

Summary

This PhD dissertation explores how people, who are confronted with death, and their relatives experience, think about and act in relation to existential aspects of life like death, faith, social relations and the meaning of life.

International research has demonstrated that life-threatening disease leads to an intensification of existential and spiritual concerns, and that these concerns increase as the likelihood of death increases. Studies have further shown that it still remains a challenge for health professionals to sustain patients in palliative care and their relatives in their existential suffering.

Danish research in the field is not unambiguous with regard to whether seriously ill Danes become more religious, but studies indicate that existential aspects in relation to religion and spirituality are of significant importance to many of these patients. Still research among patients near end-of-life is limited. Furthermore, Danish studies have mainly focused on the patients' religiosity and spirituality, but less on secular existential reflections such as thoughts of death and meaning-making. In this field there is limited research in a Danish context. Similarly, there is a lack of studies dealing with relatives' existential concerns and problems.

The objective of this PhD project was to generate scientific knowledge about how dying patients at Danish hospices and their families relate to existential (spiritual, religious and secular existential) aspects of life near death. Thus, the aim was firstly to provide a basis for further research in the field, secondly to contribute to the development of palliative practice in both basic and specialised palliative care. The objective was achieved through two partial aims:

1. To explore how patients in the late palliative / terminal phase, admitted to a Danish hospice, experience, search for meaning in, interpret, think about and / or act in relation to existential aspects like death, faith, social relations and meaning of life.
2. To explore how next of kin related to patients in the late palliative / terminal phase admitted to a Danish hospice, experience, search for meaning in, interpret, think about and / or act in relation to existential aspects like death, faith, social relations and meaning of life.

Data were generated through ethnographic fieldwork in three different Danish hospices using the following qualitative methods: 1) 38 days of participant observation at three hospices, 2) semi-structured interviews with 17 patients admitted to hospice, and 3) semi-structured interviews with nine next of kin related to patients admitted to hospice.

The empirical data (field notes and transcribed interviews) were analysed by the methodological approach “Interpretive Description”, introduced by the American professor in nursing research Sally Thorne. Further analytical inspiration was drawn from ethnographic research approach.

The first phase of the analysis consisted of close reading of the empirical material and resulted in selection and coding of three recurring themes. Through three following analyses it was demonstrated how the participants related to three different existential aspects: death, social relationships and faith.

The results are presented in three articles: The first article “*Existential concerns about death – A qualitative study of dying patients in a Danish hospice*” describes how the patients' thoughts, feelings and coping in relation to death were expressed in words and action. The analysis of the transcribed patient interviews resulted in seven themes: 1) Awareness of death, 2) Grief leaving life, 3) Anxiety about death, 4) Avoiding the topic of death, 5) Reconstructing ideas about afterlife, 6) Planning death, and 7) Focusing on life. Inspired by the American psychologist Jerome Bruner, the themes were categorised into two categories: “Thoughts and feelings” about death (themes 1,2 and 3) and “Managing death” (themes 4, 5, 6 and 7). The analysis showed that most patients in relation to thoughts and feelings about death were aware that they were going to die in the near future, and they were deeply sad about leaving life. They did not express anxiety in relation to death in an understanding of "nothingness", but several were concerned about the process of dying. The way they managed death was varied and partly inconsistent. Accordingly, the results demonstrated how the participants avoided talking and thinking about death. Instead they wanted to focus on life. At the same time an immediate inconsistency was demonstrated in the participants' way of managing death. Thus, the results showed how the participants sought to avoid dealing with death and yet planned details related to funeral and reconstructed ideas about afterlife.

The results were related to the American existential psychiatrist Irvin Yalom's theory about death anxiety, the American psychiatrist Elisabeth Kübler-Ross's theory about “five stages of grief”

and other research studies, which inspired by the German philosopher Martin Heidegger argue about the importance of everyday life in a life near death. It is thus concluded that the patients were looking for an authentic being in relation to their own values. This authenticity could be found in their involvement in daily activities, which were perceived as meaningful, in the way they were planning death, and in their reconstruction of notions of afterlife. It is argued how the results could not be fully captured either by Yalom's existential psychology, or by Kübler-Ross's theory about death stages. The results could be more fully explained taking an outset on the basis of research of everyday life inspired by Heidegger's phenomenological thinking.

The second article *"She doesn't disappear" - a qualitative study of dying patients' and relatives' considerations about a continuing relationship after death*, demonstrates how the patient's and the relative's thoughts and ideas of a continuing relationships after death were expressed in stories. Through a narrative-inspired analysis, parallels in the stories were identified and grouped into two categories: "Meeting places", which included the themes "Memories," "The Grave, and" "The unknown place in the hereafter", and "Ways to meet", which included the themes "Connection through memory" and "A direct connection". These results were related to the American psychologist Robert Neimeyer's research about grief processes. Neimeyer suggests that grief processes must be understood as meaning constructions. Hence, he focuses on how people in grief construct new narratives through which they create new meaningful plots in their story of life. On this basis it is concluded that a consistent meaningful plot in the participants' stories were, "the dying person does not disappear with death," by which a continued relationship, secular and / or transcendent, could survive.

In the third article *"Where is God in my dying? - An investigation of faith reflections among hospice patients in a secularised society"* the purpose was to explore how dying patients in a secular society like the Danish reflected and acted in relation to a potential faith. The use of the term "faith" as a general term for the belief in something spiritual or religious is argued with reference to Danish research about faith. The analysis of the empirical material was inspired by the American sociolinguistic Joshua Fish Man's sociological terms, knowing, doing and being and resulted in three categories. The category of "Knowing" encompassed the themes of "What to believe in" and "Talking about faith", and here the focus was on the patients' cognitive approach to faith. The category "Doing" contained the theme "Living out the faith", where the focus was on the

patient's praxis according to faith. The last category "Being" contained the themes "Focusing on faith" and "Faith as support" and focused on the importance that faith had to the patients. It is argued how two of the three basic pillars of the approach to faith, "knowing" and "doing", only had a weak, but increased significance. The findings suggest that faith considerations mainly rested in the third pillar, that of "being". Hence it is demonstrated how thoughts about faith were mostly intensified, searched for and explored in a new light according to the actual situation. These reflections could be imbued with deep feelings and hereby give support in both negative and positive ways. On the basis of, among others, the Danish theologian Jørgen Jensen's theoretical thinking it is concluded that even among patients living in a society characterised as secular, most of them had a hesitant but important faith, for which they had limited language and unclear conceptualisation.

A summary of the results from the three articles in the dissertation demonstrates on a descriptive level, how transcendence in the participants' ideas about life after death was expressed in different ways and in different contexts. With reference to the Danish researchers anthropologist Cecilie Rubow's and theologian Christine Johannesen-Henry's research on "Variations of life in death," it is argued how the unifying results from the three articles in different ways point to a transcendence of death, which cannot be captured in traditional theology or science of religion, but is characterised as polydox and varying. The transcendence of death opens up for a transformation of death, as an inevitable final condition of life to be a continuation, beyond death. The transcendence of death and hereby the transformation of death create elements of meaning in death, both for the dying and for the relatives.