and paper II p. 6-7).

10.2.3 Compassion satisfaction

Coetzee and Klopper's (2010) distinction between *"compassion fatigue"* and *"compassion satisfaction"* supports Sabo's (2011a) study. Coetzee and Klopper (2010) point out that although nurses are exposed to the exact same risk factors of contact, use of the self and stress, some nurses continue to flourish in these circumstances. According to Coetzee and Klopper (2010) nurses who experience compassion satisfaction are able to connect with their patients regardless of the circumstances, which leads to meaningful and purposeful interactions between nurses and their patients, whilst nurses who experience compassion fatigue, gradually distance and isolate themselves from their patients, which results in the fact that neither the nurses' nor the patient's needs are fulfilled.

Sabo (2011a) and Coetzee and Klopper 's (2010) studies suggest that being deeply involved in the nurse-patient relationship may provide more protection against compassion fatigue than using emotional survival strategies (Sandgren et al., 2006) to avoid the painful impact of witnessing dying patients' suffering. While the process of compassion fatigue is cumulative and progressive, moving from discomfort to stress and finally to fatigue, the process of compassion satisfaction is restorative and circular, presenting a symbiotic relationship between the patient and the nurse, as each finds fulfillment in the other (Coetzee & Klopper, 2010). It is interesting to note that Coetzee and Klopper's (2010) definition of compassion satisfaction resonates with Norberg et al.'s (2001) claim that nurses and patients may experience mutual consolation through communion and dialog.

While the results in this study show that bearing witness to "unconsolable" patients' suffering could be emotionally draining and challenging (paper II p.7), they also reveal that the nurses felt that conveying consolation could be deeply meaningful and rewarding (paper I p.6, paper II p.7). Bearing witness to a patient's peaceful passing

filled them with reverence and awe: “The room was very quiet and the patient died calmly and peacefully. It was a very special moment” (paper II p. 7), and the nurses expressed that they felt “honored and touched” when the patients shared their trust and chose to confide in them (paper II p.7).

In light of Sabo’s (2011a) and Coetzee and Klopper’s (2010) studies, it is interesting to note that none of the nurses mentioned that they had considered changing their line of work or taking a leave of absence, although they could feel emotionally drained and helpless when they were unable to console their patients. Taking this into consideration and the fact that the nurses’ working experience in end-of-life- care ranged from five to thirty-five years, it seems reasonable to assume that the nurses experienced sufficient *compassion satisfaction* through their relationships with the dying that it counter-balanced possible adverse effects of compassion fatigue. These results, together with the afore mentioned studies underscore the value of the relational dimension in consolation work (paper I p. 3-5 and paper II p. 6-7).

10.3 Compassion and Courage

10.3.1 Compassion

According to Rushton et al., (2013) compassion optimally involves a quality of presence that conveys stability and resilience with a balanced concern and heartfelt connection, but is not depleting or overwhelming to either person. Lazarus (1991) points out that compassion implies feeling personal distress at the suffering of another and wanting to ameliorate it: “The core relational theme for compassion, therefore, is being moved by another’s suffering and wanting to help” (Lazarus, 1991, p. 289). This resonates with the results, which show that the nurses were deeply moved and touched by their patients and yearned to console them (paper I p.6, paper II p.7). However, the results also indicate that the nurses in paper I and II, as well as the care workers in paper III, could be ambivalent and reluctant to address their patients’ spiritual and existential anguish because it confronted them with their own vulnerability and latent fears of suffering and death (paper I p. 7, paper II p.8, paper III p. 4-5).

These reactions are understandable according to Sasser and Puchalski (2010, p. 3). They (2010) point out that caring for dying patients over the course of their illness trajectory exposes health care providers to gut-wrenching stories of human tragedy, which over a period of time may evoke a certain amount of *"accompaniphobia"* that may lead to avoidance strategies (Sandgren et al., 2006). According to Sasser and Puchalski (2010) the tendency to avoid addressing patients' suffering may stem from a possible resonance with unhealed wounds deep within the health care providers' own souls that needs further work on their part. This suggests that nurses and care workers must possess courage as well as compassion in order to suspend their personal reluctance and anxiety no matter how disquieting this might be in order to accompany the dying where they want to go, when they want to go there, and whether the nurses and care workers want to or not (Sasser & Puchalski, 2010). Taking this into consideration, it is interesting to note that the word compassion is derived from the Latin "*pati"* and "*cum"* which literally means, "to suffer with" (Nouwen, McNeill, & Morrison, 2008). Nouwen et.al. (2008) point out that:

> Compassion asks us to go where it hurts, to enter into places of pain, to share in brokenness, fear, confusion and anguish. Compassion challenges us to cry out with those in misery, to mourn with those who are lonely, to weep with those in tears. Compassion requires us to be weak with the weak, vulnerable with the vulnerable, and powerless with the powerless. Compassion means full immersion in the condition of being human. When we look at compassion in this way, it becomes clear that something more is involved than a general kindness or tenderheartedness. (Nouwen et al., 2008, pp. 3-4)

Nouwen et al.'s (2008) description of "*the challenge of compassion"* resonates deeply with the nurses' and care workers' challenges related to conveying consolation. While Nouwen et al. (2008, p. 4) state that "Compassion means full immersion in the condition of being human", Norberg et al. (2001, p. 549) maintain that consolation involves being willing to "sink into somebody else's hell and stay there". Being in communion with patients in order to share their suffering (Norberg et al., 2001), - or in Nouwen et al.'s (2008) words: "going where it hurts", demands openness, presence and availability, which creates trust. When the relationship is trusting, there is room to uncover the wound (the cause of the suffering), which calms the suffering patient who dares to look at his or her wounds, while the nurse who mediates consolation by "walking alongside" shows the patient that his or her weakness, grief and expressions of pain are accepted.

In the short perspective "uncovering the wound" may increase the pain because the wound becomes obvious, exposing "all that is ragged and broken" (Norberg et al., 2001, p. 548).

Uncertainty

The results show that the nurses and care workers often felt uncertain about the right and best thing to say or do to alleviate their patients' spiritual and existential suffering. Although in the first consolation narrative ("Breaking the boil" paper I p. 4) the nurse thought that some patients could "need a little push" to help them transcend a depressive spiral of existential loneliness and alienation, the nurses expressed that striking the right balance between mild persuasion and accepting the patients' choices to "bottle up their suffering" could be difficult. Choosing the right approach was fraught with uncertainty, especially related to ethical dilemmas concerning the patients' vulnerability, autonomy and the asymmetrical power structure in the nurse-patient relationship. The nurses expressed that they could never be certain about making the right choice due to unpredictable changes in the patients' condition, and they could also be uncertain about how their patients might react towards their attempts to console them. As the nurses pointed out: "Each patient is different and there are no easy answers." (paper I p. 4)

10.3.2 Courage

These results indicate that to convey consolation nurses and care workers must be willing to expose themselves to their own as well as their patients' vulnerability, to accompany their patients into the experience of uncertainty, and to give up control and self-determination. This demands courage because a window is opened to the unknown (Thorup, Rundqvist, Roberts, & Delmar, 2012). Jordan (2003) defines courage as "the capacity to act meaningfully and with integrity in the face of acknowledged vulnerability "(Jordan, 2003, p. 2). According to Jordan (2003), courage and vulnerability are inextricable linked together and there can be no real courage where vulnerability and fear are denied. Drawing on a feminist perspective, Jordan (2003) points out that the traditional male Eurocentric myth of the courageous, lone individual who defies

vulnerability and fear obscures the fact that we all need encouragement and connection throughout our entire lives, and that having the courage to move beyond certainty and invulnerability enables us to enter the world of learning, curiosity and love. From Jordan's (2003) point of view, courage is built through vulnerability and connectivity, where one's openness to being affected is essential for connection. Without openness people relate inauthentically, adopting roles and coming from distanced and protected places, whereas when we have the courage to be vulnerable, we are capable of being "moved" by our internal affective experience as well as being affected by other people (Jordan, 2003), which enables us to experience compassion for the suffering of others (Lazarus, 1991). Jordan's (2003) understanding of courage resonates with Løgstrup's views on the interdependent nature of human existence and the ethical demand "to take care of the life which trust has placed in our hands" (Løgstrup, 1997, p. 18), as mentioned in section 10.1.6. According to Delmar (2004), cited in Thorup et al. (2012), entering into serious patient relationships demands courage, because it requires a willingness from the nurse to run the risk of rejection. In line with Nouwen et al. (2008) and Norberg et al. (2001), Thorup et al. (2012) point out that theoretical and empirical studies show that the nurses' courage lays in his or her willingness to walk alongside the patients on their journey to overcome their suffering, no matter where the road leads. This journey is highly unpredictable and seems to require the willingness and ability to bear witness to the patients' vulnerability and suffering (Thorup et al., 2012).

Thorup et al.'s research (2012) reveals that courage becomes evident in situations where nurses are capable of coping in an indeterminate situation, of standing out "in the open" of engaging with and listening to vulnerable and suffering patients, in situations that expose them to the risk of rejection. Courage manifests itself as the ability and willingness to help patients to face their own vulnerability and suffering, to bear witness to patients' vulnerability and suffering and to have the self-confidence to argue for and provide for professional care (Thorup et al., 2012). Thorup et al.'s (2012) work resonates with this study, which shows that the nurses and care workers needed courage to overcome their fear and emotional ambivalence to console the dying, because this exposed them to their own fears of mortality, vulnerability and professional helplessness. As previously mentioned courage was especially needed in order to endure being with the "unconsolable" patients. (paper II p.7)

According to Thorup et al. (2012), courage is a prerequisite inner quality and a first step towards the existential caring encounter. This supports the study results, which show that having the courage to overcome their fears and reluctance to be with the dying was a prerequisite for the nurses' willingness to engage in compassionate and consoling relationships with their patients. Thorup et al. (2012) point out that on this existential level, in facing the unpredictable, courage contributes to the nurturance of personal and professional development. In light of Thorup et al.'s (2012) study, it is interesting to note that the nurses in paper II experienced that their older colleagues seemed to be more willing to engage themselves in the patients' spiritual and existential suffering than the younger nurses, and they assumed this was because the older nurses' personal and professional life experiences had made them more mature and robust to bear the weight of the patients' distress than their younger colleagues (paper II p. 12).
(See section 10.4.1, table 1)

10.4 Can courage and compassion be taught?

This study indicates that consoling the suffering and dying is a deeply relational and compassionate activity, which rests on nurses' and care workers' courage to overcome their fear and reluctance to address their dying patients' spiritual and existential distress. This raises important pedagogical questions about how to teach and train nurses and care workers to convey consolation:

- Can compassion and courage be taught?
- What are the pedagogical implications for teaching and training nurses and care workers to convey consolation?

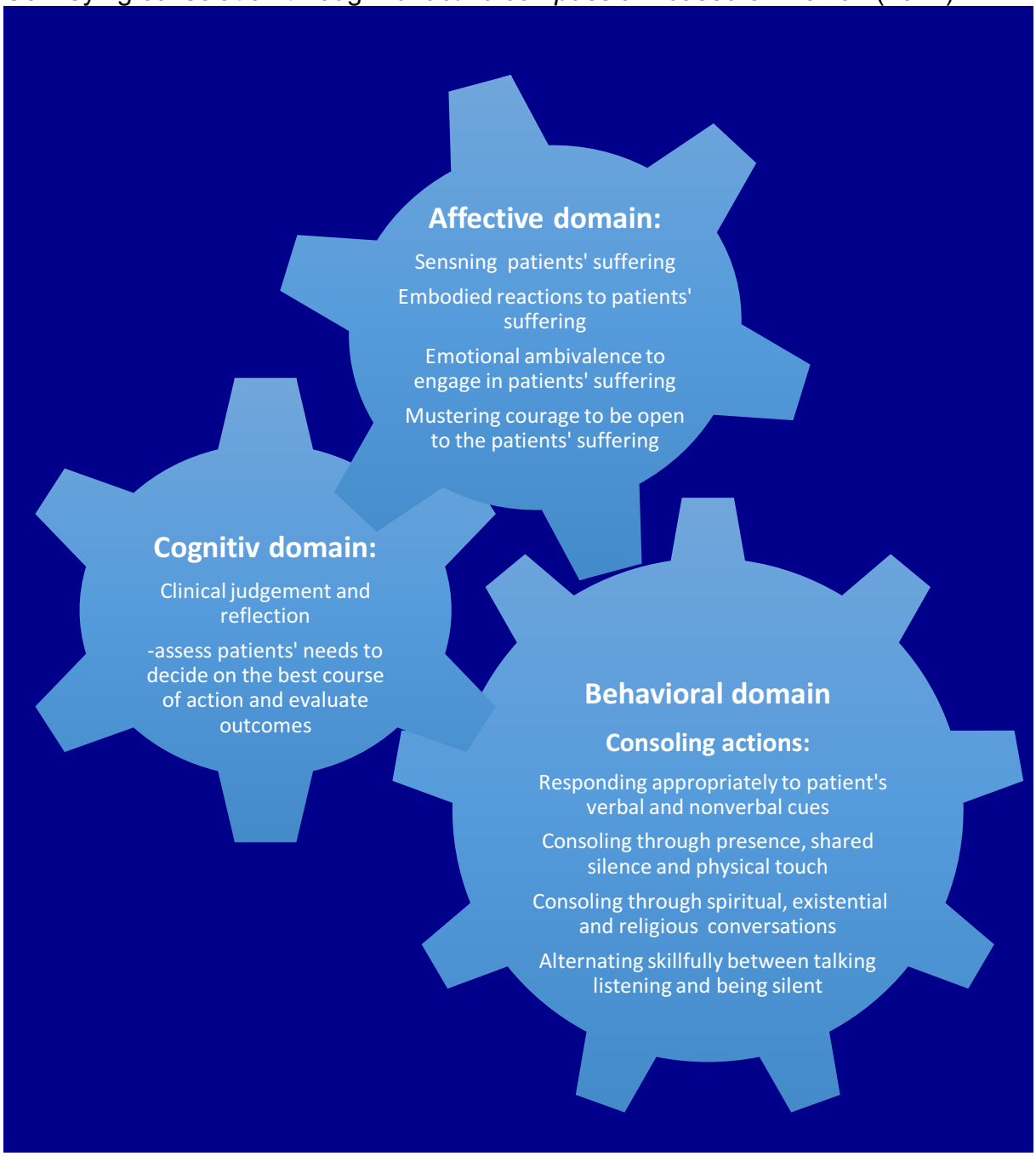
These issues will be discussed in the following:

10.4.1 Can compassion be taught?

Halifax (2012) points out that the factors which foster compassion are not well understood. According to her (2012), whether compassion is an inherent personal quality, or if it can be taught and learned is a central question in the emerging field of compassion research (Halifax, 2012, 2014; Sinclair et al., 2016; Stanford University School of Medicine, 2008). The answer to this question is important because it has pedagogical implications for teaching and training current and future nurses and care workers to convey consolation.

While the conventional description of compassion is based on two main components from the *affective domain*: the affective feeling of caring for the sufferer and the motivation to relieve suffering (Lazarus, 1991), Halifax (2012, 2014) drawing on recent neuroscience research, describes compassion as a contingent and emergent process, which arises out of the interaction between a number of interdependent non-compassion elements, which belong to *the cognitive and behavioral domains* as well as the affective domains. According to Halifax (2012, 2014), these non-compassion elements, (which include *attention and affect* (the affective domain)*, intention and insight* (the cognitive domain) and *embodiment and engagement* (the behavioral domain)), interact with each other in a complex and adaptive system. As a consequence, one cannot directly train in compassion *per se,* according to Halifax (2012, 2014). However, Halifax (2012, 2014) points out that one can indirectly set the field for the emergence of compassion by training the individual in situations and processes which are related to the non-compassion elements in the affective, cognitive and behavioral domains. The consolation process which emerged through the study, bears close resemblance to the contingent and emergent process between the affective, cognitive and behavioral non-compassion elements which are described in Halifax's (2012) model of *enactive compassion*. As such, conveying consoling can be understood as a form for enactive compassion (Halifax, 2012). This is illustrated in figure 1:

Figure1:
Conveying consolation through *"enactive compassion"* based on Halifax (2012)



According to Halifax's research (2012, 2014), it is possible to indirectly prime nurses' and care workers' capacity for compassion by designing teaching and training schemes, aimed at developing nursing competencies, which pertain to the trainable non-compassion elements. The following table provides a summary of the consolation challenges and competencies, which were identified in the three papers and their relationship to Halifax's (2012, 2014) "non-compassion elements".

Table 1. Overview of the nurses' consolation challenges and competencies

Non-compassion elements (Halifax 2012, 2014)	**Consolation challenges**	**Competencies needed to provide consolation through *"enactive compassion"*** (Halifax 2012, 2014)
Affective Domain *Attention and affect*	**Emotional challenges:** - Painful embodied reactions to patients' suffering - Fear of death and dying - Vulnerability and helplessness - Experiencing reluctance and ambivalence to share the patients' suffering	**Courage to overcome emotional challenges in order to remain open and receptive to the patients' suffering** **Courage to engage in consoling actions** - Personal and professional maturity and experience - Self-awareness
Cognitive Domain *Intention and insight*	**Overcoming uncertainty:** - Being uncertain about the patients' spiritual and existential suffering and needs - Being uncertain about the best course of action - Being uncertain about addressing dying patients' religious issues - Risk taking	**Clinical judgment and reflection** - Assessing patients' spiritual and existential suffering and needs - Deciding on the best course of action - Evaluating the outcomes
Behavioral Domain: *Embodiment and engagement*	**Providing appropriate responses to patients' verbal and nonverbal cues:** - Using natural openings to integrate consolation whilst performing nursing care - Adopting behavior to match fluctuations in the patients' physical, psycho-social and spiritual/existential suffering	**Relational and presencing skills:** - Being with the dying: Consoling through silent presencing and physical touch - Engaging in spiritual, existential and/or religious conversations - Alternating skillfully between talking, listening and sharing the silence

10.4.2 Can courage be taught?

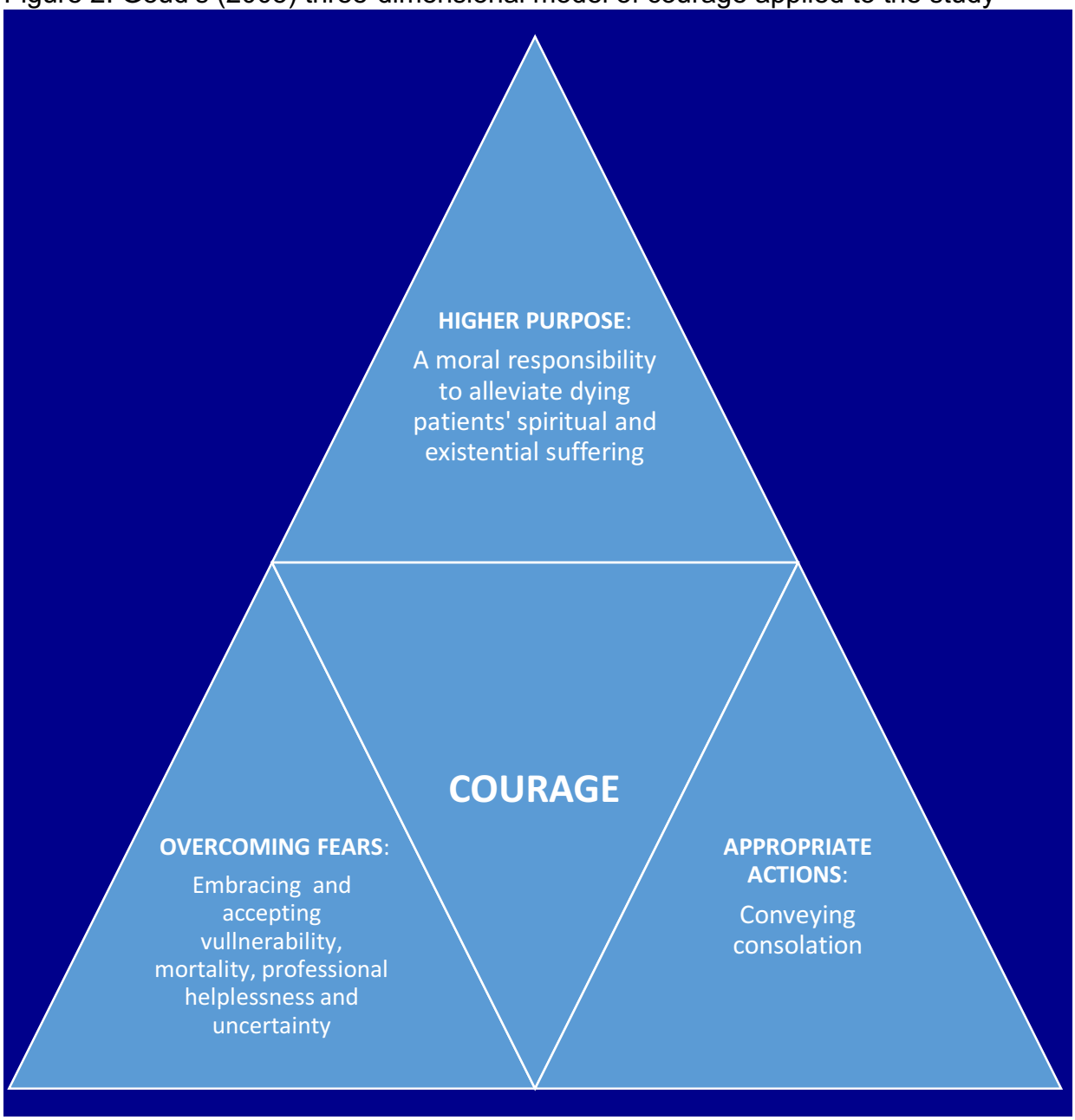
As mentioned in section 10.3.2 Jordan (2003) describes courage as the ability to be moved and affected by others and to embrace and accept vulnerability and uncertainty. This poses an important pedagogical question: Is it possible to teach and train nurses and care workers to overcome their fears and reluctance to walk with the dying to share their suffering (Norberg et al., 2001)?

While Thorup et al. (2012) found that courage is a prerequisite inner quality, which contributes to the nurturance of personal and professional development; they also point out that courage is not only an isolated and inherent quality, because aspects of volition are also involved in nurses' courageous actions. Taking this into consideration, it seems reasonable that the volitional aspects of courage may be developed. This suggests that it is possible to train one's ability to act courageously. In the following this will be discussed in light of Goud's (2005) study concerning the nature and development of courage. Drawing on several psychological schools and theorists, which emphasize that all organic and human life has an innate drive towards growth and self- actualization (Horney, 1950; Jung & Von Franz, 1968; Maslow, 1968, 1972; Maslow, Frager, Fadiman, McReynolds, & Cox, 1970; Rogers, 1961, 1980). Goud (2005, p. 102) defines courage as the "energizing catalyst for choosing growth over safety needs". According to Gould (2005) a gap is created whenever growth forces encounter powerful safety forces (fears) and this gap must be leaped in order for growth to proceed. Gould (2005) points out that courage allows one to effectively act under conditions of danger, fear, and risk. Without courage, the individual or group remains stuck in existing patterns or immobilized in fear.

In order to present a conceptual model of courage and to describe guidelines for developing courage Goud (2005) examined a variety of disciplines for their views on courage. The disciplines spanned from military history and research, various schools of psychology, literature and philosophy. Gould (2005) performed a content analysis of the divergent sources of literature, which yielded three primary dimensions of courage, which included: *fear, appropriate action and a higher purpose*. Gould (2005) found that while there are wide variations among students of courage as to the kinds of fears,

which involve courage, all seem to agree, that facing fears is essential in a courageous act. However, in light of Aristotle, Gould (2005) maintains that acting in the face of fear is not enough. One must have a higher purpose for a courageous act. Drawing on Nietzsche, Goud (2005) states that the level of commitment to a courageous act is directly related to a felt sense of purpose. According to Goud (2005) a higher purpose refers to affirming or securing a value beyond one's self-interests. As such, the nurses' deep relational connection with their dying patients and their moral responsibility to console them (paper I and II) can be characterized as a courageous higher purpose. (Conveying consolation as a moral responsibility has been discussed in section 10.1.6)

Figure 2: Goud's (2005) three-dimensional model of courage applied to the study



As mentioned earlier, although studies (Halifax, 2012, 2014; Thorup et al., 2012) indicate that, compassion and courage seem to be inherent personal qualities, these studies also indicate that it may be possible to cultivate these qualities through training. Goud's (2005) study which, draws on Rachman's research (1978) supports these results. According to Rachman (1978), cited in Goud (2005), training in dangerous jobs such as firefighting, emphasizes gradual and graduated practice of the dangerous tasks. Rachman (1978) concluded that: "Courageous behavior is determined predominantly by the combination of competence and confidence, and both of these qualities are strengthened by repeated and successful practice." (Rachman, 1978, p. 248), cited in Goud (2005, p. 111). As such, practicing for courage is a process of moral, psychological, and physical "toughening" according to Goud (2005). Henceforth, "doing the right thing" in the face of fear demands a good amount of confidence, fortitude and discipline. Accordingly, developing the ability to tolerate risks and uncertainty, means accepting fear and anxiety as part of this process, rather than something to be avoided (Goud, 2005).

Drawing on Rachman (1978), Gould (2005) states that developing confidence and self-efficacy, observing role models and bolstering a sense of purpose are potent forces for developing courage and counteracting fears. Developing confidence in one's capabilities is a primary force in countering fears, risks and the safety impulse, where self-efficacy, which is a specific form of self-confidence, is of special import. Self-efficacy is an estimate of one's capabilities to handle specific challenges and tasks. According to Goud (2005) self-efficacy is an important determinant of how much effort people will exert and how long they will persevere in the face of significant challenges. In light of Rachman's (1978) summary of studies about fear and courage, Goud (2005) recommends risk taking and comfort zone expansion as a means for courage development. The idea is to engage the learner in gradual risk taking activities, which are just beyond the individual's comfort zone (in the same way a parent coaxes a toddler to take a few steps). Attempting tasks too far beyond one's capabilities usually results in overwhelming failure and fears. The fearful person will then, quite reasonably retreat to safety and be extremely hesitant to risk any new behaviors.

In addition to facilitating courage building opportunities through activities, which involve gradual risk exposure, Goud (2005) recommends observational learning or modeling as another powerful modality to develop courage. Drawing on Bandura (1986), Goud (2005) states that watching someone similar to oneself succeed in a task tends to increase one's confidence in performing the same tasks (while the revers also holds true). According to Goud (2005), being exposed to direct models that demonstrate courageous behaviors increases the likelihood that it will encourage the same behaviors in the observer. Goud's (2005) research supports the results in paper III which show that situated, relational and experiential teaching approaches in the clinical context seem to be an efficient means to teach and train care workers to provide spiritual and existential care for the dying. This will be explicated in the following:

The mobile hospice nurse teaching team in paper III frequently experienced that the care workers felt fearful and reluctant about addressing their dying patients' spiritual and existential suffering. The teaching team believed that the care workers' fear of exposing themselves to their patients' spiritual and existential suffering stemmed from personal insecurity as well as insufficient communication and listening skills (paper III p.5). To strengthen the care workers' courage and competency, the mobile teaching team transferred their personal spiritual and existential care knowledge through situated bedside teaching, which involved participating actively in patient care together with the care workers. Acting as role models and by providing individual supervision and feedback before, during and after patient care, the team gradually encouraged the care workers to conduct the spiritual and existential care conversations, which they were afraid of initiating.

In the beginning, the team members would act as *role models,* (Goud, 2005): "Sometimes they need to hear the kind of questions I ask and see how I relate to the patient." (paper III p.5) The teaching team gradually encouraged the care workers to step out of their comfort zone (Goud, 2005) to conduct the patient conversations independently while the team member would stay in the background to provide support. As the teaching team observed that the care workers became more courageous and competent, they gradually withdrew their support, transferring the responsibility to the care workers:

"Many just need a little push and encouragement to talk with the patients alone, using me as a conversation partner to help them reflect on how they handled the situation." (paper III p. 5) According to the mobile hospice nurse teaching team, supervising, supporting and encouraging the care workers through their challenges over a period of time had made them more courageous to be with the dying and to talk with them about their spiritual and existential suffering. Drawing on care worker feedback and their own observations, the teaching team considered that situated bedside teaching had proven to be an important tool:" When I have accompanied the same care worker to the same patients several times I've noticed that they have gradually become braver because they actually dare to ask their patients some of the difficult questions." (paper III p. 6) ……" I see that they dare to involve themselves more in these situations, exposing their vulnerability. I see that they have become braver." (paper III p.6)

10.5 Pedagogical implications

As mentioned in section 10.4.1 and 10.4.2, studies indicate that it is possible to prime nurses' and care workers' courage and compassion to convey consolation through training (Goud, 2005; Halifax, 2012, 2014; Thorup et al., 2012) and that this might increase their endurance to be with the dying. (See section 10.2.3)

In the following, the pedagogical challenges related to teaching and training nurses and care workers to convey consolation will be discussed in light of educational nursing research, which draws on the Aristotelian concept of *phronesis* (Benner, 1984, 2000a, 2000b; Benner, Sutphen, Leonard, & Day, 2010; Rowe & Broadie, 2002) and situated learning theory (Brown, Collins, & Duguid, 1989; Gieselman, Stark, & Farruggia, 2000; Lave & Wenger, 1991).

According to Öhlen (2001), Aristotle views human action as a practical skill which involves the following three knowledge forms: *episteme*, (theoretical or formal knowledge), *techne* (hands-on skills) and *phronesis* (the personal ability to take action in a wise and prudent manner). Öhlen (2001) points out that all three knowledge forms are each other's prerequisites. As such, none of them are sufficient alone. The ability to act prudently and wisely to alleviate suffering (phronesis) presumes theoretical knowledge

(episteme) about suffering and alleviating suffering as well as hands-on nursing skills (techne) to alleviate that suffering and vice versa (Öhlen, 2001)

The study revealed that consoling the dying was a complex, multidimensional and deeply personal and relational nursing challenge which demanding clinical judgment and reflective practice. This is illustrated in the three papers which show that the nurses (paper I and II) and the hospice nurse teaching team (paper III) strove to integrate and merged their theoretical and practical knowledge into a holistic effort to console and ease the spiritual and existential suffering of the dying. (This is illustrated in Figure 1 and Table 1 in section 10.4.1.)

The results show that both the nurses in paper I and II and the hospice nurse teaching team in paper III, demonstrated a form for spiritual and existential care, which is consistent with Swinton and Pattison's (2010) pragmatic and functional approach to spirituality and spiritual care, which has been described in chapter 4.2. According to Swinton and Pattison (2010) in order to provide functional and pragmatic spiritual and existential care, nurses and care workers must have the competency to identify and respond effectively to the particular spiritual and existential quests that they encounter, within whatever situation they find themselves in. Swinton and Pattison (2010, p. 235) note that:

> what is called for in terms of nurse education is therefore flexibility and consciousness raising. This will mean teaching nurses the significance of spirituality in ways that are flexible and contextually workable and raises the nurses' consciousness to dimensions of their caring practices that are often hidden or forgotten.

Hence, to rise to the challenge of consolation, nurses and care workers are in need of phronetic knowledge (Öhlen, 2001). This will be explicated in the following:

Drawing on Aristotle, Benner (2000a) points out that learning to be a good practitioner requires developing the moral imagination and skills of being a good practitioner. According to Benner (2000a), Aristotle labeled the kind of knowing which requires moral agency, discernment and relationship as phronesis, in contrast to techne, which involves knowledge about making things or producing outcomes and she (2000a)

emphasizes that nursing, as a practice requires both techne and phronesis as described by Aristotle. Benner (2000a) emphasizes that while techne, or the activity of producing outcomes, is governed by a means-end rationality, phronesis by contrast, is lodged in a practice which cannot rely strictly on a means-end rationality because one's acts are governed by concern for doing good in particular circumstances, where being in relationship and discerning particular human actions are at stake and guide action. Benner (2004) emphasizes that means and ends are inextricably related in caring for the ill.

According to Benner (2000a, 2004) the nurse and the patient bend and respond to each other so that horizons and the world are opened and reconstituted so that new possibilities emerge. Healing and recovery of one's embodied relationship to the world is mysterious. It is lived rather than mastered and requires relationship, openness and trust. (Benner's viewpoints (2000a, 2004) resonate with the relational and healing dimensions of consolation, which have been discussed in sections 10. 1.2 and 10.1.3.) Hence, technique alone cannot address the interpersonal and relational responsibilities, discernment, situated possibilities and challenges that nurses and care workers encounter in their efforts to console the vulnerable suffering and dying.

Benner (2000a) notes that the phronetic knowledge which experienced nurses possess can only be transferred to the less experienced through situated experiential learning in communities of practitioners who for the sake of good practice continue to live out and improve practice. One of the features of learning in a practice context is that experts are able to guide novices through the complexities of practice (Benner, 1984). Benner (1984) emphasizes that much clinical knowhow is situational and tacit and can only be demonstrated as the particular situation arises. The variety and exceptions in actual clinical practice elude textbook descriptions but gradually yield to the experienced nurse's fund of past similar and dissimilar situations. It is this demonstration that is so essential to the novice (Benner et al., 2010). Benner (1984, 2000a) and Benner et al.'s (2010) viewpoints are supported by situated learning theorists, who maintain that knowledge is embedded within the context in which it is used and cannot be separated from the activity, context and culture of that situation (Gieselman et al., 2000). According to Lave and Wenger (1991) situated learning is central for becoming

proficient and they state that learning in practice is a matter of acculturation, of joining a community of practice, rather than the application of decontextualized skills and principles.

According to Cone and Giske's (2013) study, nursing students need to see how spiritual care can be promoted in the fast paced hospital-environment as well as other clinical settings, and they point out that making spiritual care assessments and interventions more visible and explicit in clinical studies will promote students' maturation and thus improve their professional growth. Cone and Giske (2013) found that there is a great need for nursing students to see nurses who role-model assessment, spiritual care giving and documentation, and they (2013) point out that nurses can play a key role in providing support for students to stay in difficult or challenging situations. By promoting an open atmosphere for nursing students it is easier for them to overcome their vulnerability and to safeguard ethical issues. Cone and Giske (2013) point out that although the importance of role modeling is widely reported in the literature it is often missing in practice. This challenges nurse educators to collaborate with nurses to help them be more explicit in sharing how they provide spiritual care. If nurse educators are not directly involved in clinical supervision of students it is critically important for them to assist nurses and nurse preceptors to model spiritual care assessment and interventions and to demonstrate how it is discussed and documented as a part of nursing responsibilities (Cone & Giske, 2013). Cone and Giske (2013) emphasize that this is especially important in a Norwegian context were spirituality and religion are regarded as very private and personal areas (Botvar & Schmidt, 2010; Stifoss-Hanssen, 1999; Stifoss-Hanssen & Kallenberg, 1998; Ulland & DeMarinis, 2014).

10.5.1 Recommendations

The results from this study suggests that nursing leaders (in specialist care as well as in home care and nursing homes) and nurse educators should collaborate to create teaching and training schemes based on situated experiential and relational teaching formats, in order to enable current and future nurses and care workers to provide competent and compassionate spiritual and existential care for the dying. This is supported by situated learning theory (Brown et al., 1989; Gieselman et al., 2000; Lave &

Wenger, 1991), and educational nursing research (Benner, 1984, 2000a, 2000b, 2004; Benner et al., 2010; Cone & Giske, 2013), which underpin the importance of developing phronetic spiritual and existential care competency by learning from experienced nurses in communities of clinical practice (Lave & Wenger, 1991).

Nevertheless, although the study shows that the nurses' maturity as well as their personal beliefs and professional experience were important (as illustrated in the consolation narratives in section 10.1.2), the study also shows that sometimes this was not enough. With the exception of the two nurses who had studied theology prior to taking up nursing careers, the nurses said they had mixed feelings about their ability to provide existential and spiritual care because they felt insecure and uncertain about providing religious consolation (paper I p.4). According to the nurses, their discomfort and uncertainty stemmed from their own personal attitudes towards religion (paper I p.4) as they did not consider themselves to be religious or *"very Christian"* as one of them put it (paper II p.5.) and they also expressed that they did not have enough formal knowledge about religion. (See section 10.1.1)

This suggests that spiritual and existential care needs to be "moved" from the private commitment of the individual nurse and care worker to a public understanding (Ødbehr, 2015). Practical training programs in spiritual and existential care should, (in addition to providing experiential learning opportunities through situated bedside teaching), introduce nurses and care workers to the nature and lexicon of lived religion, religious perspectives on suffering and religious reasoning (Pesut, 2016; Swinton & Pattison, 2010). Practical training programs could also include interdisciplinary and cross professional collaboration between nursing staff and chaplains. (Ødbehr, 2015). This might enhance nurses' and care workers' courage to rise to the challenge of consolation in situations where the complexities of spirituality and religion come into play: As Pesut points out: "The degree to which patients continue to bring religious perspectives to care is the degree to which nursing needs to consider those perspectives." (Pesut, 2016, p. 7)

Baldacchino (2011) constructed a study unit in spiritual care for qualified nurses named *"Spiritual Coping in Illness and care"*. The study unit consisted of 4 ECTS and employed a variety of didactic methods, which included lectures, patient case studies, small group discussions and sharing clinical experiences, self-reflective exercises on personal spirituality and nursing practice. According to Baldacchino (2011), the evaluation reported that the study unit had been beneficial as the learners had time to think critically about their own spirituality and their current clinical practice. The evaluation suggested that the nurses' increased knowledge about concepts of spirituality, spiritual distress, spiritual wellbeing, spiritual coping and spiritual care appeared to help them to see the possibility of meeting patients' needs through the implementation of holistic care and to become a resource of knowledge for their colleagues. However, Baldacchino (2011) also pointed out that in a long-term perspective, mentorship is needed in order to enable nurses to put theory into practice and to sustain them in practicing what they have learned.

A less qualified workforce increasingly dominates nursing homes and homecare nursing at a time of increasing prevalence of complex heath concerns (Annear et al., 2014; Colombo et al., 2011; Leclerc et al., 2014; Norwegian Ministry of Health and Care Services, 2012). Mobile expert nurse teaching teams in spiritual and existential care, (and other relevant fields of nursing, such as hospice, dementia and geriatric care) may be a pedagogically effective and practical means to redress the widening gap between work force quality and the demand for high quality care in primary health care (Annear et al., 2014). However, while the level of individual nursing competency is important, one must also keep in mind that the quality of the care which is delivered also rests on institutional variables, such as the general work place culture, philosophy, leadership and organization of care, including time and staff resources (Casey et al., 2011).

11. Concluding remarks

The study shows that consolation is a deeply relational practice, and that entering into relationships with the suffering and dying demands courage and compassion. Being willing to embrace and accept one's own as well as the patients' vulnerability, mortality and helplessness requires personal maturity and endurance as well as clinical competency and professional judgment (phronesis). The study suggests that nurses and care workers may ease some of the dying patient's existential and spiritual loneliness through the power of consoling presence. When nothing else can be done, bearing witness and sharing the patients' suffering may be consoling acts in themselves. Nurses and care workers in end-of-life care confront intractable suffering. Hence, they cannot always expect to be successful in their efforts to alleviate the spiritual and existential suffering of the dying. Therefore, the study results, which indicate that consolation can be conveyed and sustained through presence and relatedness, are extremely important.

Further empirical research (qualitative as well as quantitative) is needed to uncover how nurses provide spiritual and existential care for dying patients in everyday practice and to devise practical, experiential and relational tools and curricula to teach and train current and future nursing staff (nurses and care workers) to provide competent and compassionate spiritual and existential care for the dying. Such research is an important and valuable knowledge supplement to theoretical studies in this field.

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Paper I-III

Appendix