Hope in palliative care: A longitudinal qualitative study

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Chapter 1: General Introduction

“How do you see your future?” asks the lung physician. Mr Johnson starts smiling and replies: “I hope that I will recover a bit from my COPD because our son lives abroad and we want to visit him another time.” The lung physician starts to winkle up his forehead: “You should realize that you are very ill, Mr Johnson.” Mr Johnson responds in an accusing tone: “That’s also what she’s been telling me constantly.”

Ten minutes later Ms Johnson is sitting in the waiting room while her husband is on the toilet. The lung physician passes by and Ms Johnson says: “I hope it won’t take too long: every day things seem to be going worse.” The lung physician smiles friendly: “The two of you are quite different in that, aren’t you? I hope I can alleviate his suffering as much as possible.”

The example shows that patients, family members and healthcare professionals may hope for different things. In some situations it may lead to conflicts, in other situations hope develops in more or less similar ways. Hope has been described as an important factor in palliative care and this thesis describes hope of palliative care patients, their family members and healthcare professionals.

Objective

Although hope is important, the concept itself remains elusive, which is already reflected in early traditions. For example, ancient Greek and Christian writers described hope as both external and internal, and as both a gift and a virtue that required effort. Whereas hope was a praiseworthy quality for Christian writers, it generally was not for the ancient Greeks (1,2). In the twentieth century several authors described hope in relation to a future transformation of the political landscape, like a transformed world where human beings are no longer alienated from themselves or where oppressors and oppressed are reconciled and see each other as equal (3–5). Others emphasized the subjective and existential dimensions of hope
by locating it within the human soul (6), or describing it as an ethical obligation that is needed to endure evil and tragedy (7). During the past decades several philosophers (and others) have described hope’s characteristics (8–11), which included: 1) futurity – a future dimension of what is hoped for, 2) possibility – the outcome is possible but not certain (neither zero nor one), 3) desirability – what is hoped for is seen as good in some respect, and 4) agency – hoping agents engage in activities to reach their hope. These dimensions offer opportunities for moral reflection and they relate to vulnerability and contingency because the outcome of hope is uncertain and hope may be disappointed (12,13).

However, empirical approaches and definitions of hope in healthcare are still diverse (1,14–16), and as a consequence, conceptual clarification is needed. In addition, although there are some longitudinal studies that have elaborated on hope (17–20), these few studies can only offer preliminary understanding of hope over time. Moreover, debates on ethics of hope have often been reduced to a physician’s conflict of duties: do not lie versus do not destroy hope (21,22). However, such a way of framing the ethics of hope may emphasize (only) the possibility dimension of hope, and it may privilege healthcare professionals’ perspectives over patient perspectives. Thus, what is needed is an ethics of hope that is based on perspectives of all those involved in the caring process. Furthermore, hope has been perceived as a difficult factor during end-of-life communication (23–26), and it may delay end-of-life discussions (27–30). As a consequence, hope should be scrutinized within the context of palliative care in order to support healthcare professionals to address end-of-life issues during clinical encounters with palliative care patients.

The objectives of this study are to provide insight into hope in palliative care and to offer healthcare professionals clinical and moral guidance. The central questions are: 1) What are healthcare professionals’ perspectives on hope? 2) How can hope, hopelessness and despair be understood over time, as experienced by palliative care patients? 3) How can healthcare professionals address hope, hopelessness and despair during encounters with palliative care patients? And 4) What should an ethics of hope consist of?
**Hope in Palliative Care**

This thesis will describe hope of the following palliative care patients: patients with incurable cancer, patients with severe chronic obstructive pulmonary disease (COPD), and patients with severe heart failure (HF). Severe COPD means GOLD (Global Initiative for Chronic Obstructive Lung Disease) 3 or 4, and severe HF means NYHA (New York Heart Association) III or IV. Palliative care patients have to live with their severe illness and in this process hope is important, which has been associated with their psycho-spiritual well-being (16,31–33). It has been described as “transcending possibilities” which included the integration of transcendence and positive reappraisal (34). In addition, a distinction has been made between living with hope, which is the existential being of hope and fundamental to maintain relationships, and hoping for something, described as the action of hope and as a future oriented goal (1). However, this future dimension of hope may be complicated by the fact that prognosis is hard to determine in patients with severe COPD and severe HF. This is one of the reasons that these patients hardly receive palliative care or that their healthcare professionals hardly discuss end-of-life issues with them (35–40), which is unfortunate because they may benefit from end-of-life communication and treatments of their anxiety and depression (41–43).

Family members also have to live with the consequences of the illness. They have to balance the care for their own needs and those of their family member(s) (44). Partners, for instance, are sources of information with respect to changes in their severely ill partner (45), and they may worry about financial costs (46). Hope in family members has been described as an important resource that helps them to cope with their situation (17,47,48). Hope may be a significant topic during communication between family members and healthcare professionals, and communication is important to support family members (49,50). However, research interventions that improve the quality of care for family members have hardly been developed (51–54).

In the last place, education for healthcare professionals on end-of-life communication is important (55), which may help these professionals to
address hope during clinical encounters. However, outcomes that describe the impact of communication skills on, for instance, patient satisfaction, adaptation and quality of life are generally lacking (56,57). Hope has been described as an important factor in healthcare professionals’ well-being because it fosters positive relationships and helps them to provide comfort to palliative care patients (58). Furthermore, healthcare professionals associated their hope with their own comfort and competence during the provision of palliative care (59), and they harmonized their hope with the hope of others (60).

**Method**

The research questions are answered by using a longitudinal qualitative approach that is based on narrative theories. Narrative theories discern many elements, like time, character and plot (61,62). They are based on the idea that people give meaning to their experiences by making use of language, which goes back to hermeneutics, with its focus on interpretation (of texts) (63). Others have emphasized how people, in their stories, try to justify their actions and create a convincing plot that is plausible for an (imagined) audience, which involves membership categories (64), and relates to justification of actions and ethics.

For our study, the narrative perspective implies that we acknowledge participants’ subjectivity by carefully analyzing what they say about hope, while simultaneously recognizing that how we speak about hope is affected – not determined – by dominant discourses to which we (have to) relate. In addition, a narrative perspective means that the interpretation of transcribed interviews can never be a solo entreprise but has to be embedded within a research team, in which interpretation is an ongoing process.

Most of the findings presented in the following chapters are based on semi-structured interviews with palliative care patients, their family members or friends, and their healthcare professionals. We decided to interview participants every six months with a maximum of three times. In order to stay close to patient participants’ subjective understandings of changes of hope over time, we called patients every six weeks and asked
them if something around their hope, hopelessness or despair had changed. If this was the case, another interview was planned earlier than originally scheduled. Hospice patients were interviewed every month because in The Netherlands, in order to be admitted to hospice, prognosis has to be less than three months. The time frame is an important topic in qualitative longitudinal studies (65), which will be further discussed in the final chapter. Details about the method of the studies will be provided in each chapter.

**Outline**

The following two chapters answer the research question What are healthcare professionals’ perspectives on hope? It elaborates on conceptual and ethical dimensions of these perspectives. Chapter 2 outlines an interpretative synthesis of the literature describing healthcare professionals' perspectives on hope of their palliative care patients. This synthesis study presents how healthcare professionals defined hope, what they saw as criterion to judge hope and how they responded to hope of palliative care patients. Chapter 3 describes healthcare professionals' implicit perspectives on hope by presenting the metaphors of hope they spontaneously used to describe their own hope and the hope of palliative care patients and patients' family members.

Then, the perspectives of palliative care patients will be our concern. Chapter 4 answers the question How can hope, hopelessness and despair be understood over time, as experienced by palliative care patients? It offers ways of understanding these concepts over time. Chapter 5 presents an ethics of hope, in which perspectives of all those interviewed in this study – palliative care patients, their family members and their healthcare professionals – are taken into account. This study offers possibilities for moral reflection on hope. Chapter 6 describes how hope and related concepts could be addressed in clinical practice. More specifically, it describes how healthcare professionals evaluated the feasibility of a hope communication tool that was based on synthesis studies.

This thesis will end with a general discussion in chapter 7, which reflects on the research method and synthesizes the findings. The moral
and clinical implications and recommendations for future research will be outlined as well.

References


